

**Adapting the protocol for Narrative Exposure Therapy for adults with Mild
Intellectual Disabilities**

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Thesis Abstract

Background: The rise of trauma-informed care in health services in the UK has highlighted the need for patients to receive care that considers trauma and includes referral for trauma-focused treatment where appropriate (Sweeney et al., 2016). Adults with Intellectual Disabilities (ID) are more vulnerable to developing post-traumatic stress disorder (PTSD) than the general population (Fletcher et al., 2016), however, research exploring effective trauma-focused therapies within this population is limited. Narrative Exposure Therapy (NET; Schauer et al., 2011) is recommended by the National Institute for Health and Care Excellence (2018) to treat PTSD in adults. There is a lack of research exploring firstly, the effectiveness of NET among adults with ID and secondly, what adaptations are required for this population.

Study aim: To adapt the protocol for NET for delivery with adults with Mild ID.

Research questions:

- How can NET be adapted for adults with Mild ID to create a new protocol (IDNET) for further investigation in clinical practice?
- What are the views of service users on the IDNET therapy materials developed and how can they be incorporated?
- What are the views of professionals on using NET in ID services and on the adapted protocol (IDNET), and how can they be incorporated?

Methods: Stage one of the study involved systematically adapting the NET protocol for adults with Mild ID in collaboration with a service user group who provided feedback on the 'easy read' therapy materials developed. Stage two involved gaining professionals' views on the adapted protocol and on the use of NET in ID services, to inform subsequent amendments to the protocol. This comprised a focus group of Clinical Psychologists (CPs) specialising in ID and an expert panel of NET clinicians. The framework approach was conducted on the focus group data.

Results: A new protocol was developed (IDNET) which comprised recommendations for how NET could be adapted for adults with Mild ID. This included information sheets and handouts in 'easy read' format which mapped onto the psychoeducational examples in the NET manual. Eight CPs and three NET clinicians provided feedback on IDNET which led to amendments. Two key core concepts were developed as a result of applying FA to the focus group: 'Optimism and motivation to adapt NET for people with ID' and 'Factors related to NET in practice'. Issues raised by professionals regarding the delivery of IDNET highlighted further research questions for when the adapted protocol is trialled in practice.

Discussion: This research is the first attempt to systematically adapt NET for adults with ID, in collaboration with a number of different expert groups including service users. Professionals were optimistic about IDNET, however, they highlighted a number of issues which require further consideration. These include the impact of adaptations to NET (for example, extending the lifeline exercise, involving caregivers) on the client, the way NET is delivered and the theory underpinning NET. Future research should aim to trial IDNET in practice to explore feasibility and effectiveness in reducing symptoms of PTSD among adults with ID.

Acknowledgements

The greatest thanks to my research supervisors Professor Thomas Schröder and Dr Anna Tickle. You have been so calm and wise throughout this process, which was very much needed during the COVID-19 pandemic when the original research plan became unfeasible. It has been a real privilege to have had both of you on the project to guide me through some difficult research crossroads. I will miss working with you both. I must also thank the sponsor team at the university for their unwavering guidance throughout the ethics process both before and during the pandemic. They unknowingly stopped me from throwing in the ethics towel on more than one occasion.

The start of training also marked the beginning of my marriage to my husband Matt who has literally been there every step of the way. If we can get through a pandemic, whilst both finishing degrees, I like to think we can get through anything. A special thanks to my parents too for their love and support always. My dad proofread this thesis many, many times and my mum inspired my interest in the wellbeing of people with Intellectual Disabilities in the first place. I am also very grateful to my best friend Azaria for her endless kind words and her encouragement to use a referencing software early on - it really made a huge difference.

Lastly, I would like to thank Jess Renton for her expertise during the first stage of the project, and the collaboration of the Learning Together North West Ltd. People with Intellectual Disabilities remain underserved by society in every domain, and I hope that this will not always be the case. I feel privileged to have had the opportunity to conduct my research in an area which I feel so passionate about and as I take my next steps as a qualified psychologist within the Intellectual Disabilities team, I look forward to many more opportunities to work alongside this population.

Statement of Contribution

Katie Marlow was responsible for the planning and designing of the research, gaining of ethical approval, collaboration with the service user group, recruitment, data collection, data analysis and the write up of the research.

Professor Thomas Schröder and Dr Anna Tickle provided support as research supervisors on the design of the research, ethical approval processes, data analysis and the write up.

Jess Renton provided support during the first stage of the research when adapting the Narrative Exposure Therapy protocol for adults with Intellectual Disabilities.

Table of Contents

Systematic Literature Review	9
Journal Paper	50
Abstract	52
Accessible summary	53
Background	53
Methodology	58
Results	61
Discussion	72
References	76
Extended Paper	85
1.0 Extended background	86
2.0 Extended methodology	101
3.0 Extended results	118
4.0 Extended discussion	156
5.0 Reflections	161
6.0 Extended references	168
Appendices	188
Poster	222
Small Scale Research Project	224

List of Tables

Table 1: Summaries of studies included in the review.....	21
Table 2: Quality appraisal.....	29
Table 3: Components of TFCBT specified in the NICE (2018) guidance.....	34
Table 4: Examples of how IDNET was developed.....	62
Table 5: Key concepts developed from initial codes and themes.....	67
Table 6: Examples of feedback from CPs by category.....	130
Table 7: Additional quotes to illustrate ‘Factors related to IDNET in practice’	139
Table 8: Feedback from NET clinicians and how it was actioned by the research team.....	143
Table 9: NICE (2018) components of TFCBT.....	234

List of Figures

Figure 1: PRISMA flow diagram of study selection process.....	20
Figure 2: The major adaptations of psychotherapy techniques (taken from Hurley et al., 1998).....	96
Figure 3: Cognitive deficits that can cause difficulties in CBT (taken from Lindsay et al., 2013).....	98
Figure 4: The definition of inclusive research with people with learning disabilities (taken from Walmsley & Johnson, 2003).....	103
Figure 5: The research procedure.....	111
Figure 6: Psychoeducational example of normalisation converted into 'easy read'.....	123
Figure 7: Example of written feedback provided by the service user group.....	126
Figure 8: Example of how written feedback was incorporated into the 'easy read' materials.....	128

List of Appendices

Appendix A: Journal submission guidelines.....	189
Appendix B: Stage one - University of Nottingham Sponsorship Statement.....	190
Appendix C: Stage one - Research Ethics Committee Approval Letter.....	191
Appendix D: Stage one - Health Research Authority Approval letter.....	193
Appendix E: Stage one - Confirmation of capacity and capability from local NHS Foundation Trust.....	194
Appendix F: Stage two - University of Nottingham approval letter.....	195
Appendix G: Stage two - University of Nottingham amendment approval letter.....	196
Appendix H: Example feedback provided by SALT on easy read materials.....	197
Appendix I: Example feedback sheet for service user group.....	199
Appendix J: Participant Information Sheet ID Clinical Psychologists.....	201
Appendix K: Participant Information Sheet NET Clinicians.....	209
Appendix L: Consent form ID Clinical Psychologists.....	216
Appendix M: Consent form NET Clinicians.....	217
Appendix N: Interview schedules.....	218
Appendix O: Examples of indexing.....	220

Systematic Literature Review

A Systematic Review of Trauma-Focused Cognitive Behavioural Therapies for Post-Traumatic Stress Disorder in Adults with Intellectual Disabilities

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Abstract

Background Cognitive behavioural therapies have been found to be effective for mental health difficulties in people with intellectual disability (ID). Trauma-focused cognitive behavioural therapy (TFCBT) is recommended for treating Posttraumatic Stress Disorder (PTSD) in adults, however, evidence for people with ID is lacking. This systematic review considers the evidence base for TFCBT for PTSD in adults with ID and its consistency with National Institute for Health and Care Excellence (NICE) guidance.

Method Studies were identified in a systematic search and selected if they reported individual TFCBT for an adult with ID. A quality appraisal and narrative synthesis was completed on abstracted data.

Results Eight case studies met the criteria. Quality of studies and inclusion of components of TFCBT recommended by NICE varied. All studies utilised recognised adaptations and reported positive outcomes for clients.

Conclusions Further high-quality research is needed to provide an evidence base for the application of the key components of TFCBT specified by NICE, to adults with ID.

Introduction

Intellectual Disability (ID) is defined as the presence of significant impairments in both intellectual functioning and adaptive behaviour which commenced before adulthood (BPS, 2015; American Psychiatric Association [APA], 2013; World Health Organisation [WHO], 1992). ID has also been broken down in terms of severity into mild, moderate, severe and profound (WHO, 1992) and the number of adults living in England with an ID in 2015 was estimated to be 930,400 (Public Health England, 2015).

People with ID have a substantially higher prevalence of mental health conditions when compared to the general population (Hughes-McCormack et al., 2017). They are also at greater risk of exposure to adverse life events (Wigham & Emerson, 2015). In a survey of 177 people with mild to moderate ID, 75% had experienced at least one traumatic event (Martorell et al., 2009). It is therefore not surprising that, when compared to the general population, people with ID are more vulnerable to the development of post-traumatic stress disorder (PTSD; Fletcher, Barnhill, McCarthy, & Strydom, 2016). The Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5; APA, 2013) outlines the following diagnostic criteria for PTSD: exposure to actual or threatened death, serious injury or sexual violence; presence of one or more intrusive symptoms associated with the traumatic event, such as distressing dreams; persistent avoidance of stimuli associated with the event; negative alterations in cognitions and mood and alterations in arousal and reactivity associated with the traumatic event. These changes must have persisted for at least one month after the event and cause distress or impairment in the individual's functioning. As well as increased exposure to events likely to result in PTSD, other difficulties may also result in the vulnerabilities of people with an ID to

developing the disorder. For example, difficulties in communication may mean people with ID have less opportunity to process traumatic experiences through conversations with others (Cowles, Randle-Phillips, & Medley, 2018).

In the UK, the National Institute for Health and Clinical Excellence (NICE) provides guidance for clinicians in the treatment of mental health disorders (Dagnan, Jackson, & Eastlake, 2018). NICE recommends individual trauma-focused cognitive behavioural therapy (TFCBT) as a first line treatment for PTSD in adults. These interventions include cognitive therapy for PTSD, cognitive processing therapy, narrative exposure therapy and prolonged exposure therapy (NICE, 2018). TFCBT includes four main techniques to support an individual following a traumatic experience which can be emphasised in various degrees; psychoeducation, anxiety management, imaginal or in vivo exposure and cognitive restructuring (Bisson, Roberts, Andrew, Cooper, & Lewis, 2013). There are no specific guidelines for the treatment of PTSD in adults with ID, however, NICE (2018) specify that interventions for PTSD for people with additional needs should build in extra time to develop trust, take into account the safety and stability of the person's circumstances, help the person to manage engagement issues and plan ongoing support after treatment has ended.

People with an ID within the mild range have been found to have the necessary skills to engage in the cognitive component of cognitive behavioural therapy (CBT; Taylor, Lindsay, & Willner, 2008) and there is a manual of CBT for people with mild ID and mood disorders (Hassiotis et al., 2012). There is an increasing evidence base for the effectiveness of CBT for people with ID for presentations such as anger and depression (Vereenooghe & Langdon, 2013). The BPS (2016) outlines a number of adaptations for CBT for use with people with ID

which includes education and skills teaching to address deficits such as in problem solving and assertiveness, the involvement of significant others and strategies to manage difficulties with memory and concentration such as visual aids, role play and adapting the pace and number of sessions. Hurley, Tomasulo and Pfadt (1998) identified nine categories of adaptations to psychotherapy for people with ID: simplification, language, activities, developmental level, directive methods, flexible methods, involvement of care givers, transference/countertransference and disability/rehabilitation approaches. These will be elaborated and referred to in the results section. In a recent review of adaptations to CBT for people with ID (Surley & Dagnan, 2019), the most frequently reported adaptations, using the above categories, were the use of activities to facilitate learning and the use of directive methods, including the structuring of sessions. However, these are arguably central components of CBT for the general population regardless of intellectual ability.

People with ID have previously been excluded from research looking at the effectiveness of mental health interventions and have not been offered interventions such as CBT (Taylor et al., 2008). The inequalities in the way people with ID are supported by mental health services, compared to the general population, is an ongoing issue and the quality of mental health care for people with ID needs to be improved so that they too have access to evidence based treatments (Foundation for People with Learning Disabilities, 2014). Whilst the research suggests that people with ID have an increased risk of developing PTSD, there is a lack of research into trauma-focused interventions for this population (Mevissen, Didden, & de Jongh, 2016).

Narrative reviews of the literature regarding the treatment of PTSD in people with ID (Mevissen & de Jongh, 2010; Mevissen et al., 2016) and a systematic review

of CBT for anxiety in adults with ID (Dagnan, Jackson, & Eastlake, 2018) found just six case studies exploring CBT for PTSD in people with ID. Dagnan et al. (2018) reported the need for focused study of specific anxiety presentations, such as PTSD and there is a need for these studies, and additional studies found through systematic searching, to be assessed for quality. When literature in this area has been reviewed before, no quality assessment has been completed due to the descriptive nature of the case studies reporting the interventions and little guidance for assessing quality of such studies (Dagnan et al., 2018). Critical appraisal of these studies, in terms of consistency with recently updated NICE guidance for the treatment of PTSD in adults, would also inform future research and interventions and highlight gaps in the evidence base for people with ID regarding the different components of TFCBT recommended by NICE (2018). It might also lead to the development of more specific guidance for treating people with ID, which considers necessary adaptations to TFCBT.

Therefore, the aim of this review is to consider the evidence base for individual TFCBT for PTSD in adults with ID and its consistency with current NICE guidance. The objectives are: 1) To conduct a systematic search of peer reviewed research and unpublished theses and dissertations into TFCBT for PTSD in adults with ID; 2) To critically appraise the quality of the research and reporting; 3) To summarise how therapies have been adapted for people with ID; 4) To summarise the outcomes of the studies; 5) To critically appraise the interventions reported in terms of consistency with current NICE (2018) guidance for TFCBT in adults; 6) To make recommendations for future research, based on the findings of the review.

Method

The review was approached from a pragmatist epistemological position. This position prioritises the phenomenon under investigation, and how best to study this, rather than the philosophical position of the researcher (Fishman, 1999). Therefore, this review was interested in identifying all studies of TFCBT for PTSD in adults with ID, regardless of design or methodology.

Study selection

Studies selected for the review, using the search strategy outlined below, were managed using the online EndNote referencing programme. Duplicates were removed and the remaining studies were screened for content using inclusion and exclusion criteria. Studies were included if: a) they reported a TFCBT intervention for symptoms of PTSD; b) the intervention was aimed at people with ID; c) the intervention was individual; d) participants were over the age of 18 years. A narrow definition of CBT was adopted for the purpose of this review and therefore studies were excluded if the intervention was considered third-wave CBT due to the absence of these types of therapies in the NICE (2018) guidance for the treatment of PTSD in adults.

Search strategy

A systematic search was undertaken using six major electronic databases (MEDLINE, PsycINFO, EMBASE, CINAHL, Scopus and PTSDPubs). The timeframe for searching was between 1980 (when PTSD was first introduced in the DSM-III; APA, 1980) and the day of the searches (22nd July 2019). Search terms were put into Boolean format and applied to the keyword, title and abstract. The search terms

used were: (intellectual* disab* OR learning disab* OR developmental* disab* OR mental* retard* OR mental* handicap*) AND (PTSD OR post traumatic stress OR post-traumatic stress OR posttraumatic stress) AND (CBT OR TFCBT OR TF-CBT OR cognitive behav* OR cognitive therap* OR behavio* therap* OR exposure OR psychoeducation OR psych-education OR anxiety management OR cognitive restructuring). Free-text searches were combined with controlled vocabulary to create search terms individualised to the online databases specified above.

Grey literature searching was restricted to unpublished dissertations and theses using the database ProQuest; this allowed for a quality measure which may not be evident in other grey literature which has not been examined. A prior scoping review had identified a lack of published research in this area and so a search of this grey literature aimed to widen the possible scope of the review as well as reduce the potential for publication bias and provide a more balanced view of the available evidence (Paez, 2017).

Reference lists of all relevant studies were reviewed to identify additional literature, and Google Scholar and the PlumX Metrics facility at Lincoln University library were accessed which allowed the review of studies which had cited those already identified. In addition to this, the references of the following were searched; the NICE guidelines for PTSD (NICE, 2018), the BPS document "Psychological therapies and people who have intellectual disabilities" (BPS, 2016), and reviews of the literature regarding the treatment of anxiety and PTSD in people with ID (Dagnan et al., 2018; Mevissen & de Jongh, 2010; Mevissen et al., 2016). Finally, Google Scholar was searched to identify any further studies.

Data abstraction

After studies had been selected, the following information was abstracted; aims, sample size and characteristics, presenting problem (symptom of PTSD), description of intervention, adaptations made to the intervention for ID, outcomes measured and results of the intervention. The study design and methodology were not abstracted due to all studies being case reports which included measurable outcomes. Studies were then reviewed for the presence or absence of components of TF CBT specified in NICE (2018) guidance for the treatment of PTSD in adults using a deductive content analysis as described by Elo and Kyngäs (2008).

Quality appraisal

Concerns about weak inferences and likelihood of bias have resulted in a lack of research to develop frameworks for appraising and synthesising case studies (Murad, Sultan, Haffar, & Bazerbachi, 2018). However, quality assessment is considered integral in informing the findings of systematic reviews (Seehra, Pandis, Koletsi, & Fleming, 2016). Therefore, for the purpose of this review, a checklist was devised using guidelines available in the literature for evaluating case studies and qualitative data across multiple disciplines (Atkins & Sampson, 2002; Centre for Evidence Based Medicine, 2014; Elliott, Fischer, & Rennie, 1999; The Joanna Briggs Institute, 2007). This consisted of 18 quality criteria which were applied to each study, scored as follows: zero if not met; one if partially met or unclear; and two if met. Due to the lack of research in this area, none of the studies were excluded from this review on the basis of quality. It was decided all studies might have something to contribute to the review, for example, even if only to demonstrate the lack of high-quality research in this area.

Whilst this checklist meant that a 'quality score' could be determined for each study, the use of an aggregate score to represent methodological quality of a study may not be appropriate when certain criteria could be considered more important than others to the validity of a study. In cases such as these, an overall judgement of quality can be made based on the criteria which are most important to the research question (Murad et al., 2018). In the case of this review and the specific focus on TF CBT components consistent with NICE (2018) guidelines for the treatment of PTSD, it is argued that the questions regarding the reporting of the intervention and outcomes are the most important when considering the quality of the studies.

Synthesis of findings

A narrative synthesis was used to describe and compare the quality of the studies, the adaptations made to therapy for people with ID, the outcomes of the interventions and the components of TF CBT identified in the interventions consistent with NICE (2018) guidance. Detailed comparison of two or more cases, as in the current review, also allows us to gain insight into the ways in which case study methodology can be refined (Iwakabe & Gazzola, 2009).

Results

The results of the search strategy and filtering process are represented in Figure 1 using a PRISMA flow diagram (Moher, Liberati, Tetzlaff, & Altman, 2009). A total of eight studies were included in the final systematic review, all of which were case studies published in peer reviewed journals. Each of the studies were assigned a number for the purpose of this review and numbers are referred to throughout the

results section. The total number of participants is nine with all studies, except one, reporting a single case.

Figure 1

PRISMA flow diagram of study selection process

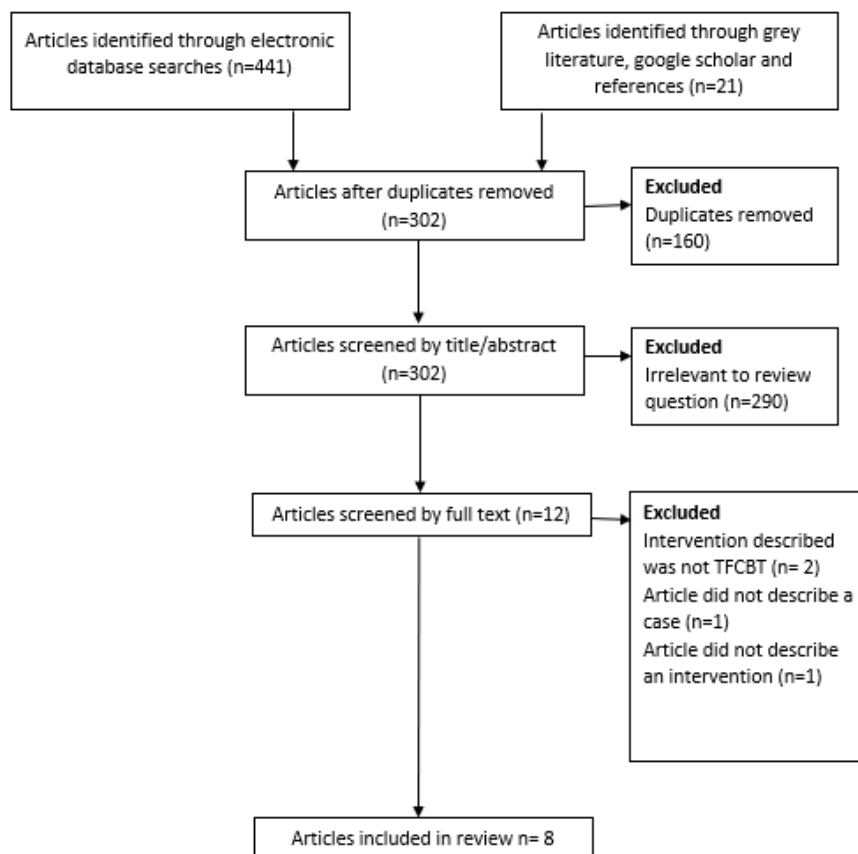


Table 1*Summaries of studies included in the review*

Study	Authors (year), location, source	Study aims	Sample (N, age, gender, ethnicity, level of ID, other diagnoses)	Presenting problem (PTSD symptoms)	Description of intervention (including No of sessions)	Description of how the therapy was adapted	Outcomes measured	Results
1	Bradshaw (1991), UK, references	To report the treatment of nightmares in people with a learning difficulty.	N=1 40-year-old male, level of ID not reported, Down's syndrome.	Nightmares occurring approx. every night.	Number of sessions not stated (likely to be 1). Rescripting of nightmare, rehearsed several times a day.	Support from family to rehearse.	Self-report-frequency of nightmares.	No recurrence of the nightmare in the 3 months following the intervention. In the second month after intervention, the participant returned to full social functioning.
2	Carrigan and Allez (2017), UK, database	To report the treatment of PTSD in a young man diagnosed with autism and a mild ID.	N=1 26-year-old male, mild ID, ASD.	Flashbacks, nightmares, avoidance.	12 sessions Psychoeducation about reactions to trauma, cognitive restructuring around trauma-related emotions such as self-blame, imaginal exposure to the trauma, psychoeducation around consequences of trying to suppress thoughts.	Initial meeting at family home, simplified model of PTSD using a metaphor to explain reactions to trauma.	Self-report questionnaire - Revised Child Impact of Events Scale (CRIES-8, Smith et al. 2003)	Decrease in score on the CRIES-8 from 32 at assessment to 11 at the end of therapy (suggested cut-off 17). Qualitative accounts of improved sleep and better relationships with siblings and nephew; these were maintained at 6 month follow up. No CRIES-8 administered at follow up.
3	Davison et al. (1994),	To describe the psychological	N=1	Flashbacks, intrusive thoughts,	8 sessions in phase 1, number of	Drawing pictures to explain the	Self-report questionnaire - Impact	At the end of treatment; no reported flashbacks and nightmares,

Study	Authors (year), location, source	Study aims	Sample (N, age, gender, ethnicity, level of ID, other diagnoses)	Presenting problem (PTSD symptoms)	Description of intervention (including No of sessions)	Description of how the therapy was adapted	Outcomes measured	Results
	UK, database	effects on a man with a learning disability who was sexually assaulted whilst in prison, and the treatment which was carried out.	19-year-old male, mild ID.	nightmares, avoidance.	sessions not stated in phase 2. Imaginal exposure to the assault, subsequently listened to on a tape between sessions, systematic desensitization to the traumatic experience of imprisonment preceding the assault.	traumatic experience.	of Events Scale (Horowitz et al. 1979), Beck Depression Inventory (Beck et al., 1961; Beck 1978). Observations of mood and behaviour.	physiological signs of distress when discussing the incident, IES score close to the score reported for men suffering from stress syndrome prior to treatment. At 2 month follow up, IES had reduced to within one standard deviation of men who have not suffered any trauma. Participant did not want to complete the BDI; psychiatric state mental examinations and observations indicated he was no longer suffering from depression.
4	Fernando and Medlicott (2009), New Zealand, database	To report the successful treatment of a client with an ID who experienced PTSD following abuse in an intimate relationship.	N=1 24-year-old female, mild ID.	Flashbacks and nightmares occurring approx. 4 times a week, avoidance of thinking about the abuse.	9 sessions Psychoeducation, relaxation training, problem solving, cognitive restructuring and limited exposure.	Individualised diary and Likert scale, use of analogy to explain trauma reactions, use of paper to visually create analogy of shield, role play.	Self-report –diary recording presence/absence of nightmares/flashbacks, daily ratings of mood on	Decrease in the number nightmares/flashbacks to zero a week, maintained at 5 month follow up. Improvement of average weekly mood over 12 weeks.

Study	Authors (year), location, source	Study aims	Sample (N, age, gender, ethnicity, level of ID, other diagnoses)	Presenting problem (PTSD symptoms)	Description of intervention (including No of sessions)	Description of how the therapy was adapted	Outcomes measured	Results
5	Jones and Banks (2007), UK, references	To describe the treatment of post-traumatic stress disorder in a 30-year-old man with moderate to severe ID.	N=1 30-year-old man, moderate ID.	Marked change in personality to aggressive and demanding, nightmares 4-5 times a night, anxiety around cars, avoidance of the site of the accident.	5 sessions Construction of a narrative of the car accident, taped onto a DVD with photos of the crash site and model cars used during the narration. DVD watched at least once per day and revised when the participant remembered more information.	Use of model cars to explain accident, support from father to recall narrative and visit crash site between sessions.	Likert scale. Self-report questionnaire (completed with support from father)-PTSD checklist (based on DSM-IV criteria, no reference given).	Positive change in the participant's appearance e.g. healthy nails (as opposed to bitten), new hairstyle, different dress. By the fourth session, the participant was largely symptom free and no longer met criteria for PTSD on the checklist, maintained at 14 week follow up. Father reported "it's put the 2 of us right", referring to himself and his son and the beneficial effects of the intervention.
6	Lemmon and Mizes (2002), USA, database	To describe a case study in which short-term exposure therapy, following numerous sexual assaults, was effective in reducing the symptoms of	N=1 32-year-old female, Caucasian, mild ID.	Distress/reactivity at exposure to external cues that resembled an aspect of the trauma, persistent avoidance and numbing,	25 sessions Relaxation and breathing exercises, imaginal exposure to traumatic events, imaginal and in vivo exposure to trauma-related cues.	First 4 sessions focused on establishing rapport and trust, simplified treatment rationale using metaphor, modified SUDS scale, adapting of processes; no requirement to tell the story in present tense, in vivo	Self-report measure - SUDS (Wolpe and Lazarus, 1966) taken before and after exposure.	SUDS ratings reduced by half for each traumatic event and trauma-related cue, indicating effective intervention. At discharge, the participant no longer appeared distressed/reactive when exposed to

Study	Authors (year), location, source	Study aims	Sample (N, age, gender, ethnicity, level of ID, other diagnoses)	Presenting problem (PTSD symptoms)	Description of intervention (including No of sessions)	Description of how the therapy was adapted	Outcomes measured	Results
		PTSD in a woman with mental retardation.		persistent symptoms of arousal (anger, hypervigilance).		exposure done during sessions rather than as homework.		trauma-related stimuli, no longer avoided talking about the events and anger outbursts and hypervigilance had significantly decreased.
7	Stenfert Kroese and Thomas (2006), UK, database	To present two case studies to illustrate the application of an adapted form of imagery rehearsal therapy to adults with learning disabilities.	N=2 Case 1= 18-year-old female, mild ID, dwarfism. Case 2 = 24-year-old female, mild ID, Down's syndrome.	Case 1 = Nightmares (approx. 6 per week). Case 2 = flashbacks and nightmares (approx. 3 per week).	Case 1 = 2 sessions Case 2 = 3 sessions Eliciting thoughts, feelings and meanings associated with nightmares, relaxation and imagery rehearsal therapy.	Use of drawings on a flipchart to help illustrate the dream and changes made to the dream (both cases), support from mother to rehearse (case 2).	Self-report - frequency of nightmares.	Case 1 = Frequency of nightmares reduced to approx. 3 per week within first 2 weeks of intervention. In the following 2 weeks the participant reported they had ceased, maintained at 4 and 6 month follow up. The participant also gained confidence in her ability to make changes in other areas of her life. Case 2 = By the end of the intervention the nightmares had ceased, maintained at 3 and 6 month follow up.
8	Willner (2004), UK, database	To describe the treatment of two recurrent nightmares,	N=1 29-year-old male, mild-moderate ID.	Nightmares (nightly), post-traumatic	3 sessions Relaxation, recounting of nightmare,	Use of fingers to remember 5 points to the new ending of the nightmare, support from staff	Self-report - frequency of nightmares	1 nightmare reported in the week following the first session and 1 nightmare in the second week.

Study	Authors (year), location, source	Study aims	Sample (N, age, gender, ethnicity, level of ID, other diagnoses)	Presenting problem (PTSD symptoms)	Description of intervention (including No of sessions)	Description of how the therapy was adapted	Outcomes measured	Results
		one of which was accompanied by congruent post-traumatic ruminations, in a man with mild to moderate learning disabilities.		ruminations (daily).	rescripting of ending (1 session), post-traumatic ruminations elaborated to include the factual ending (2 sessions).	to rehearse the new ending morning and night. Support from staff to rehearse the factual ending of the rumination morning and night.	(reported to staff).	At 6 and 12 month follow up, nightmare had occurred just once at 4 months. Ruminations ceased after two sessions. No reoccurrence reported at follow up. After intervention, the participant expressed empathy and regret for the victim of his own offence for the first time.

Quality appraisal

Table 2 shows that only one study (5) reported a clearly focused question, however, this may reflect the nature of clinical case studies; interventions may not have been considered for write up and submission for publication until after the participant had been discharged (as was reported in study 4). Therefore, at the time of delivering the intervention, there may have been no clear research question in mind. However, research questions could be implied for all studies due to the quantitative measures taken to explore the effect of different TFCBT techniques on symptoms of PTSD in people with ID. With this in mind, none of the studies were designed appropriately to answer these questions; all of the studies failed to report stable baselines before interventions commenced which is necessary in order to establish whether any improvement in the participant's presentation is a result of the intervention they have received and not just by chance (McLeod, 2010). This was compounded by the fact that some studies (2,3,6) failed to report or inadequately reported follow up data.

The rationale was made clear in all studies; a gap in the literature regarding trauma-focused interventions for people with ID. However, as with the lack of reporting a clearly focused question, none of the studies reported the criteria used to select the participant, probably because the intervention was undertaken as part of routine service. However, the demographics, history and presentation of participants were clearly described in all cases (within the limits of confidentiality). The participants in the research also appeared typical of the population to which findings will be referred, however, the transferability of findings to other settings was unclear for one study (3) which was conducted in a hospital setting; all other studies were community based.

None of the studies reported the epistemological position of the authors and only one study (7) included any information as to where the authors were positioned in relation to the participants and research process under study. The descriptions of interventions were also mixed; some studies (3,4,8) were too vague in their descriptions or only described one aspect of the intervention in detail which could be critical to quality in the current review due to its focus on components of TFCBT. Similarly, some studies (7,8) did not clearly describe methods for collecting data which affected the ability to appraise the research process fully. The outcomes of the interventions were clearly described in all studies.

All studies reported qualitative descriptions of outcomes, such as changes in presentation and a quantitative component, such as the number of self-reported symptoms (1,3,4,7,8) and/or the use of standardised measures (2,3,5,6). It is not common practice for authors of more quantitative studies to report their epistemological stance or position in the research which may reflect the absence of this, as mentioned above. Only the studies which used standardised measures scored points for the use of methods likely to be valid and reliable and the reporting of significance (i.e. cut off scores, reliable change). However, not all of these studies obtained a score of 2 due to the lack of credibility and trustworthiness of the qualitative methods also reported (3,6) and the use of a measures developed for children (2).

Only two studies (3,4) reported any potential biases within the research which is concerning considering the high likelihood of bias which can be associated with case studies (Murad et al., 2018). Furthermore, only one study (1) reported conclusions which were wholly grounded in the data. As already noted, study 1 was the oldest study reviewed and these more careful conclusions may reflect the lack of

research in the area at that time and perhaps a lack of prior assumptions about the effectiveness of interventions. Similarly, only some studies acknowledged and described the limitations of the research (1,2,3,4,5). Not all studies identified areas for future research (5,6), this is perhaps surprising when these studies are among the oldest reviewed when the gap in the literature for trauma-focused interventions for people with ID was even more pronounced.

Table 2*Quality appraisal*

Quality criteria	Study							
	1	2	3	4	5	6	7	8
1. Does the study address a clearly focused question?	0	0	0	0	2	0	0	0
2. Is the study design appropriate for answering the question?	0	0	0	0	0	0	0	0
3. Is it clear why the study is needed? (i.e. a gap in the literature/practice)	2	2	2	2	2	2	2	2
4. Is the epistemological position of the author(s) stated?	0	0	0	0	0	0	0	0
5. Has the author(s) stated where they position themselves within the research? (In relation to the subject, participants and research process.)	0	0	0	0	0	0	1	0
6. Are the criteria used to select the participant(s) clearly described?	0	0	0	0	0	0	0	0
7. Are the demographics, history and presentation of the participant(s) clearly described? (Within the limits of confidentiality.)	1	2	2	2	2	2	2	2
8. Are both the setting and participant(s) typical of the population to which the findings will be referred?	2	2	2	2	2	2	2	2
9. Is the intervention clearly described?	2	2	1	1	2	2	2	1
10. Are methods for collecting data clearly described?	0	2	2	2	2	2	1	1
11. Is there evidence that potential biases have been considered when reporting the study?	0	0	1	2	0	0	0	0

Quality criteria	Study							
	1	2	3	4	5	6	7	8
12. Are methods for analysing the data likely to be valid and reliable for quantitative methods and credible and trustworthy for qualitative methods?	0	1	1	0	2	1	0	0
13. Are the outcomes of the intervention clearly described?	2	2	2	2	2	2	2	2
14. Has significance been reported for quantitative data and credibility checks been completed for qualitative data?	0	1	1	0	2	1	0	0
15. Are the conclusions drawn justified by the data?	2	1	1	1	1	0	1	1
16. Are findings transferable to other settings?	2	2	1	2	2	2	2	2
17. Are limitations acknowledged and described?	1	2	1	2	2	0	0	0
18. Are areas for future research identified?	0	2	0	2	2	0	2	2
Total (36)	14	21	17	20	25	16	17	15

Adaptations

The number of adaptations reported by the studies ranged from one (1,3) to four (4,6). The adaptation most frequently reported, and by over half of the studies, was the use of visual aids (3,4,5,7,8). This ranged from the use of model cars to explain traumatic experiences (5) to the use of fingers to remember five points regarding a rescripted nightmare (8). With regards to the categories identified by Hurley et al. (1998), the inclusion of visual aids relates to the category 'developmental level', as techniques and the presentation of material were adapted to match the developmental level of the participant. It also relates to 'activities' in that participants were encouraged to actively participate in therapy sessions to facilitate therapeutic processes, such as when drawing out traumatic experiences (3,7) or making a shield out of paper to represent new coping strategies (4). Study 4 also made use of role play to make concepts more concrete. Both the use of visual aids and role play also demonstrates 'flexible methods' where usual techniques were adjusted to suit cognitive level.

The second most frequently reported adaptation was the addition of support from others to rehearse interventions outside of sessions (1,5,7,8). With regards to Hurley et al. (1998); this category was referred to as the 'involvement of care givers' to assist with therapeutic change and included the assignment of homework/rehearsal to be completed at home with the help of others.

The use of metaphors and analogies within therapy was also reported by three of the studies (2,4,6). These were used to facilitate understanding of trauma reactions and to explain the rationale for treatment. This type of adaptation could fall under a number of the categories identified by Hurley et al. (1998); the adaptation of techniques and material to the 'developmental level' of the participant; 'simplification'

of usual techniques to reduce complexity, adapting of 'language' to reduce level of vocabulary, sentence structure and level of thought required and 'flexible methods' to suit cognitive level. For example, study 2 reported the use of a simplified explanation of PTSD using the metaphor of the brain as a kitchen cupboard where the tins (trauma memories) have not been stacked properly and keep falling out.

Two studies (4,6) reported the modification of scales/diaries to report outcomes. This suggests adaptations under the categories of 'simplification', 'language', 'developmental level' and 'flexible methods' (Hurley et al., 1998). Two studies (2,6) also reported sessions that specifically focused on building rapport, such as an initial visit at home (2). This is in line with NICE (2018) guidance for the treatment of PTSD which recommends that when working with an individual with additional needs, extra time should be given to develop trust.

Finally, study 6 reported adapting the process of CBT techniques, for example completing all tasks in the session, rather than setting homework, which is usually a central component of CBT and allowing the participant to tell her story in the past tense, rather than the present tense which is usually required in exposure therapy. This again demonstrated 'simplification, 'language', 'developmental level' and 'flexible methods' (Hurley et al., 1998).

Outcomes

All studies reported positive outcomes (Table 1). Of the studies that used standardised measures (2,3,5,6), all reported decreased scores, some of which indicated effective intervention (6) or that the participant was no longer considered in the clinical range by the end of therapy (2,5). Only one study (5) reported a follow up period where tests had been re-administered, and a decrease in scores had been

maintained. For the studies that did not use standardised measures and simply reported the frequency of prominent symptoms, such as nightmares and flash backs (1,4,7,8), all reported a decrease in symptoms and that this decrease had been maintained at follow up.

With regards to the more qualitative descriptions of outcomes, again these all described positive changes and included; a decrease in distress when talking about traumatic experiences, improvements in confidence, changes in appearance, improved relationships and a return to full social functioning. For example, Study 2 reported that the participant seemed like a changed person; his sleep had improved, he was less argumentative with his parents and he was more affectionate with his siblings and nephew. Study 7 reported that following the intervention, the participant gained confidence to make positive changes in other areas of her life.

Table 3

Components of TFEBT specified in the NICE (2018) guidance

Study	Intervention based on a validated manual	Provided over 8 to 12 sessions	Delivered by trained practitioners	Includes psychoeducation about reactions to trauma, strategies for managing arousal and flashbacks, and safety planning	Includes elaboration and processing of the trauma memories	Includes processing of trauma-related emotions, including shame, guilt, loss and anger	Includes restructuring trauma-related meanings for the individual	Includes providing help to overcome avoidance	Includes focus on re-establishing adaptive functioning, for example work and social relationships	Includes preparing the client for the end of treatment	Includes planning booster sessions if needed
1					✓		✓				
2	*	✓		✓	✓	✓	✓	✓			
3				✓	✓	✓	✓	✓	✓		
4		✓		✓		✓					
5					✓			✓			
6	✓			✓	✓		✓	✓	✓	✓	✓
7	*			✓	✓	✓	✓				
8					✓		✓				

*Intervention follows a published protocol.

NICE (2018) guidance

None of the studies included in the review contained all of the components of TFEBT, as specified in NICE (2018) guidance (Table 3). The number of components included in interventions ranged from three (1,8) to nine (6). All but one of the studies included the elaboration and processing of the trauma memories either directly, through recalling the story (2,3,5,6), or indirectly through recalling nightmares of traumatic experiences which were subsequently processed and rescripted (1,7,8). Study 4 did not report, in the description of the intervention, that the original events resulting in the PTSD symptoms had been elaborated or processed during the course of the intervention.

Almost all of the studies (1,2,3,6,7,8) reported the restructuring of trauma-related meanings for the individual. This ranged from changing the meaning of nightmares from threatening/frightening to more positive scenarios (1,7,8) to distinguishing between situations that were globally dangerous, such as walking to the shop and specifically dangerous situations, such as walking to the shop alone at night (6).

The majority of studies (2,3,4,6,7,8) included an element of either psychoeducation about reactions to trauma, strategies for managing arousal and flashbacks and safety planning. This consisted mainly of teaching breathing and relaxation exercises (3,4,6,7,8); only some studies included psychoeducation about reactions to trauma (2,4,6). Only half of the studies in the review processed trauma-related emotions including self-blame/guilt (2,4,7) and anger (2,3,4). The other studies either did not report the presence of any trauma-related emotions (1) or did not directly treat them (5,6,8). Only half of the studies (2,3,5,6) reported interventions that were clearly provided to help

participants' overcome avoidance, such as in instances where participants blocked out thoughts regarding the traumatic experience or avoided the place where the incident took place. Help to overcome avoidance was most formally reported in study 6 where exposure hierarchies were constructed and systematically worked through.

Study 6 was the only study that reported preparing the participant for the end of treatment and included a section in the write up on discharge planning. They also included additional sessions at the end of treatment when the participant's brother committed suicide and therefore fulfilled the component regarding booster sessions. However, this component of TFCBT is only required if necessary. Only two studies (3,6) included a focus on re-establishing adaptive functioning, such as general assertiveness training and the inclusion of educational and leisure activities in the intervention plan; possibly because of lower expectations regarding adaptive functioning within the ID population generally, such as low rates of employment (Lysaght, Ouellette-Kuntz, & Lin, 2012). Study 6 was also the only study to base the intervention on a validated manual. However, both studies 2 and 7 clearly identified a published treatment protocol in their introduction which they had based their intervention on. The other studies did not report basing their interventions on validated manuals or published protocols and none of the studies reported that interventions had been delivered by trained practitioners.

Only two of the studies (2,4) provided between 8-12 sessions as recommended. Study 8 had 'brief cognitive therapy' in the title and consisted of three sessions altogether and studies 5 and 7 were also below the recommended number of sessions by NICE (2018). Whilst the number of

sessions is not stated in study 1, it would be reasonable to assume this intervention took place during one session. It has not been possible to identify the number of sessions involved in study 3. Study 6 consisted of 25 sessions and even without the additional sessions mentioned above, this would be considerably over the recommended amount. However, NICE (2018) recommends increasing the duration of sessions or the number of sessions for people with additional needs to build trust and this study specifically reported four sessions focused on building therapeutic alliance. This therefore suggests a likely adaptation to the nice (2018) guidelines when completing TFCBT specifically with adults with ID.

Discussion

The aim of this review was to consider the evidence base for individual TFCBT for adults with ID, and its consistency with current guidance (NICE 2018). Of the 11 components that NICE (2018) specify should be included in TFCBT, eight of these were present in a study dating back to 2002 and six of the components were identified in a study from 1994, suggesting some early anticipation of these guidelines. We can conclude that there is some consistency in the current evidence base with components of TFCBT specified by NICE (2018). However, future research should aim to incorporate all of the components of TFCBT into an intervention delivered in at least 8-12 sessions as we would expect the number of sessions to be increased for people with ID (BPS, 2016). Furthermore, TFCBT interventions specifically named in the NICE (2018) guidelines, such as narrative exposure therapy, should be explored for their effectiveness in reducing symptoms of PTSD in adults with ID. If this does

not occur, the lack of research into trauma-focused interventions for people with ID (Mevisen et al., 2016) will remain, denying this population the opportunity for evidence based treatments for PTSD to be established, as has happened previously with other mental health difficulties (Taylor et al., 2008).

The adaptations made to therapy for people with ID in the studies reviewed were consistent with most of the categories of adaptation identified in previous research (Hurley et al., 1998; Whitehouse, Tudway, Look, & Kroese, 2006). None of the adaptations in the studies reviewed appeared to fall in the categories of 'transference/countertransference' or 'disability/rehabilitation approaches', which was also reported by Surley and Dagnan (2019) in their review of adaptations of CBT for people with ID. However, they reported that the use of 'directive methods' was one of the most frequently reported interventions, in contrast to the current review where this was not apparent in any study. This could potentially reflect a more client-led approach when working with trauma more generally and encouraging post-traumatic growth (Joseph, 2015). The adaptations in the studies reviewed were also consistent with guidance for adapting CBT for people with ID by the BPS (2016) including the use of visual aids, flipcharts and role play as strategies to assist with poor memory and concentration, the involvement of significant others to facilitate real life change and efforts to establish therapeutic bond considering that people with ID may have little experience of working with professionals collaboratively.

All of the studies reported positive outcomes using different adaptations to therapy and different methods of assessing outcomes, therefore it is not possible to say whether interventions with more or less components of TFCBT specified by NICE (2018) or with more or less adaptations differed in

effectiveness. It does suggest that the adaptations, as outlined above, should be utilised in future research to maximise the potential for further positive outcomes. Due to issues in the quality of the research, as outlined below, it is also not possible to conclude, from the current evidence base, that TFCBT for PTSD in people with ID is effective. However, it is clear that the conclusions drawn by Mevissen et al. (2016) regarding the need for controlled studies to establish the effectiveness of TFCBT still very much stand and the positive outcomes reported by the studies in this review indicate a rationale for systematically trialling and evaluating TFCBT for people with ID.

A strength of this review is the inclusion of all research that was identified into the individual treatment of TFCBT for PTSD in adults with ID, as opposed to specifying design or methodology. This literature consists solely of case studies; we are aware of a group TFCBT pilot study (Stenfert Kroese et al., 2016) which reported positive qualitative accounts from participants. As far as we are aware, this is the only study in the literature to research group TFCBT for people with ID and to obtain qualitative accounts from people with ID of their experience of this therapy. The current focus on clinician reports is concerning considering the evidence that people with ID are capable of contributing towards research about their experience of psychological therapy (Ramsden, Tickle, Dawson, & Harris, 2016). The potential utility of third-wave CBT, specifically compassion-focused therapy for trauma in people with ID, has also been recently explored (Cowles et al., 2018). The authors cited three case studies of people with mild or moderate ID and reported improvement in several trauma related symptoms which warrants further exploration. The use of a positive behavioural support plan has also been cited in reducing challenging behaviour and trauma-related

symptoms (Langdon et al., 2017) and highlights an area of intervention not evident in the NICE (2018) guidelines for the treatment of PTSD in adults which could potentially benefit individuals with ID.

Although the construction of a quality appraisal tool for the purpose of this review could be considered a strength, through application of the criteria to studies, it became apparent that some criteria were redundant and could be omitted in future research. For example, when interventions have been implemented as part of routine practice, the research question and process of selecting the participant is often absent. If we put these criteria aside, the quality of the studies varied substantially which also made identifying the components of TFCBT, as specified by NICE (2018), difficult to establish and some studies may well have been underrated in their consistency because of this.

The quality appraisal did offer suggestions for how case study research in this area could be improved in the future. These include the consideration of potential biases in the research and limitations, adequate baseline and follow up measures for recording outcomes, valid and reliable methods of collecting data for quantitative methods and trustworthy and credible methods of collecting data for qualitative methods, sufficient detail given of the intervention to be replicated and more accurate drawing of conclusions that are grounded in the data.

A limitation of the current review is the restriction of grey literature searching to unpublished dissertations and theses. Expanding this search could have identified additional studies and further reduced the chances of publication bias; all studies in the current review are published and report positive outcomes. However, the review recommends that future research into TFCBT for PTSD in adults with ID should include: all components of TFCBT as

specified by NICE (2016); adaptations to interventions identified by previous research, which may contradict the guidance; high quality reporting of research; qualitative accounts from participants of their experience of the intervention. This would allow the current evidence base to be developed in order for clear guidelines for treating adults with ID to be established.

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Adapting the protocol for Narrative Exposure Therapy for adults with Mild Intellectual Disabilities

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Abstract

Background: Narrative Exposure Therapy (NET) is recommended by the National Institute for Health and Care Excellence (2018) to treat post-traumatic stress disorder in adults, however, there is a lack of research exploring the effectiveness of NET with adults with Intellectual Disabilities (ID). This study aimed to adapt the NET protocol for delivery with this population (IDNET).

Methods: Stage one of the study involved systematically adapting the NET protocol for adults with Intellectual Disabilities in collaboration with a service user group. Stage two involved gaining professionals' views on the adapted protocol and on the use of NET in ID services, to inform subsequent amendments. This comprised a focus group of Clinical Psychologists (CPs) specialising in ID and an expert panel of NET clinicians. The framework approach was conducted on the focus group data.

Findings: An adapted NET protocol and collection of 'easy read' therapy materials were developed (IDNET) which incorporated feedback from three expert groups. Key concepts of 'Optimism and motivation to adapt NET for people with Intellectual Disabilities' and 'Factors related to NET in practice' were developed to describe the views of CPs. A number of issues were raised by professionals regarding the delivery of IDNET.

Conclusions: Professionals were optimistic about IDNET, however, issues raised regarding the delivery of IDNET require exploration when IDNET is trialled in practice. Specific implications for clinical practice and future research are discussed.

Keywords: Intellectual Disabilities, Post-traumatic Stress Disorder, Narrative Exposure Therapy

Accessible summary

- A traumatic experience is something that happens to us that is very scary. It is also scary when we think about it afterwards.
- Narrative Exposure Therapy is a talking therapy. It helps people who have had more than one traumatic experience.
- We do not know if this therapy can help people with Intellectual Disabilities. Here, we talk to people with Intellectual Disabilities and those who work with them. We ask them how we can make this therapy suitable for people with Intellectual Disabilities.
- This is important because people with Intellectual Disabilities are more likely to have traumatic experiences than others.
- We hope that people will try using this therapy with people with Intellectual Disabilities. This will help us find out whether it is useful.

Background

Trauma

Psychological trauma has been defined as “the experience and psychological impact of events that are life-threatening or include a danger of injury so severe that the person is horrified, feels helpless, and experiences a psychophysiological alarm response during and shortly following the experience” (Schauer et al., 2011, p. 7). Although it is common to experience distressing symptoms following a traumatic event, for most people, symptoms resolve within the following weeks (Watkins et al., 2018). However, when symptoms persist and cause impairment in functioning, individuals may receive a diagnosis of post-traumatic stress disorder (PTSD).

The rise of trauma-informed care within health services in the UK has highlighted the need for patients to receive care that considers trauma and includes referral for trauma-focused treatment where appropriate (Sweeney et al., 2016). The National Institute for Health and Care Excellence (NICE; 2018) recommends individual trauma-focused cognitive behavioural therapy (TFCBT)

to treat PTSD in adults. Narrative Exposure Therapy (NET) is a TFCBT recommended by NICE (2018) *[see section 1.1 in extended for further information on NICE guidance for the treatment of PTSD]*.

Trauma among adults with Intellectual Disabilities

In 2015, it was estimated that just under one million adults living in England had Intellectual Disabilities (ID; Public Health England, 2016) *[see section 1.2 in extended for the definition of ID]*. Adults with Intellectual Disabilities experience a substantially higher prevalence of mental health conditions, when compared to the general population (Hughes-McCormack et al., 2017). They are also at greater risk of experiencing adverse life events (Wigham & Emerson, 2015); surveys suggest that three quarters have experienced at least one traumatic event, compared to one third of individuals within the general population (Martorell et al., 2009; McManus et al., 2016). It is therefore unsurprising that adults with Intellectual Disabilities are more vulnerable to PTSD than the general population (Fletcher et al., 2016). A recent review reported the pooled prevalence rate of PTSD to be 10% among people with Intellectual Disabilities (Daveney et al., 2019); this is in comparison to 4.4% among the general population (McManus et al., 2016). It is likely traumatic stress in adults with Intellectual Disabilities is even higher than rates suggest, due to factors such as diagnostic overshadowing, where symptoms are attributed to ID, and communication difficulties which prevent a diagnosis being identified (Byrne, 2020; Fletcher et al., 2016). Furthermore, in individuals with more severe Intellectual Disabilities, PTSD can often be misinterpreted as challenging behaviour or misdiagnosed as a feature of another psychiatric disorder (Bakken et al., 2014).

Treating trauma in adults with Intellectual Disabilities

There are no specific NICE guidelines for the treatment of PTSD in adults with Intellectual Disabilities. NICE (2016) advise guidance relating to specific mental health problems should be referred to when treating adults with Intellectual Disabilities, in conjunction with recommendations regarding

communication, tailoring interventions to individual needs, collaboration on decision making and additional support. However, NICE (2018) do make additional recommendations regarding the care of people with PTSD and complex needs. Whilst this does not refer to adults with Intellectual Disabilities, it suggests allocating extra time to develop trust, considering the safety/stability of the individual's circumstances, managing barriers to engagement, and planning ongoing support following treatment.

A systematic review found just eight case studies regarding TFCBT in adults with Intellectual Disabilities; the quality of these studies varied, as did adherence to NICE (2018) guidelines for TFCBT (Marlow et al., 2019) [*see section 1.3 in extended for further discussion on CBT for adults with ID*]. Therefore, whilst research suggests this population are at increased risk of developing PTSD, there is a lack of controlled research in this area (Byrne, 2020) and an absence of adapted TFCBT manuals. Consequently, clinicians working in ID services are forced to rely on clinical judgement to adapt evidence-based treatments developed among the general population (Truesdale et al., 2019). This is concerning given the inequalities in how people with Intellectual Disabilities are supported by mental health services, as opposed to the general population (Foundation for People with Learning Disabilities, 2014) and seminal work by Valerie Sinason dating back to the 1980s demonstrating the extent of abuse among this population and the improvements in emotional functioning following psychotherapy (Galton, 2018). If treatments are in NICE guidance, they should be adapted so that they are available to all, and this includes all TFCBT specified by NICE (2018), including NET.

Narrative Exposure Therapy

NET was developed for victims of multiple trauma and incorporates exposure therapy and testimonial therapy by exposing clients to traumatic events in chronological order and in the context of the rest of their life (Neuner et al., 2002; Robjant et al., 2017) [*see sections 1.4.1, 1.4.2 and 1.4.3 in extended for further information regarding the theory underpinning NET, the process of NET and the evidence base*]. A number of adaptations have allowed

NET to be delivered with children/adolescents (KidNET; Schauer et al., 2011), veterans/violent offenders (FORNET; Hecker et al., 2015), survivors of a single traumatic event (NET-R; Zang et al., 2014) and gender diverse people (TA-NET; Lange, 2020). However, there is a lack of research literature exploring how NET can be adapted for adults with Intellectual Disabilities, in fact, having an ID can exclude participants from research exploring the effectiveness of NET (for example Orang et al., 2018; Peltonen & Kangaslampi, 2019). This is despite the notion that treatments recommended by NICE should be available for all and evidence to suggest that adults with Intellectual Disabilities can access psychological therapies for traumatic stress with appropriate adjustments (Truesdale et al., 2019).

At face value, the directive and repetitive nature of NET appears suited to an ID population. As far as the authors are aware, there is only a single published article which reports the use of NET with a client with Intellectual Disabilities (Fazel et al., 2020); the authors state that the lower cognitive demands placed on individuals during NET may mean it is more accessible for this population (Fazel et al., 2020). Whilst this research relates to an adolescent, adaptations which could be generalised to adults with Intellectual Disabilities are outlined, such as the provision of written prompting questions *[see section 1.5 in extended for further information on NET with people with ID]*. The literature base relating to KidNET can also be consulted for developmentally appropriate adaptations for use within an ID population *[see section 1.6 in extended for further information about KidNET]*.

Adapting psychological therapies for adults with Intellectual Disabilities

In addition to the NICE (2016) guidelines, a number of other guidelines and recommendations exist to support the adaptation of psychological therapies for adults with Intellectual Disabilities. The British Psychological Society (BPS) offers guidance on adapting CBT which is relevant to NET as a TFCBT specified by NICE (Jahoda, 2016). This proceeded Lindsay et al. (2013), who outlined implications for therapy based on cognitive deficits and earlier work by Hurley et al. (1998) who described the major adaptations required for psychotherapy within this population. It is also essential to consider the

guidance around accessible communication formats to inform the development of 'easy read' therapy materials, such as that provided by the Department for Work and Pensions (DWP; 2018); Department of Health (DOH; 2010); and NHS England (2018) *[see sections 1.7 and 1.8 in extended for further information on adapting psychological therapies for adults with Intellectual Disabilities and accessible communication formats]*. The above literature can therefore be drawn upon when exploring how NET can be adapted for adults with Intellectual Disabilities *[see section 1.9 in extended for further information on rationale]*.

Study aim

To adapt the protocol for NET for delivery with adults with Mild Intellectual Disabilities.

Research questions:

- How can NET be adapted for adults with Mild Intellectual Disabilities to create a new protocol (IDNET) for further investigation in clinical practice?
- What are the views of service users on the IDNET therapy materials developed and how can they be incorporated?
- What are the views of professionals on using NET in ID services and on the adapted protocol (IDNET), and how can they be incorporated?

Methodology

Design

Stage one: Developing IDNET

The lead researcher collaborated with a Speech and Language Therapist (SALT) to develop IDNET. This was triangulated by consultation with a service user group who provided feedback on the accessibility of the therapy materials for an ID population *[see sections 2.1 and 2.2 in extended for further information relating to the SALT and service user involvement in research]*.

Stage two: Gaining the views of professional experts

A focus group comprising CPs working in ID services was conducted *[see section 2.3 in extended for justification for the focus group and alternative methods of data collection considered]*. CPs were required to be registered with the Health and Care Professions Council and have at least 2 years of experience working in ID services. This stage also involved an expert panel comprising NET clinicians who were required to be English speaking and have an active interest in and practical experience of delivering NET *[see sections 2.4 and 2.5 in extended for information regarding the gaining of ethical approval and ethical considerations and epistemology underpinning the current research]*.

Procedure

Stage one: Developing IDNET

The NET manual (Schauer et al., 2011) provides a step-by-step description of the process of NET. This was worked through systematically by the lead researcher and SALT over the course of nine virtual meetings, considering at each step how the therapy could be adapted and what 'easy

read' therapy materials were required. This process was continuous and iterative and involved referring to the following:

- Adaptations to psychotherapy techniques for adults with Intellectual Disabilities (Hurley et al., 1998)
- Adapting CBT for people with Intellectual Disabilities and cognitive deficits (Jahoda, 2016; Lindsay et al., 2013).
- Guidance on developing accessible communication formats (DWP, 2018; DOH, 2010; NHS England, 2018).
- Developmentally appropriate adaptations to NET already documented in the literature (Fazel et al., 2020; Schauer et al., 2011).

Following this, the service user group was consulted to provide written feedback on the accessibility of the 'easy read' materials. A virtual meeting was held subsequently between the lead researcher and the group in order to clarify written feedback where necessary, gain a majority decision on certain changes to the materials and to gain verbal feedback from the group. The lead researcher met with the SALT subsequently to discuss this feedback and agree changes to the therapy materials.

Stage two: Gaining the views of professional experts

Recruitment. CPs were recruited via an advert circulated by the Chair to all members of the British Psychological Society's Division of Clinical Psychology Faculty for People with Intellectual Disabilities. NET clinicians were recruited via a snowballing sample where the lead researcher emailed clinicians prominent in the field (see section 2.6 in extended for further information about how NET clinicians were recruited). Potential participants were asked to contact the lead researcher directly and were subsequently sent a Participant Information Sheet which included information relating to ethical considerations. If willing to participate, CPs and NET clinicians were asked to complete a Consent Form and a demographics questionnaire. All correspondence with

participants was conducted via email [see appendices J, K, L, and M for Participant Information Sheets and Consent Forms].

Data collection. CPs were emailed IDNET and asked to provide written feedback on how the therapy materials and adapted protocol could be improved. Most of the feedback was integrated anonymously by the lead researcher if it included minor changes to wording or was suggested by the majority of the participants. The remaining feedback was taken to the focus group discussion. The amended IDNET was returned to CPs to review prior to the focus group and CPs were asked to inform the lead researcher of any amendments which they believed were inappropriate. Following this, CPs participated in a virtual focus group discussion facilitated by the lead researcher; the first half involved participants reaching majority agreement in relation to changes to IDNET suggested by the remaining feedback, the second half was a group discussion facilitated using a semi-structured interview schedule exploring participants' views regarding the use of NET within ID services.

Following the CP focus group, NET clinicians were emailed the amended IDNET to review prior to the virtual expert panel discussion. This was facilitated by the lead researcher using a semi-structured interview exploring participants' views on delivering NET with adults with Intellectual Disabilities and the consistency of IDNET with the theory underpinning NET [see appendix N for interview schedules developed in collaboration with the research team and section 2.7 in extended for a visual depiction of the research procedure].

Data analysis

The focus group discussion was transcribed by the lead researcher and a deductive framework approach (FA; Ritchie & Spencer, 1994) was employed, which was reviewed within the research team to uphold quality. A top-down deductive approach to the data was deemed more suitable than a bottom-up inductive approach, due to the prior understanding that the research team had in relation to the topics explored by the research, meaning a truly inductive approach was not possible. FA was chosen for the analysis as this approach is

suites to “research that has specific questions, a limited time frame, a pre-designed sample (for example, professional participants) and a priori issues” (Srivastava & Thomson, 2009, p. 73) *[see sections 2.8 and 2.9 in extended for further discussion regarding FA/other methods of analysis considered and upholding quality]*.

Due to the smaller number of participants recruited to the expert panel, a qualitative analysis was not appropriate. Instead, participants’ comments were summarised, and a collaborative decision was made within the research team regarding whether comments were either: actioned and led to amendments to IDNET; were disregarded due to already existing within IDNET or because they were deemed inappropriate for an ID population; and/or identified as future research questions to be explored when IDNET is trialled in practice.

Results

Stage one: Developing IDNET

Developing therapy materials and adapting the NET protocol

A protocol was developed which comprised recommendations for how NET could be adapted for adults with Mild Intellectual Disabilities, in addition to six information sheets and nine handouts in ‘easy read’ format which mapped onto the psychoeducational examples in the NET manual *[see section 3.1 in extended for a summary of meetings between the lead researcher and SALT]*. Table 4 shows examples of how IDNET was developed *[see section 3.2 in extended for further information relating to the development of the ‘easy read’ materials]*. Guidance relating to ‘easy read’ was referred to throughout the development of the therapy materials and therefore is not referred to specifically in Table 4. However, this includes the use of at least 14-point font size and ensuring that sentences are short and include only one verb (DWP, 2018).

Table 4

Examples of how IDNET was developed

What was developed?	How was relevant guidance followed?	How did it differ to the NET manual?
Information sheet 'Is this normal?'	<ul style="list-style-type: none">• Material was presented visually to support cognitive deficits (Beail, 2016; Fazel et al., 2020; Lindsay et al., 2013).• Material was simplified by breaking information into smaller chunks to support executive functioning (Hurley et al., 1998; Lindsay et al., 2013).• Language was adapted to reduce the level of vocabulary (Hurley et al., 1998; Lindsay et al., 2013).	<ul style="list-style-type: none">• Psychoeducational examples are provided for therapists to use verbally.• Complex sentences are used including more than 15 words and one verb.• Complex vocabulary is used, such as perceive and hypervigilant.
IDNET: The Lifeline exercise	<ul style="list-style-type: none">• Repetition of the rationale for the lifeline exercise is recommended (Fazel et al., 2020; Lindsay et al., 2013).	<ul style="list-style-type: none">• It is not stated when/how the rationale is explained to clients.

What was developed?	How was relevant guidance followed?	How did it differ to the NET manual?
	<ul style="list-style-type: none"> • Visual aids are recommended, such as emotion pictures to support the client’s understanding of the meaning of the rope/stones/flowers (Fazel et al., 2020; Lindsay et al., 2013). • Directive questioning is recommended to keep the client focused on the lifeline as a whole once completed (Hurley et al., 1998). • The way in which carers might support the client, if necessary, is suggested (Beail, 2016; Hurley et al., 1998; Lindsay et al., 2013). • Completing the lifeline in one session is recommended if possible, however, it may need to be broken down (Beail, 2016; Hurley et al., 1998). 	<ul style="list-style-type: none"> • There is no reference to the use of visual aids during the lifeline exercise. • There is no reference to how this is achieved. • There is no reference to how carers can be involved. • It is stated the lifeline exercise should be completed within one session.

What was developed?	How was relevant guidance followed?	How did it differ to the NET manual?
IDNET: Narration sessions	<ul style="list-style-type: none"> <li data-bbox="512 472 970 730">• Increased prompting and direction from the therapist are recommended to support the client’s narration (Hurley et al., 1998). <li data-bbox="512 808 970 1171">• Repetition of the rationale for narration, including psychoeducation about exposure, is recommended throughout sessions (Fazel et al., 2020; Lindsay et al., 2013). <li data-bbox="512 1249 970 1944">• Visual resources are recommended to support the client’s expression. This includes the use of drawings, role play and visual prompts to guide the client in narrating different aspects of their experience, which also increases predictability for the client (Fazel et al., 2020; Hurley et al., 1998; Schauer et al., 2011). 	<ul style="list-style-type: none"> <li data-bbox="999 472 1350 618">• Some example questions are suggested. <li data-bbox="999 808 1350 1066">• A rationale for the narration is only described during the initial psychoeducation. <li data-bbox="999 1249 1350 1666">• There is no reference to visual aids when exploring . sensory, cognitive, emotional, and physiological elements of the narration.

What was developed?	How was relevant guidance followed?	How did it differ to the NET manual?
IDNET: The duration and number of narration sessions.	<ul style="list-style-type: none"> • Additional time in sessions is recommended for clients to process information/emotions and return to baseline levels of arousal (Fazel et al., 2020). • Shortening of session duration is recommended as well as breaks if necessary, which may mean the number of sessions is increased (Beail, 2016; Hurley et al., 1998; Lindsay et al., 2013). 	<ul style="list-style-type: none"> • There is no reference to how long this usually takes. • It is stated that 8-12 sessions of NET are usually necessary.

Consultation with the service user group

The service user group provided 76 written comments on the ‘easy read’ materials. This included both positive comments, relating to where the group believed the materials were accessible for adults with Mild Intellectual Disabilities, and suggestions for improvement. Suggestions included changes to the formatting of the materials and to the choice of certain words and symbols. Feedback was clarified subsequently at the virtual meeting and the lead researcher and SALT agreed all suggestions from the service user group were in line with guidance being adhered to and were therefore incorporated [see section 3.3 in extended for further information on the service user group

feedback and an example of how feedback was incorporated into the 'easy read' materials].

Stage two: Gaining the views of professional experts

Feedback from CPs

Eight CPs working in ID services across the UK and the Republic of Ireland were recruited; this included four females and two males (two did not disclose gender identity). Participants ages ranged from 35-54 years and all participants had at least eight years of experience working within ID services. CPs provided 341 written comments relating to IDNET and the 'easy read' materials. A large proportion of the comments were repeated across the feedback from the CPs. Comments were condensed into the following categories *[see section 3.4 in extended for examples of written feedback from CPs pertaining to each of these categories]:*

'Easy read' materials

- Positive comments relating to accessibility
- Suggestions for alternative formatting
- Suggestions for alternative wording
- Suggestions for additional information

The adapted protocol

- Positive comments relating to the protocol
- Suggestions for preparing clients for NET
- Suggestions for how carers are involved
- Suggestions for how the safety and well-being of clients is considered
- Suggestions for supporting the content of sessions
- Suggestions for adapting the structure of NET

Of the 341 comments, 318 were implemented immediately due to meeting the conditions outlined in the methodology section. No concerns were

raised by CPs subsequently with regards to the suitability of these amendments. The remaining 23 comments were taken to the focus group to seek a majority consensus on whether they should be actioned or not (this consisted of seven CPs as one participant was unable to attend). For example, there was disagreement within the written feedback about the use of photos versus symbols to depict emotions and the use of different terminology, such as ‘trauma’ as opposed to ‘bad or difficult thing’. Following these majority decisions, the ‘easy read’ materials and adapted protocol were refined.

Focus group discussion with CPs

Table 5 shows the development of the two key concepts identified as a result of FA.

Table 5

Key concepts developed from initial codes and themes

Initial codes	Final themes	Core concepts
<ul style="list-style-type: none"> • The feasibility and potential usefulness of NET • NET working well in practice • The accessibility of NET compared to other trauma therapies • NET matching expectations about trauma therapy 	Optimism about the suitability of NET for people with Intellectual Disabilities	Optimism and motivation to adapt NET for people with Intellectual Disabilities
<ul style="list-style-type: none"> • Recognising and understanding trauma in people with Intellectual Disabilities 	Motivation to adapt NET for	

Initial codes	Final themes	Core concepts
<ul style="list-style-type: none"> The lack of treatment options for trauma in people with Intellectual Disabilities The benefits of adapting evidence-based treatment 	<p>people with Intellectual Disabilities</p>	
<ul style="list-style-type: none"> The complexities of working with people with Intellectual Disabilities The potential challenges of trauma therapy generally The potential challenges of delivering NET The resistance from others to adapt therapies for people with Intellectual Disabilities 	<p>Challenges to overcome</p>	<p>Factors related to IDNET in practice</p>
<ul style="list-style-type: none"> Understanding and support required from the system around the client The potential challenges related to the system around the client 	<p>The system around the client during therapy</p>	
<ul style="list-style-type: none"> Practical considerations when delivering IDNET Decisions about who should deliver therapy The similarities of NET to other therapies Thinking about adaptations to NET and the need to learn more 	<p>The practicalities of delivering and adapting NET</p>	

Initial codes	Final themes	Core concepts
<ul style="list-style-type: none"> Adapting approaches for people with Intellectual Disabilities generally 		

Optimism and motivation to adapt NET for people with Intellectual Disabilities. Whilst this key concept supports the rationale for the research, focus will be on the second key concept due to its relevance to the study aim [see section 3.5.1 in extended for further information relating to the key concept of ‘Optimism and motivation to adapt NET for people with Intellectual Disabilities’].

Factors related to IDNET in practice. This comprised three themes which are illustrated below with accompanying quotes [see section 3.5.2 of extended for additional participant quotes].

Challenges to overcome. CPs highlighted the diversity of clients with Intellectual Disabilities, who require treatment which is flexible and adapted to their needs. The specific challenges of delivering trauma-focused therapy within ID services were also discussed, such as the need for some level of stability for the client and being unable to fully adhere to manualised approaches. Furthermore, CPs identified resistance from those trained in certain models to adapting therapies and experiences where access to training had been restricted/difficult due to being unable to fully adhere to the approach or because there was no evidence using that model within the population. However, one clinician did report an instance of perceiving a trainer as more open to adaptations.

the client group being so diverse and all of the adaptations and the flexibility that you have to do-Sam

when we're delivering trauma work it seems we're also trying to sort out their general lives as well and how that fits with a manualised therapy, I think it would very quickly, there'd be issues with the fidelity of the treatment -Hugo

we've had exactly the same battles, huge battles with EMDR [Eye Movement Desensitization and Reprocessing] people about, they call it model drift and sticking to the protocol-Lisa

The system around the client during therapy. CPs highlighted the need for the system to have an understanding of NET, including how it might impact the client during therapy, so that the client is supported accordingly. Discussions also highlighted potential challenges, such as the impact of carers' emotional responses on the client and the risk that others in the system may attempt to continue NET sessions themselves without appropriate training.

there's the issue about support between sessions . . . it's important the people around the person are aware of perhaps the approach and some of the impacts it may have on the person as they're going through-Marcus

if someone you know feels worse before they get better, family members or carers can really panic, which you know can really unsettle the service user-Mary

The practicalities of delivering and adapting NET. This included practical considerations, such as the time and cost implications of NET, as well as which professionals are able to deliver NET. CPs also reflected on aspects of NET that may be similar to other therapies which already work in practice within this population. The need for NET to be adapted and trialled in practice was highlighted, in order to review and identify further adaptations and CPs discussed the process of adapting approaches for people with Intellectual Disabilities more generally. It was highlighted that in practice this responsibility often falls to individual clinicians.

there are these things that are the kind of contextual factors that hold these therapies-Hugo

I suppose in a way we won't know until we try it a bit more and then we come back together and you review it and you adapt and you change it again-Lisa

to pick things up and implement them and adapt them and change them around it does require a broad range of understanding and experience and knowledge-

Mo

Feedback from NET clinicians

Three NET clinicians were recruited internationally; participants were female with at least nine years of experience delivering NET and ages ranged from 45-64 years. One participant reported instances of using NET in practice with adults with Intellectual Disabilities and all participants believed the delivery of NET may not differ drastically from other populations. Examples of topics discussed and how they were responded to are given below [see section 3.6 in extended for further details on feedback from NET clinicians and how it was actioned, which will be submitted as an appendix to the journal]:

Actioned and led to amendments to IDNET. The expert panel suggested if carers were present, as suggested in IDNET, therapy might continue outside of sessions and therefore the protocol was amended to emphasise that this should not occur. NET clinicians stated that clients do not need to be able to manage their own arousal, again as suggested in IDNET, as this is managed by the therapist. However, within ID services, if clients are unable to manage their own arousal, this could have potentially devastating consequences, such as a break down in their accommodation placement. Therefore, the protocol was amended to state that if the client is unable to manage their own arousal, the team around the client should understand that increases in distress are possible and have appropriate ways of managing this.

Disregarded due to already existing or being deemed inappropriate.

The expert panel advised against carers supporting in lifeline and narration sessions. However, NICE (2016) recommends carers are involved in the treatment of mental health difficulties within ID services, therefore it was deemed inappropriate to exclude carers at this stage. Furthermore, IDNET outlines factors to consider when determining appropriate carers.

Identified as a future research question when IDNET is trialled in practice. The impact of the presence of carers in all sessions during IDNET, and whether the client is required to have some ability to manage their own arousal prior to starting therapy, were identified as areas to be explored further.

Discussion

As a first attempt to systematically adapt NET for adults with Intellectual Disabilities, in collaboration with a number of different expert groups and drawing on a range of published guidance, this study demonstrates an original contribution to the literature relating to trauma-focused therapies for this population. The study also adheres to recommendations regarding the involvement of people with Intellectual Disabilities in both the development of 'easy read' materials (DWP, 2018; DOH, 2010) and research (Walmsley & Johnson, 2003). Studies such as this, offer further avenues for clinicians working within ID services to explore when considering suitable treatments for PTSD and a more rigorous process was followed when developing IDNET, than the clinical judgement often used in practice when adapting evidence-based treatments for this population (Truesdale et al., 2019). However, the study is limited by the failure to recruit more than three participants to the expert panel, which may mean the views expressed here are only representative of a very small number of NET clinicians. Additionally, dominant voices existed among all expert groups involved within the research, which may have silenced participants who held opposing views (Kitzinger, 1995). Similarly, the order in which groups gave feedback on IDNET may have meant the views of earlier

groups were unintentionally overridden during subsequent stages *[see section 4.1 in extended for further information relating to limitations]*.

The focus group highlighted a number of issues which warrant further consideration, such as the impact of the system around the client during therapy and the practicalities of adapting and delivering NET, which have important clinical implications *[see section 4.2 in extended for further discussion on the system around the client during therapy]*. The challenges faced by clinicians when trying to adapt and deliver trauma-focused therapies were also highlighted; mirroring topics raised previously by professional (Truesdale et al., 2019). Among these was resistance to adapting evidence-based approaches, perhaps in an attempt by others to avoid what has been termed ‘therapist drift’ (Waller & Turner, 2016). However, there may be some confusion between ‘therapist drift’, where clinicians deviate from evidence-based practice when treatments are viable, and the need to adapt treatments to make them accessible for all *[see section 4.3 in extended for further discussion on ‘therapist drift’ in the context of the current research]*. Challenges such as this highlight why people with Intellectual Disabilities are among those most disadvantaged in our society (Equality and Human Rights Commission, 2016), not only due to impairments in functioning, but also as a result of the multiple barriers they face in their environment *[see section 4.4 in extended for further discussion on the multiple disadvantages of people with ID]*. Although, it does point to further research implications regarding how adherence to IDNET can be measured in practice.

The expert panel also raised a number of contradictions to IDNET, which require further consideration, and which may lead to changes in the theory underpinning NET. For example, CPs thought that clients with Intellectual Disabilities should have some ability to manage their own arousal prior to completing IDNET, however, NET clinicians advised that this contradicts NET practice. Whilst the current evidence base may support certain ways of delivering NET, it is inevitable that when NET is trialled among people with Intellectual Disabilities, new ways of working are likely to emerge, as has been observed in KidNET, FORNET, NET-R and TA-NET. In relation to this, whilst a strength of the research design is the gaining of contributions from three major stakeholders in this area, it raised questions about which views are given

preference when developing IDNET. NET is a manualised and structured approach to treating trauma, which was designed to be delivered individually (Schauer et al., 2011), whereas key adaptations to psychotherapy when working with people with Intellectual Disabilities are the need to use flexible methods and involve carers (Hurley et al., 1998). Therefore, this raises the question of what happens when these two different approaches to therapy come together. Whilst this has been explored initially in the current research, this question will not be answered fully until the adapted protocol is trialled in practice.

The feasibility and effectiveness of IDNET will also need to be explored in practice, including the 'easy read' materials. Research is required to evaluate whether these materials are effective in increasing understanding of NET among people with Intellectual Disabilities, as the current evidence may not support the effectiveness of 'easy read' (Chinn & Homeyard, 2017; Hurtado et al., 2014). However, the fact that NET was developed among refugee populations (Robjant & Fazel, 2010), who may share similar characteristics to adults with Intellectual Disabilities in terms of risk of ongoing trauma, often powerlessness and need for social justice, provides further hope that this therapy can benefit this population. The focus group also showed optimism for IDNET and both groups of professionals reported instances of the use of NET with people with Intellectual Disabilities in practice already. The current research therefore indicates a number of implications for research and calls for a piloting and feasibility stage *[see section 4.5 in extended for a full list of future research questions]*. This is in line with guidance from the Medical Research Council regarding the development of complex interventions (Craig et al., 2008) and would mark the next step in what should be the long-term aim of conducting a randomised controlled trial (RCT) into the use of IDNET. Although RCTs can be challenging within this population, they are possible with adaptations and are a moral necessity (Mulhall et al., 2018) in order to increase the evidence base with regards to trauma-focused therapies for adults with Intellectual Disabilities.

Finally, during the course of the current research, Mayer (2020) conducted an intervention study with adults with Intellectual Disabilities comparing a control group with a group receiving NET. This provided initial evidence of the positive impact of NET within this population and echoed

recommendations arrived at during the current research, such as the need to shorten the duration of sessions and the use of more visual tools during therapy. The current research adds to this by systemically adapting the NET protocol with a number of stakeholders including service users, who were not consulted by Mayer (2020). The two studies therefore offer hope that NET may benefit clients with Intellectual Disabilities, and initial guidance for clinicians on how delivering NET may differ within this population.

Conclusions

The current research demonstrates the process of systematically adapting a NICE (2018) recommended trauma-focused therapy (NET) for adults with Mild Intellectual Disabilities, in collaboration with a number of expert groups. Research like this creates a starting point when developing the evidence base for PTSD treatment in adults with Intellectual Disabilities. Future research should aim to explore the delivery of IDNET in practice to not only understand more about whether NET is feasible and effective in reducing symptoms of PTSD among adults with Intellectual Disabilities, but also to answer further questions raised in relation to how IDNET is delivered.

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Extended Paper

1.0 Extended background

1.1 National Institute for Health and Care Excellence guidance for the treatment of post-traumatic stress disorder

NICE provides guidance for clinicians in the health service, including the treatment of mental health difficulties (Dagnan et al., 2018). NICE guidelines enable research into different clinical presentations to be “carefully interpreted and translated to ensure its appropriate application to routine clinical care” (Forbes et al., 2010, p. 552). The guidelines are advisory, rather than mandatory, and should be considered in line with the individual needs of the client (Murphy, 2017). Whilst the guidelines have been formulated to facilitate optimal standards of care, their implementation in clinical practice is variable and may depend on a number of factors such as whether the service has a system for tracking implementation and whether clinicians are isolated (Sheldon et al., 2004).

In relation to the treatment of PTSD, NICE (2018) recommends trauma-focused cognitive behavioural therapy (TFCBT). TFCBT comprises a number of therapies which include four main techniques to support an individual following a traumatic experience, each of which can be emphasised in various degrees: psychoeducation; anxiety management; imaginal or in vivo exposure; and cognitive restructuring (Bisson et al., 2013). Whilst the therapies outlined as TFCBT in the NICE (2018) guidance differ in terms of their emphasis on the above components (Byrne, 2020); psychoeducation, accessing and altering of memories, reappraising the meaning of traumatic experiences, and discriminating between the past trauma and the present are common across TFCBT approaches (Schnyder et al., 2015). TFCBT was found to be clinically effective in treating PTSD in a recent meta-analysis (Lewis et al., 2020), however, a number of limitations to the evidence base were outlined including the possibility of publication bias and the exclusion of clients with psychosis, substance dependence or severe depression in some of the studies. This limits the generalisability of treatment effects to more diverse and perhaps marginalised clients with PTSD, such as those with ID.

1.2 Definition of Intellectual Disability

ID is defined as the presence of significant impairments in both intellectual functioning and adaptive behaviour, commencing during the developmental period (American Psychiatric Association, 2013; BPS, 2015; World Health Organisation [WHO], 2020). ID has been broken down in terms of severity into Mild, Moderate, Severe and Profound. Mild ID is defined as impairment falling two to three standard deviations below the population mean, based on standardised testing. However, most individuals diagnosed with Mild ID can master basic skills and live independently with some support. Those with moderate levels of ID show impairment in intellectual functioning and adaptive behaviour three to four standard deviations below the mean and therefore generally require much more support than those with Mild ID to achieve independent living. Severe and profound ID is characterised by four or more standard deviations below the population mean and is differentiated based on adaptive functioning, as standard intelligence testing is not suitable for these individuals. Those with severe ID may have limited language abilities and whilst they typically require daily support, they may be able to learn basic skills for self-care with intensive training, whereas those individuals with profound ID have very little communicative abilities and typically require daily support in a supervised environment. In terms of IQ scores, the different levels of ID correspond to the following IQ ranges; Mild ID 50-69, Moderate ID 35-49, Severe ID 20-34, and Profound ID 0-20 (WHO, 2020).

1.3 CBT with people with ID

People with an ID within the mild range have been found to have the necessary skills, or the ability to learn the necessary skills, required to engage in aspects of the cognitive component of cognitive behavioural therapy (CBT; Bruce et al., 2010; Taylor et al., 2008). Furthermore, adults with Mild ID report positive experiences from engaging with CBT, however, there is a lack of research exploring experiences of CBT from the clients themselves (Pert et al., 2013). Reviews of the literature demonstrate the increasing evidence base for the effectiveness of CBT for people with ID for presentations such as anger,

depression, and anxiety (Nicoll et al., 2013; Unwin et al., 2016; Vereenooghe & Langdon, 2013; Willner et al., 2013). A published treatment manual also exists for the use of CBT for people with Mild ID and mood disorders (Hassiotis et al., 2012). However, the current research base is limited by a lack of comparative control groups, small samples sizes and a lack of attention to treatment fidelity (Nicoll et al., 2013; Vereenooghe & Langdon, 2013). Whilst Cooney et al. (2017) reported a reduction in anxiety symptoms as a result of computerised CBT, using a randomised-controlled design, research in this area is also sparse. This results in clinicians in ID services making decisions about the appropriateness of CBT based on the limited research available (Cooney et al., 2018). Mulhall et al. (2018) explored the barriers to completing randomised-controlled trials (RCTs) with people with ID: difficulties with recruitment, consent, adapting interventions and resources for people with ID, and appropriate outcome measures, were all noted. The authors concluded that whilst there are challenges to including people with ID in RCTs, it is possible with adaptations and a moral necessity.

With regards to the research literature relating to individual TFCBT for adults with ID, the following studies were identified by Marlow et al. (2019) in a systematic literature review: Bradshaw (1991); Carrigan and Allez (2017); Davison et al. (1994); Fernando and Medlicott (2009); Jones and Banks (2007); Kroese and Thomas (2006); Lemmon and Mizes (2002); Willner (2004). This research base comprises only case studies and the small number identified, dating back to the early 1990s, further emphasises the lack of research into trauma-focused treatments for adults with ID and the slow rate of development in the evidence base generally (Mulhall et al., 2018). All of the studies identified reported positive outcomes in the treatment of symptoms of trauma and this included a range of both qualitative and quantitative methods of evaluation. However, there were a number of limitations in the quality of the methodology employed by the studies and in the reporting of the research, such as a lack of: clearly focused research questions; use of adequate baseline and follow up assessment measures; and consideration of potential biases and limitations. This variability in the methodological quality of research relating to CBT with people with ID has been reported previously (Vereenooghe & Langdon, 2013). There was some consistency in the above TFCBT research base with regards

to the components of TFEBT currently specified by NICE (2018), despite predating the guidelines. For example, the majority of the studies included psychoeducation, elaboration and processing of trauma memories, and the restructuring of trauma related meanings. However, there was a lack of research which demonstrated inclusion of all elements of TFEBT outlined by NICE (2018) and only a few studies reported adherence to a specific treatment manual. Therefore, the need to explore TFEBT named in the NICE (2018) guidance, such as NET, and which includes all components of TFEBT specified, was recommended (Marlow et al., 2019). A review since this time made similar conclusions regarding the methodological quality of the evidence base and suggested that whilst TFEBT appears feasible among adults with ID, further high-quality research is required to confirm both the effectiveness of TFEBT and the appropriate adaptations required (Byrne, 2020).

1.4 Narrative Exposure Therapy

1.4.1 The theory underpinning NET

NET incorporates elements of both exposure therapy and testimonial therapy (Neuner et al., 2002). In exposure therapy (Wolpe, 1976), clients are encouraged to confront a feared stimulus until the point of habituation; where a decrease in anxiety levels is observed in response to the feared stimulus (Benito & Walther, 2015). In NET this involves repeatedly discussing traumatic experiences in detail, including the emotions, cognitions, physical sensations, and sensory experiences at the time of the event (Schauer et al., 2011) and this exposure to the traumatic experience is theorised to be one of the mechanisms of change. Exposure during NET is slightly different to exposure in other TFEBT approaches as the therapist is much more directive in guiding the client through exposure and any affect regulation or dissociation is managed by the therapist during exposure, rather than learnt by the client in an initial stabilisation phase (Robjant et al., 2017). NET also draws on concepts from emotional processing theory during exposure (Foa & Kozak, 1986). The process of NET allows trauma memories to be activated during the narration of an event, however, as clients are exposed in a safe therapeutic environment, the client encodes new

information that is now incompatible with the trauma memory. This includes cognitions related to the absence of current threat, and the difference between the here and now and the trauma memory. By recollecting an event and activating the associated emotions during therapy, a corrective experience also occurs which allows the memory to be reconsolidated (Lane et al., 2015).

Testimony therapy (Cienfuegos & Monelli, 1983) involves “the construction of a detailed and coherent report of the survivor’s biography” (Neuner et al., 2002, p. 206). During NET, contextual information is integrated into traumatic memories so that these memories are incorporated into the individual’s life and autobiographical memory is completed (Robjant et al., 2017). Clients are also encouraged to discuss positive memories within NET and when constructing their autobiography in order to develop their coping resources (Schnyder et al., 2015). Autobiographical memory can often be distorted in individuals with PTSD, where trauma memories lack detail relating to the point in time in which they occurred (Schauer et al., 2011). This can lead to inconsistent and fragmented verbal recall of traumatic experiences (Ehlers & Clark, 2000; Herlihy et al., 2002). The dual representation theory of PTSD (Brewin et al., 1996) suggests trauma memories can be encoded non-verbally at the time of the event, which results in incoherent narrative regarding the specific time and place it occurred in the individual’s life. The reconstruction of autobiographical memory is therefore also theorised to be a mechanism of change in NET. Furthermore, the reconstruction and reconsolidation of autobiographical memory is theorised to interact with semantic memory structures, which are drawn upon in order to respond to novel situations (Lane et al., 2015). Viewing autobiographical memory and semantic memory as connected in this way helps to explain how traumatic experiences affect our behaviour in the here and now, and the potential impact on symptoms of reconsolidating these memories for clients experiencing PTSD.

1.4.2 The NET process

NET is a short-term treatment and is usually completed within 4-12 sessions of around 90 minutes. After a thorough assessment, the client is given

psychoeducation to explain both their symptoms of PTSD and the rationale for NET. The session following this requires the client to physically create an overview of their life in chronological order using flowers and stones to represent positive and negative life events, and rope to represent time. This session also allows preliminary contextual information about time and place to be identified. It is important to complete the lifeline in one session and if the client shows signs of emotional arousal or begins to recall events in detail, the client is reminded that events will be processed in future sessions. Following the lifeline session, the narration sessions begin, initially with pertinent background information, and then moving on to the first significant event in the client's life. Time spent during sessions prior to the narrating of a traumatic event can be viewed as the development of a therapeutic alliance and familiarising the client with the therapeutic process. Narration sessions continue in chronological order and each stone is processed by exposing the client to the emotional, cognitive, sensory, and bodily sensations of the traumatic experience, whilst integrating the experience into the contextual narrative. During or after the session, the therapist takes notes of the client's narration and this autobiographical memory is repeated to the client in the subsequent session, incorporating the contextual information. Following this, further significant events are processed in the same way and the procedure is repeated until a final version of the client's autobiography has been created. The final session of NET involves either a relaying of the lifeline or a narration of the client's entire life and a copy of the entire narration, written by the therapist throughout NET, is given to the client (Elbert et al., 2015).

1.4.3 The evidence base for NET

A review of treatment trials (Robjant & Fazel, 2010) suggested that NET was beneficial compared to other techniques, such as counselling and interpersonal therapy, in reducing symptoms of PTSD. However, the authors acknowledged that sample sizes were small and there was a lack of comparison with well-established methods, such as CBT and Eye Movement *Desensitization and Reprocessing (EMDR)*. Lely et al. (2019) conducted a more recent meta-analysis into the effectiveness of NET and whilst NET showed

positive effects relating to both PTSD and depression, there were limitations regarding the quality of the studies and comparison with other CBT approaches and EMDR was again lacking. A meta-analysis into different psychological therapies for PTSD identified prolonged exposure, cognitive processing therapy and cognitive therapy as having the strongest evidence base among the TFCBTs, however, there was some evidence in support of the effectiveness of NET (Lewis et al., 2020).

1.5 NET with people with ID

The single published article found by the research team which refers to the use of NET with people with ID was that by Fazel et al. (2020). However, it is unclear whether the conclusions made about the applicability of NET to individuals with ID were drawn from their experience using NET with an adolescent with autism. There is no explicit reference within any of the case studies referring to a client with ID, however, this may be an issue in the reporting. Regardless, the authors note important adaptations which could be generalised to people with ID, and which require further research to establish the impact of the adaptations on the efficacy of NET. The adaptations outlined by Fazel et al. (2020) were: increased time spent exploring each stone in order to provide enough exposure to observe a reduction in physiological arousal and increase the clarity of trauma recollection; increased repetition and written explanation of the rationale and process of NET to support engagement; increased time given to process information; the provision of written prompting questions during sessions to increase predictability; and methods to reduce chances of dissociation and to provide additional sensory coping strategies, such as completing sessions whilst walking. The authors concluded that young people who may not usually access trauma-focused therapies, such as those with ID, could engage and should have access to NET, which has the potential to be adapted to enable populations such as these to engage. However, this could be said of all the TFCBT outlined by NICE (2018), given the review by Marlow et al. (2019) which showed TFCBT is possible with adults with ID and demonstrates promising results.

1.6 KidNET

KidNET has been found to reduce PTSD in children (Schauer et al., 2011) and follows the same structure as the original manual: assessment and psychoeducation, lifeline exercise, narrative exposure (Schauer et al., 2017). During psychoeducation in KidNET, different metaphors can be used, depending on the child's age, to support explanations of the theory behind NET. For example, the 'messy cupboard' analogy can be used to explain how memories are processed and specifically how it is better to systematically organise the cupboard, so things stop falling out i.e. the memories, rather than trying to hold the door shut i.e. avoidance (Neuner et al., 2008). The therapist should provide explanations of PTSD symptoms which are appropriate to the age and level of education of the child, without using jargon. In KidNET, psychoeducation is ongoing and should be explained to both the child and the carer (Schauer et al., 2017).

In the lifeline session, which should be completed in one 90-minute session, carers are not present during KidNET (Schauer et al., 2017). The child is encouraged to make a drawing of their lifeline at the end of the session, and if during the narration sessions further events emerge, the child is asked to add these to their drawing. Alternatively, a photo can be taken of the lifeline (Neuner et al., 2008; Schauer et al., 2011). Carers are also not present for narration sessions during KidNET, and the child requires continuous praise from the therapist for their courage during the narration. Children enjoy talking about happy memories and "remembering and reliving memories of positive experiences, moments of mastery, or important relationships can mean a lot to survivors of adversity" (Schauer et al., 2017, p. 240) and these should be included in narration sessions. Whilst the main tool of NET is language, KidNET utilises other means to help the child express their experiences. Very young children can provide further details about their experiences if given the opportunity to illustrate their memories. This includes the use of drawings, role plays, and figurines to assist with memory and reporting of experiences, however, this should always be accompanied by verbal narration in line with the theory underpinning NET (Neuner et al., 2008; Schauer et al., 2011). In KidNET, the therapist must also be aware of the child's level of emotional

intelligence and teach the child about emotions, if necessary, in order for them to be integrated into the narration (Neuner et al., 2008). At the end of therapy, the child is asked to draw a final version of the lifeline and to extend the lifeline further than the present day to include their hopes and dreams for the future (Neuner et al., 2008; Schauer et al., 2011). In KidNET, additional sessions may be required after the relaying of the lifeline in order for the client, therapist, and carer to discuss how the written testimony created during NET is to be used (Schauer et al., 2017).

1.7 Adapting psychological therapies for adults with ID

Hurley et al. (1998) stated that therapists are required to adapt their techniques for all of their clients and if basic guidelines are available, adapting therapy for people with ID should not be viewed as any more complicated. Figure 2 outlines the most frequent adaptations when delivering therapy with people with ID noted in the literature, which can be used as a 'tool box' to treat clients with ID, in addition to an established therapeutic relationship (Hurley et al., 1998). In a review of the literature relating to CBT and psychodynamic therapy for people with ID (Whitehouse et al., 2006), 'flexible methods' were the most frequently employed adaptation to therapy across both approaches, whereas issues relating to 'disability/rehabilitation' were employed the least. This is surprising considering that the emotional difficulties among people with ID can often be related to the existence of a disability and are consequently likely to be a focus within therapy (Hollins & Sinason, 2000; Whitehouse et al., 2006).

Surley and Dagnan (2019) extended the review by Whitehouse et al. (2006) and focused specifically on CBT for adults with ID. The adaptation most frequently reported in this review was that of 'activities' and 'directive methods'. However, it can be argued that these are defining characteristics of CBT and therefore cannot be described specifically as adaptations for people with ID, which highlights a limitation to the original categories outlined by Hurley et al. (1998) when applied specifically to CBT literature. Again, no studies reported adaptations which fit under the category of 'disability/rehabilitation approaches'. With this factor seemingly playing such a fundamental part in the emotional

difficulties of people with ID, it raises the question of whether the reporting of research accurately captures this aspect in descriptions of interventions, rather than this issue not being prevalent in documented therapy. The quality of reporting of adaptations in studies of psychological interventions with people with ID has been highlighted consistently as a significant issue (Byrne, 2020; Marlow et al., 2019; Surley & Dagnan, 2019; Vereenoghe & Langdon, 2013). Lastly, when comparing the two reviews, Surley and Dagnan (2019) reported more adaptations in the categories of 'language', 'activities', 'developmental level' and 'involving caregivers' than the review completed by Whitehouse et al. (2006) which may suggest some progression in adaptations over time.

Figure 2

The major adaptations of psychotherapy techniques (taken from Hurley et al., 1998)

Adaptation	Definition/example
Simplification	Reduce usual technique in complexity; break down interventions into smaller chunks, shorter length of sessions.
Language	Reduce level of vocabulary, sentence structure, and length of thought. Use short sentences; use simple words.
Activities	Augment typical techniques with activities to deepen change and learning. Add drawings, homework assignments.
Developmental level	Integrate developmental level into presentation of techniques and material. Use games; assess development into relevant social issues.
Directive methods	Due to cognitive limitations, must be more direct. Outline treatment goals, progress, give extra "visual" guides.
Flexible methods	Adjust usual techniques to suit cognitive level and lack of progress. Draw from other modalities.
Involve care givers	Use family, support staff to help with change. Assign homework or rehearsals at home with the help of staff or family
Transference/countertransference	Attachments are stronger, quicker; therapist reactions similar to parental view. Therapists urged to be stronger in boundaries and to ensure peer supervision.
Disability/rehabilitation approaches	Issue of disability must be addressed with treatment. Therapists must raise issues and support positive self-view.

Literature which focuses on how therapy can be adapted to account for cognitive deficits in people with ID, and which specifically focuses on adapting CBT for adults with ID, is particularly appropriate when considering how to adapt NET. Lindsay et al. (2013) provide guidance on adapting psychological therapies for people with ID, paying particular attention to cognitive deficits. These are described as difficulties in information processing and acquisition, which can cause difficulty in CBT if not addressed. Figure 3 summarises the cognitive deficits that may be identified when working with people with ID and potential suggestions for adapting therapy to support clients and improve the chances of successful therapy. In addition, Lindsay et al. (2013) also highlighted the importance of effective communication and the collaborative aspect of CBT

when making adaptations to therapy to ensure that these are not lost. The authors refer to the use of Socratic questioning which can encourage guided discovery and lead to an increase in the ownership that clients have over sessions, as well as increase memory for information. The importance of an agenda is also highlighted by the authors, which allows sessions to be more predictable and controlled.

In addition to the work of Lindsay et al. (2013), Jahoda (2016) outlines a number of adaptations to CBT when working with people with ID, which are also relevant when exploring how NET can be adapted. These include strategies to manage cognitive challenges, such as poor memory and concentration, for example the use of visual aids and role play, and consideration of the pacing and number of sessions required. The use of visual aids has also been found to support emotional recognition in clients with ID where the communication of emotions has been facilitated by choosing visual resources, as opposed to expressing emotions verbally (Cooney et al., 2018). Jahoda (2016) also highlight the importance of the therapeutic bond and argue that people with ID may have little experience of collaborative working, so particular efforts should be made to establish a therapeutic relationship. Finally, the authors also suggest the involvement of significant others may be required to assist with therapeutic change; however, this should be balanced with ethical concerns, such as the confidentiality of the client.

Figure 3

Cognitive deficits that can cause difficulties in CBT (taken from Lindsay et al., 2013)

<i>Cognitive domains</i>	<i>Specific processes</i>	<i>Implications for therapy</i>
Intellect	Verbal understanding and reasoning	Simple words and short sentences
	Nonverbal understanding and reasoning	Use of nonverbal techniques and materials
Emotional literacy	Emotional vocabulary “CBT skills”	Psychoeducation Psychoeducation and provision of ideas
Memory	Assimilation	Frequent repetition and more sessions
	Recall of experiences	Involvement of carers
	Prospective memory	Use of reminders and involvement of carers
Executive functioning	Working memory	Chunking of information
	Behavioral inhibition	Greater use of behavioral self-control techniques
	Initiative	Provision of ideas

1.8 Accessible communication formats and ‘easy read’

The Accessible Information Standard requires that organisations providing National Health Service (NHS) or adult social care have a legal obligation, under the Health and Social Care Act 2012, to ensure that information is accessible for those with a disability, impairment, or sensory loss (NHS England, 2017). Guidance around accessible communication formats, including ‘easy read’, which is most relevant to the current research, is available in order to adhere to this standard. This can be referred to when considering how to adapt psychological therapies for adult with ID.

NHS England (2018) defines ‘easy read’ as “information which is written using simple words supported by images” (p. 6). The target of ‘easy read’ is largely people with ID in order to make standard documents more accessible, however, ‘easy read’ may also be used among other populations, such as those with cognitive impairment, low levels of literacy or for individuals who are not fluent in English (DWP, 2018; NHS England, 2018). There is no single provider of ‘easy read’ and consequently a range of different styles are used within

different sectors. The images to support words also vary and may be presented as photographs, symbols, and drawings. Among some of the advantages of 'easy read' documents are their ability to facilitate independent reading for some populations, and the provision of both text and images which offers both verbal and visual information for the reader (NHS England, 2018). 'Easy read' materials can also provide a form of social capital for people with ID who collaborate on its development and assess quality (Chinn & Homeyard, 2017), such as in the current research. However, the quality of 'easy read' can vary significantly and must always be tested out with the target audience. Furthermore, making written information accessible through 'easy read' has its limits and it is still not accessible by all. Some populations require alternative formats, such as the use of Makaton to communicate with people with profound ID (DWP, 2018; NHS England, 2018).

The DWP (2018) provides the following guidance on how to produce 'easy read' materials:

- keep the number of pages to 24 or less. If there are more, break the text up into more than one publication.
- keep sentences short – they should be no more than ten to 15 words.
- each sentence should have just one idea and one verb.
- use 14-point font size.
- make sentences active not passive: “we are following up your complaint” (active tense) not “your complaint is being followed up” (passive tense)
- take out words that are not needed, for example, say ‘for 14 days’ not ‘for a period of 14 days’.
- include a glossary explaining abbreviations and jargon, and an index, at the end of the document.
- use full words not acronyms.
- if you need to use difficult words or ideas, say what they mean – do this in the next sentence, not as part of the same sentence.
- use a different colour or bold type but keep a good contrast with the paper.
- use pictures to support the meaning of your text.

Further guidance from the DOH (2010) states that each key idea or concept requires both words and clearly linked pictures, with pictures positioned to the left of the text. Text should be broken up by the use of boxed text, bullet points and emboldened text and jargon should be avoided. When developing 'easy read' documents, the traditional rules of grammar do not necessarily apply and it is acceptable to use sentences that reflect how conversation is spoken, for example, starting a sentence with the word 'and' or 'but' is acceptable. It is also acceptable to use repetition across 'easy read' documents where you might otherwise attempt to vary language.

1.9 Further rationale

There is no literature relating to how the NET protocol can be adapted for adults with ID or regarding the effectiveness of NET among this population, other than a single publication which reports promising results (Fazel et al., 2020). However, this research did not report the systematic adaptation of NET involving different stakeholders, as in the current research. Reviews of treatment for PTSD in adults with ID continually point to the need for more research in this area (Byrne, 2020; Dagnan et al., 2018; Marlow et al., 2019; Mevissen et al., 2016). With this in mind, and the increased prevalence of PTSD among people with ID compared to the general population (Fletcher et al., 2016; Mevissen & De Jongh, 2010), there is a strong rationale for research which explores how NICE (2018) recommended treatments for PTSD, including NET, can be adapted for adults with ID. In addition to this, the Accessible Information Standard means there is a legal obligation when providing care within the NHS for information to be accessible for those with disabilities, which again includes information about therapies such as NET and which further supports the rationale for adapting NET for this population.

2.0 Extended methodology

2.1 The SALT involved in the current research

Jess Renton is a Highly Specialist Speech & Language Therapist registered with the Health and Care Professions Council. Jess holds a Bachelor of Science in Speech Sciences, a Master of Science in Human Communication and has over ten years of experience working in ID services. For the past six years, Jess has worked within inpatient services with adults who have ID and complex mental health difficulties. These individuals often have traumatic histories and display challenging behaviours. Jess also works within community services offering intensive assessment and treatment for adults with ID to prevent admission to inpatient services. Jess was known prior to the current research due to the researchers' links with local NHS services and was approached during the design phase.

2.2 Service user involvement in research

The service user group consulted in the first stage of the research was the Learning Together Northwest Ltd, which is a social enterprise established in 2013 and based in Lancashire. Members of the group are experts by experience, having a diagnosis of ID, and the group specialises in training and consultancy work. People with ID should always be involved in the process of developing 'easy read' documents; involving those from the target audience when developing accessible formats means that needs, and strategies for meeting these needs, can be identified collaboratively (DWP, 2018; DOH, 2010).

The lack of opportunity for disabled people to influence research and the need for a new research paradigm, which includes and sees people with disabilities as equal contributors, has long been recognised (Oliver, 1992; Zarb, 1992). Zarb (1992) argued that the social relations of research production needed to change in order for research to be increasingly emancipatory, where empowerment and reciprocity between researchers and participants with disabilities are central features of the research. Zarb argued that "simply

increasing participation and involvement will never by itself constitute emancipatory research unless and until it is the disabled people themselves who are controlling the research” (p. 128). Patient and public involvement in health research, also labelled as service user involvement, is now considered fundamental in the UK (Beighton et al., 2019). The National Institute for Health Research (NIHR, 2015) states that no research will be funded by the NIHR should a clear plan for involving service users not be included in the design. The NIHR also aim for service users to be equal partners and co-researchers by 2025. This should apply to people with disabilities and suggests a progression since the above articles in the nineties.

There are several models available to include people with disabilities in research and increase aspects of control and collaboration; among these is the use of consultation groups where the views and opinions of people with disabilities are sought on research topics (National Disability Authority, 2002). In the current research this involved the researchers identifying the specific area of focus i.e. how NET could be adapted for adults with ID, and then consulting with the target population. This consultation process also involved service users receiving payment for their work, namely their contributions to the design of the ‘easy read’ materials, and significant changes were made to the materials following their input, challenging social and economic exclusion (National Disability Authority, 2002). Involving researchers who have similar disabilities to those of the target population means that their experiences and expertise can directly benefit the research and consequently service user involvement has been found to improve the relevance and quality of research (Brett et al., 2014). Additionally, service user involvement has also been found to impact positively on self-esteem and self-confidence (Beighton et al., 2019; Omeni et al., 2014).

Due to the level of expertise required to answer the research questions, a truly emancipatory approach was not considered possible in the design of the current research and there is debate about whether people with ID can ever truly be involved in emancipatory research due to some level of support usually being required (Williams & England, 2013). However, commitment to a collaborative approach was evident throughout the current research and service users were able to influence the research outcomes considerably. The definition of inclusive research with people with learning disabilities, as defined by

Walmsley and Johnson (2003), was also considered throughout this research and is shown in Figure 4.

Figure 4

The definition of inclusive research with people with learning disabilities (taken from Walmsley & Johnson, 2003)

Box 3.1 Definition of inclusive research

- The research problem must be one that is owned (not necessarily initiated) by disabled people.
- It should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities.
- It should be collaborative – people with learning disabilities should be involved in the process of doing the research.
- People with learning disabilities should be able to exert some control over process and outcomes.
- The research question, process and reports must be accessible to people with learning disabilities.

2.3 Justification for the focus group and alternative methods of data collection considered

Focus groups are defined as a group interview on a predetermined topic which is facilitated by a researcher and where data is derived from group discussion and interaction (Finch et al., 2014; Morgan, 1996; Sim, 1998). Not only does this method allow data to be collected simultaneously from several people, having an obvious practical advantage, but it also benefits from the interactions between the members of the group which means views may be explored more easily than in an individual interview (Kitzinger, 1995). In focus groups, members will respond to each other's contributions, rather than communicating only with the interviewer. Therefore, focus groups have been

found to be an effective technique for creative thinking and solutions, this applies to both technical subjects, as in the current research, and in exploring views among staff, in line with the current research sample. Additionally, the amount of experience of the topic being discussed also predicts the success of a focus group, hence the minimum number of years of experience required to participate in the focus group in the current study (Kitzinger, 1995; Lewis & Nicholls, 2014; Morgan, 1996). The focus group was also deemed more appropriate than individual interviews due to the finding that focus group data is more than the sum of individual interviews; participants present their own views, query each other, and reflect on what is said which creates richer data (Finch et al., 2014; Morgan, 1996).

A potential disadvantage of the focus group method is the risk that participants will not respect the confidentiality of other participants and discussions (Webster et al., 2014). However, even with this said, focus groups can be useful for even the most sensitive topics as the sharing of views and experiences among more vocal participants can encourage others group members to share. Furthermore, participants may feel safe and empowered by being part of the group, which can encourage discussion (Kitzinger, 1995; Sim, 1998). Another potential disadvantage to consider when choosing the focus group method over more individual methods of data collection is the 'bandwagon effect' (Winkler & Moser, 2016), where individuals conform to what they perceive as the group majority. Group methods can also lead to the silencing of individuals who feel their views or experiences deviate from that of the rest of the group, and the ethical consideration of how the participant may experience this should be considered (Kitzinger, 1995; Webster et al., 2014). This further highlights the importance of the facilitator in the focus group who must manage these dynamics whilst not inhibiting discussions (Sim, 1998). Due to the nature of the research, including both the participant sample and the research topic, it was felt that these potential disadvantages could be managed appropriately within the current research.

Methods of data collection that are designed specifically with the aim of gaining an expert consensus on a topic were also considered, given that the current research aimed to seek the opinions of experts on how the NET protocol could be adapted for adults with ID. Among these methods, and most closely

considered, was the Delphi method (Dalkey & Helmer, 1963). The general structure of the Delphi method involves a topic initially being explored individually with participants in order to produce a questionnaire, which is then sent to all participants who are asked to rate their agreement with different statements. Participants' responses are then collated and summarised, and the questionnaire subsequently evolves, as a result of participants' responses, until an understanding is reached of how the group of participants view the topic i.e. a consensus (Linstone & Turoff, 1975; WHO, 2014). This method was also considered due to the pre-determined structure provided by the Delphi method in how consensus is reached among the professional experts.

In order to minimise any biases in how a consensus on adaptations to the protocol in the current research was reached, a majority decision was sought among participants in the focus group. The Delphi method does not allow for immediate and direct interaction between participants, unlike the focus group, as participants never interact directly and instead respond to each other's views anonymously through the researcher (Morgan, 1996; WHO, 2014). Discussion among the professionals regarding how the protocol should be adapted was considered invaluable in the current research, which favoured the focus group method. Furthermore, the therapy materials and list of recommendations for delivering NET with adults with Mild ID had already been produced in stage one of the research and the Delphi method may be more appropriate in producing recommendations or guidelines where none exist already (English et al., 2020; WHO, 2014).

Finally, a crucial factor in deciding the most appropriate method of data collection from the professionals was consideration of how data had been collected from the service user group in the first stage of the research. The service user group provided written feedback before meeting with the researcher for a group discussion, therefore, a similar format in which professionals were able to provide written feedback and subsequently meet with the researcher as a group seemed the most equitable approach to gathering feedback in stage two of the research. Advances in technology have also meant that focus groups are increasingly conducted virtually (Finch et al., 2014), which was particularly beneficial to the current research which took place during the COVID-19 pandemic. However, the available evidence pertaining to virtual

focus groups, as opposed to face-to-face groups, appears to relate to scenarios where participants type their responses (for example, Schneider et al., 2002; Tates et al., 2009). There is a lack of literature on the use of videoconferencing for focus group research, using apps such as Zoom or Microsoft Teams, where participants are visible to each other and engage in virtual discussions in real time, and further research is required to establish the strengths and limitations of this approach (Lobe & Morgan, 2021). The lead researcher noted from the current research that the use of videoconferencing for focus group research may have the benefit of allowing participants to contribute more easily, using functions such as 'raise your hand', where they may struggle to assert themselves in face-to-face interactions. It may also mean the researcher is able to manage dominant voices more easily due to the emphasis on turn taking in these formats. However, conversation may be more stilted, as participants leave pauses to allow others to contribute, which may disrupt the flow of conversation. Furthermore, it may be more difficult to identify non-verbal cues which can provide further information around topics (Finch et al., 2014) and can form an important part of certain focus group analysis, such as conversational analysis (Onwuegbuzie & Leech, 2005).

2.4 Gaining of ethical approval and ethical considerations

Ethical considerations are fundamental to high quality research and should be prioritised from the very early stages of research design (Webster et al., 2014). The research was conducted in two stages and via different routes of ethical approval, due to changes in the research design as a result of the pandemic. The first stage of the research involved the authors of the paper adapting the existing protocol for delivery with adults with Mild ID and consulting with a service user focus group. This gained ethical approval from the University of Nottingham Research Governance team, the 'West Midlands – Solihull' Research Ethics Committee, the Health Research Authority (HRA), and the local NHS Foundation Trust Research and Evidence team [see *appendices B, C, D and E*]. The second stage of the research involved a focus group discussion with Clinical Psychologists (CPs) and an expert panel discussion with NET clinicians. This gained ethical approval from the University of

Nottingham's Ethics Committee, specifically the Division of Psychiatry and Applied Psychology Ethics Subcommittee. This committee also approved a subsequent amendment relating to the extension of data collection and a change of format to data collection in relation to the NET clinicians [see *appendices F and G*]. The BPS Code of Human Research Ethics and Code of Ethics and Conduct (2014, 2018) and the University of Nottingham's Code of Research Conduct and Research Ethics (2020) were considered throughout the design and implementation of this research.

With regards to the first stage of the research, although the service user group were not research participants, ethical consideration was given to their involvement as consultants to the project. For example, the lead researcher ensured that all members of the service user group were informed about what their involvement in the research entailed before agreeing to collaborate. Issues of power within the relationship between the lead researcher and group members were considered and power imbalances were reduced by taking a collaborative approach, such as when deciding how the service users would provide feedback. The lead researcher also ensured to maintain professional relationships throughout the research.

With regards to the second stage of the research, to ensure that participants were giving informed consent before taking part in the research, all participants were provided with a Participant Information Sheet (PIS) [see *appendices J and K*] via email and given at least one week to consider whether they would like to take part in the research or not. The PIS followed the template provided by the University of Nottingham, which is in line with the information suggested for inclusion by the BPS (2014). Within the PIS, information was included about the participants' right to withdraw from the research at any time and without giving a reason and it was stated that there would be no negative consequences should potential participants choose not to take part. However, participants were made aware that should they wish to withdraw from the research after having taken part in the focus group/expert panel discussion, it would not be possible to remove their data as it formed part of a group discussion which would be analysed as a whole. Participants were also informed that the research was unlikely to benefit them directly but that it was highly unlikely to cause any harm or distress.

Once participants had agreed to take part, they were emailed a Consent Form to sign [see *appendices L and M*] which included consent for the focus group/expert panel to be recorded. Whilst researchers adhered to strict confidentiality procedures, all participants were made aware in the PIS that due to the group nature of the research, the researchers could not guarantee that other participants would not share information outside of the research. All participants were asked to agree to maintain the confidentiality of information discussed by participants in the focus group/expert panel within the Consent Form.

Data collected throughout the research, including Consent Forms, demographic information and recordings of the focus group/expert panel were stored and managed on University of Nottingham drives on password protected files and in line with General Data Protection Regulation and The Data Protection Act (2018). Personal data was stored separately from research data and no personal data which would be considered 'special category data', including that relating to racial/ethnic origin, political opinions, or religious beliefs, were collected from participants during the process of the research. The identity of participants was anonymised during the process of transcribing and/or analysing the focus group/expert panel discussions and each participant was allocated a pseudonym. Both groups were made aware in the PIS that anonymised direct quotations may be used within the write up of the research but that any identifiable information would be removed. Personal data and recordings will be destroyed 12 months after the research is completed and all other research data will be destroyed after seven years, including the anonymised transcript of the focus group and summary of the expert panel.

Finally, in order to recruit to the focus group comprising CPs working in ID services, the Chair of the British Psychological Society's Division of Clinical Psychology Faculty for People with Intellectual Disabilities was asked to email all members of the faculty. Therefore, the Chair may be considered a gate keeper which can sometimes raise ethical issues in research (Webster et al., 2014). Careful consideration was given to ensure that potential participants were given all of the information about the research that was required to make an informed decision, that they felt under no pressure directly or indirectly to

participate in the research from the Chair, and that nobody was excluded from the opportunity to participate by sending the email to all members of the faculty .

2.5 Epistemology

Research methods are often determined by the researcher's epistemological position. This is defined as the framework which is adopted for acquiring knowledge and learning about realities (Ormston et al., 2014; Todd et al., 2004). Researchers who advocate for a quantitative approach often identify with a positivist epistemological position which views reality objectively and believes that it should be explored in the same way that physical scientists approach physical phenomena. Positivists believe that it is possible to conduct research without affecting the phenomenon under investigation and that value-free inquiry is possible (Johnson & Onwuegbuzie, 2004; Ormston et al., 2014). On the contrary, researchers who advocate for a qualitative approach often identify as constructivists or interpretivists and believe that there are multiple, subjective realities to be explored. From this position, knowledge is gained by focusing on the meaning and interpretations of the people being studied. Furthermore, this position is at odds with the positivist approach which believes that researchers can eliminate their biases and remain emotionally detached when testing out their scientific hypotheses (Johnson & Onwuegbuzie, 2004; Ormston et al., 2014).

Pragmatism attempts to bridge the gap between the two purist positions and requires the researcher to focus primarily on providing resolution to the research questions, rather than being driven by a priori reasoning and fixed principles that accompany other epistemological positions and traditions (Florczak, 2014; Ormston et al., 2014). This position appeared to fit well with the current research which involved a very practical focus of exploring how a therapy can be adapted for a new population. Therefore, methods were chosen on the basis of how best to answer the research questions and as a result, qualitative approaches were selected.

2.6 Recruitment of NET clinicians

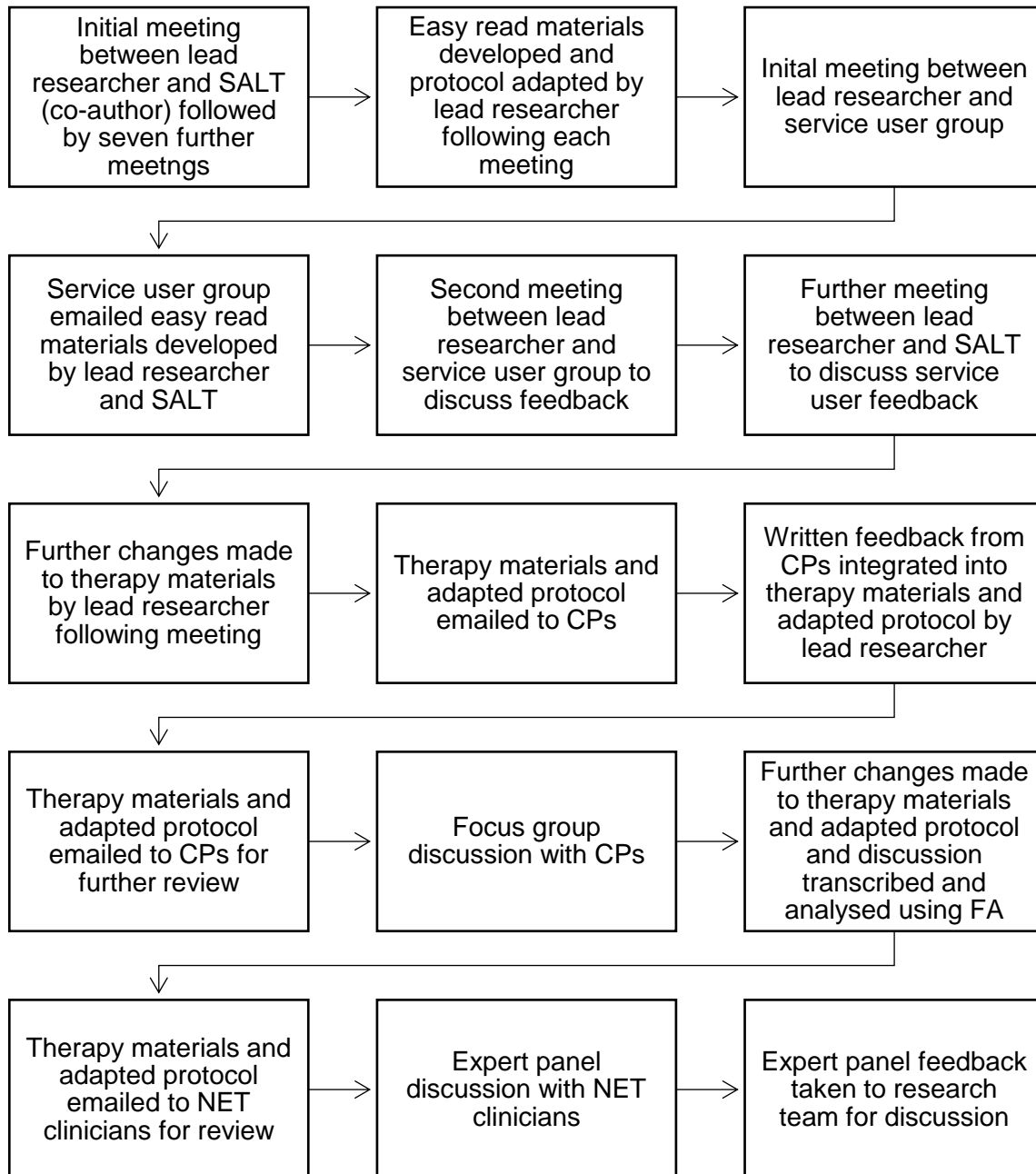
The lead researcher emailed NET clinicians prominent in the field and asked them to inform other NET clinicians about the research. The research team identified the authors of the NET manual as prominent clinicians in the field; namely Maggie Schauer, Frank Neuner and Thomas Elbert. Katy Robjant was also emailed and asked to inform other NET clinicians about the research. Katy Robjant is a highly cited NET clinician and researcher based within the UK who delivers NET training with the Eremo Institute and who has collaborated with the authors of the manual on multiple NET related research publications.

2.7 A visual depiction of the research procedure

Figure 5 shows the procedure relating to both stages of the research.

Figure 5

The research procedure



2.8 The framework approach and other methods of analysis considered

Analysing data from a focus group is no different to analysing qualitative data collected through other methods; it involves identifying themes in the data,

as well as data which deviate from overall trends displayed within the group (Kitzinger, 1995). There are many approaches to qualitative data, each treating and organising data differently according to epistemological assumptions (Spencer, Ritchie, Ormston, et al., 2014). Qualitative methods can be classified according to their overall purpose: those that explore the use and meaning of language, such as discourse analysis; those that describe and interpret views, such as thematic analysis; and those that develop theory, such as grounded theory (Smith et al., 2011). Discourse analysis and grounded theory were not considered for the current research as they did not fit with the aims of this stage of the research. Qualitative methods concerned with describing and interpreting participants' views best fit with the research aims of seeking the views of professional experts on adapting NET for adults with ID. Whilst interpretative phenomenological analysis (IPA, Smith et al., 1999) also explores participants' views, it was ruled out straight away due to its exploratory focus on interpreting participants' sensemaking of their lived experience (Willig, 2008). Due to the aims of the research in seeking participants' views about adapting NET, rather than exploring their lived experience of a phenomenon, IPA was not deemed appropriate. Therefore, thematic analysis (TA, Braun & Clarke, 2006) and the framework approach (FA, Ritchie & Spencer, 1994) were considered.

FA sits within the category of TA, which aims to identify similarities and differences in data before arriving at descriptive and explanatory conclusions which are illustrated through themes. It is argued that TA is foundational and should be the first analysis of qualitative data that is learnt by researchers (Braun & Clarke, 2006; Gale et al., 2013). In its earlier days, TA was criticised for its lack of structure and 'anything goes' approach which contributed to the development of the Braun and Clarke guidelines in 2006. However, attempts to use these guidelines have been problematic and described by Braun and Clarke (2019) as "unknowing, unreflexive and indicative of some degree of conceptual confusion" (p. 590). Reflexive TA is now the preferred term of the authors, which captures the importance of the theoretical stance of the researcher in the interpretation of data and the need to query assumptions made throughout data analysis.

A critique of TA is outlined by Smith and Firth (2011) who argue that there is the risk in TA of analytic claims not matching the data. TA has been

described as sometimes resulting in the analysis of phenomena being fragmented, which can lead to data being misinterpreted and findings seeming subjective. The risk of fragmentation is countered in FA by moving back and forth across the data until a more comprehensive account develops (Smith et al., 2011; Smith & Firth, 2011); however, using any form of TA as a purely linear process is a common misapplication (Braun & Clarke, 2019). FA was developed for use in applied qualitative research in order to systematically analyse material in relation to key themes and is suitable for both individual interviews and groups (Gale et al., 2013; Ritchie & Spencer, 1994). Therefore, FA was deemed appropriate to analyse the focus group data, which sought to answer a practical question using a deductive approach which took full advantage of the existing knowledge within the research team when developing the framework.

FA involves a data management stage and interpretative stage; however, FA is an iterative process and continuous analysis where interpretation takes place throughout (Spencer, Ritchie, O'Connor, et al., 2014). The five key stages of FA data management are as follows:

Data Management

Familiarisation. This stage involves gaining an overview of the data by listening to recordings and reading transcripts until the analyst has an understanding of the diversity within the data and begins to identify emerging themes and ideas which appear to be central to the data. The topics identified will relate to the research questions being explored and will be recurring across the data set (Ritchie & Spencer, 1994; Spencer, Ritchie, O'Connor, et al., 2014).

Constructing an initial thematic framework. During the second stage, the analyst uses the themes and ideas which have been identified to develop an initial framework within which the data can be organised. Throughout the construction of this framework, the analyst will be drawing on a priori issues which defined the aims of the research and determined the interview schedule, and emerging themes identified by participants (Ritchie & Spencer, 1994; Spencer, Ritchie, Ormston, et al., 2014). Initially the framework is likely to be based on the former, and some of the categories may be very similar to specific

areas of questioning, however, the framework usually becomes more respondent to emergent and analytical themes once applied to transcripts (Ritchie & Spencer, 1994). The initial framework is usually descriptive, with more analytic themes developing later, and has “a hierarchical arrangement of themes and subthemes which means the researcher can hold the overall structure in their head” (Spencer, Ritchie, O'Connor, et al., 2014, p. 298). Developing and refining the framework requires the analyst to ensure the research questions are being fully addressed and to make judgements about the meaning and significance of issues that arise in the data (Ritchie & Spencer, 1994). In the current research, the initial framework was developed in line with the above and based on the research aims and areas of interest pursued within the interview schedule. Therefore, initial topics within the framework included the feasibility of delivering NET within ID services, as well as the potential benefits and challenges.

Indexing and sorting. Indexing describes the process of applying the framework systemically to transcripts and annotating chunks of data with indexes (initial themes) so that particular topics can be located, and similarly labelled chunks can be further analysed. Where areas of discussion are complex, it would not be uncommon to find several important themes in close proximity and interwoven throughout the text, which should be noted for when the connection between themes (linkage) is considered. Once indexed, material can then be sorted so that similar text is viewed as a whole; it is also important in this stage that data is assigned to multiple locations if relevant (Spencer, Ritchie, O'Connor, et al., 2014). This process is visible to others and can therefore be crosschecked; in the current research 20% of the indexing was reviewed by two other members of the research team [*see Appendix O for examples of indexing*].

Reviewing data extracts. Once indexed and sorted, the analyst reads through chunks of data which have been labelled similarly to assess whether these relate to one another coherently or whether further indexes need to be developed. The framework is then refined; any revisions should be noted as it is

likely they will be significant in later analysis (Ritchie & Spencer, 1994; Spencer, Ritchie, O'Connor, et al., 2014).

Data summary and display. This stage requires a series of matrices to be created for each theme, sometimes referred to as charting, whereby each participant is allocated a row, and each column represents a subtheme. Data can then be grouped systematically by either participant or subtheme and a summary entered. Summaries must strike a balance between including enough information that the participants' voices are captured correctly, such as including key terms and limiting interpretation at this stage, but not so much that the matrix is overwhelmed with unprocessed data. Whereas some qualitative approaches require text to be extracted from transcripts verbatim, this stage involves both extraction and synthesis, so participants' responses are summarised concisely (Ritchie & Spencer, 1994; Spencer, Ritchie, O'Connor, et al., 2014). This stage of FA is what distinguishes it from other forms of TA and was particularly appealing to the current research. The summary and display stage means that the analyst can "move back and forth between different levels of abstraction without losing sight of the raw data" (Spencer et al., 2014, p. 283). Not only did this stage counter the risk of data becoming fragmented; a critique of TA outlined earlier, but it also meant that data was transparent and could be easily reviewed within the research team. In the current research, only one participant field was used to represent all participants within the focus group, as it did not seem useful to differentiate between participants, however, divergent views were still captured in the data summaries.

Like other qualitative methods, this stage of FA in particular can be time consuming and resource intensive (Gale et al., 2013). There is also the potential that this stage can turn into a quantitative exercise whereby analysts start to quantify the data, for example, in terms of the number of participants who expressed a similar view, and this is another pitfall of FA which must be avoided (Gale et al., 2013). This was managed in the current research by analysing the participants' responses as one voice, and by ensuring that the FA was overseen by other members of the research team which included those experienced in qualitative analysis.

Interpretation

Once the data has been managed by the process outlined above, the more formal process of interpretation occurs which includes both descriptive and explanatory processes. This stage is guided by the research objectives; in the current research the qualitative analysis related to exploring the views of professionals on IDNET (developed in stage one) the use of NET with adults with ID. Description involves developing categories where each theme is reviewed, the range and diversity of views are considered, and key concepts are identified that discriminate the differences in the data. This may go through several stages until the analyst is satisfied with the final categories developed and throughout this process the connection between the categories developed and raw data should be transparent. Some analysts stop at the categorisation phase, however, description may also involve 'mappage linkage' where the analyst identifies how the different concepts link together (Spencer, Ritchie, O'Connor, et al., 2014; Spencer, Ritchie, Ormston, et al., 2014). Explanatory processes in interpretation involve considering why there are certain patterns in the data (Spencer, Ritchie, Ormston, et al., 2014), however, this was beyond the objectives of this stage of the research. Participants' views concerning how NET could be adapted and the feasibility of using NET with adults with Mild ID were taken at face value and did not require explanatory interpretations, therefore analysis stopped at the descriptive stage of interpretation.

2.9 Upholding quality

The Critical Appraisal Skills Programme (CASP; 2019) checklist for qualitative studies was referred to throughout the research process to assess quality. Whilst the current research design, and in particular stage one, did not follow a typical qualitative design, the CASP checklist allowed key areas in the research to be considered. This included reflecting on the lead researcher's relationship to the research and in particular their vested interest in improving quality of life for people with ID. For example, when formulating research questions for the current study, a comprehensive literature search ensured that the rationale for the study was clear and that the research was warranted.

Furthermore, during the analysis, the lead researcher's emotional responses to certain topics discussed within the focus group were reflected on within the reflexive diary kept by the lead researcher and in supervision. This ensured that any emotive themes or key concepts were fully grounded in the data, rather than being driven by personal motivations.

A further area consider by the CASP (2019) is the rigour of the data analysis, which has some overlap with the above. As outlined previously, a percentage of the indexing was crosschecked within the research team, who were experienced in qualitative data analysis, in order to review the lead researcher's analysis and support reflections (indexing was not coded individually by researchers and subsequently compared for agreement). Furthermore, the reflexive diary allowed reflection on any assumptions and/or biases during the development of themes and key concepts. All final themes and key concepts developed by the lead researcher were also reviewed within the research team to assess quality and encourage further reflection on any assumptions and/or biases. A clear audit trail was also maintained which tracked the steps of the data analysis; this meant all themes and key concepts could be traced back to the original data, increasing the transparency of how findings were reached and overall trustworthiness.

3.0 Extended results

3.1 Summary of meetings between lead researcher and SALT

Meeting one

Initial discussion regarding what was required during this stage of the research. It was agreed that the 'easy read' materials would be developed first, including a number of information sheets and handouts, and then focus would turn to adapting the step-by-step delivery of NET for adults with Mild ID outlined in the manual. The information in the manual that required an 'easy read' format included a description of NET and psychoeducational examples. The SALT advised on the structure of the 'easy read' materials and the symbol programme to use, and guidance was given on how to break down information and extract key messages. This was in conjunction with discussions regarding the available guidance on accessible communication. It was agreed that the lead researcher would develop an initial 'easy read' material and email this to the SALT for feedback at the next meeting. The SALT also advised the lead researcher to start compiling a glossary to define key words which would then be used consistently throughout the materials.

Meeting two

The SALT provided feedback on the first 'easy read' material developed by the lead researcher. Abstract words and phrases were highlighted by the SALT which could be misinterpreted by adults with ID, such as the use of "I went through" to describe an experience, and the word "patchy" to describe fragmented memory, and alternatives were considered. The layout of the 'easy read' materials was further considered at this stage and an alternative where symbols would appear above all key words was discussed, which is how the symbol programme formats the text and symbols. However, it was agreed that this number of symbols was not required for the population targeted by the materials, furthermore, the DOH (2010) guidance states that pictures should be positioned to the left of the text. It was agreed that the lead researcher would

continue to develop 'easy read' materials, in line with guidance, and send to the SALT for feedback when completed.

Meeting three

The SALT provided further feedback and guidance on the use of both text and symbols within the 'easy read' materials developed so far [see *Appendix H for an example of a psychoeducational example from the NET manual, the 'easy read' material developed by the lead researcher, and feedback provided by the SALT*]. Further handouts required to support key ideas and concepts within the information sheets were identified including a 'Lifeline' and 'Exposure' handout. Handouts depicting emotions, senses, and physiological responses were also identified to support the client in expressing their experiences during narration sessions.

Meeting four

Discussion regarding the terminology used within NET, such as 'avoidance' and 'narration' and whether these should be defined in the 'easy read' materials. It was agreed that if terminology would assist the client in therapy and in their understanding of their symptoms, such as 'avoidance', then it would be defined within the glossary and used throughout the materials. However, if terminology could be better explained using words already within the client's vocabulary and which did not add to their understanding of their symptoms, such as 'narration', alternatives would be used. The SALT gave further feedback on the materials developed so far and recommended that the structure of the 'What happens in therapy' information sheet should be changed to a table format, rather than a narrative, in line with information given to the general population. The feedback sheets which had been developed for the service user group were also discussed and the SALT advised on how these could be made more accessible.

Meeting five

Further feedback was provided by the SALT on the materials developed so far and a particular focus was given to the use of symbols throughout the materials. The SALT identified that the same symbol had been used to describe two different concepts in some instances, such as 'talking' and therapy', and these were distinguished with different symbols. Final changes to the therapy materials were discussed and agreed in preparation to send to the service user group for consultation.

Meeting six

Focus now turned to adapting the step-by-step delivery of NET, outlined in the manual, for adults with Mild ID.. This involved discussing the literature relating to adapting psychological therapy for people with ID (Hurley et al., 1998; Jahoda, 2016; Lindsay et al., 2013). The importance of directive and concrete instructions for the client throughout therapy was discussed and how this could be achieved; for example, through increased verbal instructions from the therapist and visual aids/prompts. With regards to the 'lifeline' session, this included visual aids to support the meaning of the rope/flowers/stones and visual prompts to support the client in understanding what information would be discussed during this session and to keep them on 'cold' memories. With regards to the 'narration' sessions, this included visual prompts to support the client in understanding what information would be discussed for each event and how it would be discussed (before, during, and after the event) and handouts to support the client in their expression, including emotions, senses, and physiological responses. With regards to the increased direction required from therapists, the importance of avoiding leading questions was highlighted, such as when determining whether an event was traumatic or not. The length of NET sessions was also discussed and the need for flexibility and breaks within this population, as well as how carers might be involved and what information they would require about NET beforehand.

Meeting seven

Further discussion regarding how the delivery of NET could be adapted for adults with Mild ID. This included discussion regarding the literature relating to KidNET and developmentally appropriate adaptations, such as the use of drawing, figurines, and role play (Schauer et al., 2011). The re-narration aspect of the therapy and how this should be presented to the client was discussed and it was agreed this should also be in 'easy read' format if possible, so verbal re-narration was supported by words and pictures. The importance of understanding the client's baseline level of arousal was discussed, in order to understand when this had decreased in sessions, as well as the importance of allowing clients extra time to process emotions and return to their baseline. It was agreed that a further 'easy read' handout should be developed which gave information about what might happen for the client between sessions in order to validate and normalise these experiences, as well as suggesting sources of support. It was agreed that the lead researcher would continue to develop recommendations for delivering NET in line with discussions and send to the SALT to review.

Meeting eight

Written feedback from the service user group was discussed and it was agreed that all suggested changes so far could be incorporated into the 'easy read' materials and were in line with the guidance being followed. The final recommendations for delivering NET were discussed and agreed in preparation for the next stage of the research.

Meeting nine

Final meeting between lead researcher and SALT following virtual meeting with service user group where written feedback from the group was clarified and further verbal feedback was obtained. The verbal feedback was discussed, and it was agreed additional feedback could be incorporated into the 'easy read' materials in preparation for the next stage of the research.

3.2 The development of 'easy read' materials

The manual outlines examples of psychoeducation which should be provided to clients at the start of therapy. The following is a psychoeducational example of normalisation taken from the manual:







Anyone would be distressed after what you have experienced. The aftershock is known as the posttraumatic reaction. The human brain is designed to promote survival. Therefore, our mind and body are made in such a way that they will perceive and store threatening information to a great degree. Because this happened to you, your body is in a state of looking for and predicting danger before it occurs again. It is far preferable for us vulnerable humans to be too cautious, too hypervigilant. However, this is a survival strategy that is painful and extremely exhausting, as you know. It is no longer needed now, as the threat you survived happened in the past (Schauer et al., 2011, p. 40).





Descriptions from the manual were taken and converted into 'easy read' format by the lead research and the SALT; an example of normalisation is shown in Figure 6 which can be directly compared to the description above. This process involved consulting with guidance outlined by the DOH (2010), the DWP (2018) and NHS England (2018). As demonstrated in Figure 6, "easy read is not a simple translation of existing documents into easier to understand language. Easy read versions should concentrate on the main points of the document so that people with learning disabilities can understand the main issues" (DOH, 2010, p. 10). In Figure 6, text relating to the fight or flight response was deemed an acceptable violation to the one verb per sentence guidance (DWP, 2018; DOH, 2010) as it was deemed helpful to introduce this concept into therapy.

Figure 6

Psychoeducational example of normalisation converted into 'easy read'

Is this normal?

   	<p>When we are in danger, things happen to our bodies. This is to try and keep us safe.</p> <p>This is called the fight or flight response (see the Fight or Flight Response handout).</p> <p>This is so our bodies are ready to fight or run away from the danger.</p> <p>When this happens, we become more aware of things that might hurt us.</p>
 	<p>It is normal for our bodies to stay in fight or flight. This might happen even when we are not in danger anymore.</p> <p>You might still feel the things happening in your body to keep you safe.</p>

	<p>You might be more aware of the things that could hurt you.</p>
	<p>This happens because our brain wants to keep us safe. It wants to make sure we are not in danger again.</p>
	<p>This is normal when you think about the bad thing that happened to you. But it is really tiring and stressful.</p>
	<p>We need to teach our brain that we are now safe. We don't need to look for danger all the time.</p>

3.3 Service user group feedback

With regards to the written feedback, the service user group chose to annotate the 'easy read' materials, as opposed to completing the feedback sheets that had been provided [see appendix I for an example feedback sheet]. This was deemed an acceptable alternative by the research team and was also consistent with the definition of inclusive research with people with ID, which includes allowing people to exert some control over the research process (Walmsley & Johnson, 2003).

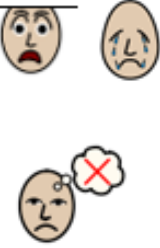
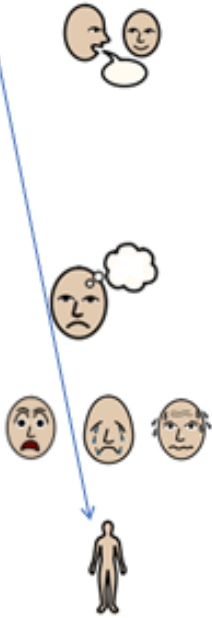
The service user group gave positive feedback relating to the general layout of the materials throughout. The group highlighted some areas for improvement in relation to the formatting of the documents. In some documents, the group suggested where text could be emboldened, and it was recommended that handouts were numbered so that they could be found more easily when referred to within the information sheets. The group also gave positive feedback in relation to the accessibility of the materials and in particular the handouts relating to physiological responses where they stated "the team really like this and can understand it", "all the team found the images and the

information clear". The group also gave positive feedback relating to the glossary and stated, "the team found explanations of the key words clear and easy to understand". Only one word was highlighted throughout the materials which the group felt was not easily understood; this was the word 'relaying' in relation the lifeline and this was subsequently changed to 'making'. The group also identified a number of pictures which they felt were either confusing, overcomplicated or did not match the text and usually an alternative image was offered.

At the virtual meeting, the service user group gave further positive feedback on the layout of the 'easy read' materials and the accessibility of the text, including the repetition across different materials. One further amendment was made to the text; the glossary was renamed 'word meanings' as opposed to 'word list', which the group felt better reflected the content. The group stated that if they were a potential client they would want to read through the information themselves, however, they thought it was important to have someone available to clarify understanding if necessary. Figure 7 shows an example of the written feedback provided by the service user group in relation to one of the 'easy read' materials developed by the lead research and SALT and Figure 8 shows how this feedback was subsequently incorporated. At this stage, the lead researcher also recognised the lack of diversity used within the symbols provided by the programme to depict different emotions; Figure 8 therefore also demonstrates how the 'easy read' materials were amended to reflect a more diverse population.

Figure 7

Example of written feedback provided by the service user group

<p>Some members of the team didn't like the body being pink, would prefer it to be an outline of a body like in the fight and flight sheet</p>	<h3>Why should I talk about the bad things?</h3>	
		<p>Thinking about the bad thing that happened to you can be really scary or upsetting.</p> <p>It makes sense that you try not to think about it. This is called avoidance.</p>
		<p>We want to talk about the bad thing in lots of detail during therapy.</p> <p>This will include:</p> <ul style="list-style-type: none">• remembering what you were thinking at the time• remembering how you were feeling at the time• remembering what was happening in your body at the time <p>This is called exposure.</p>

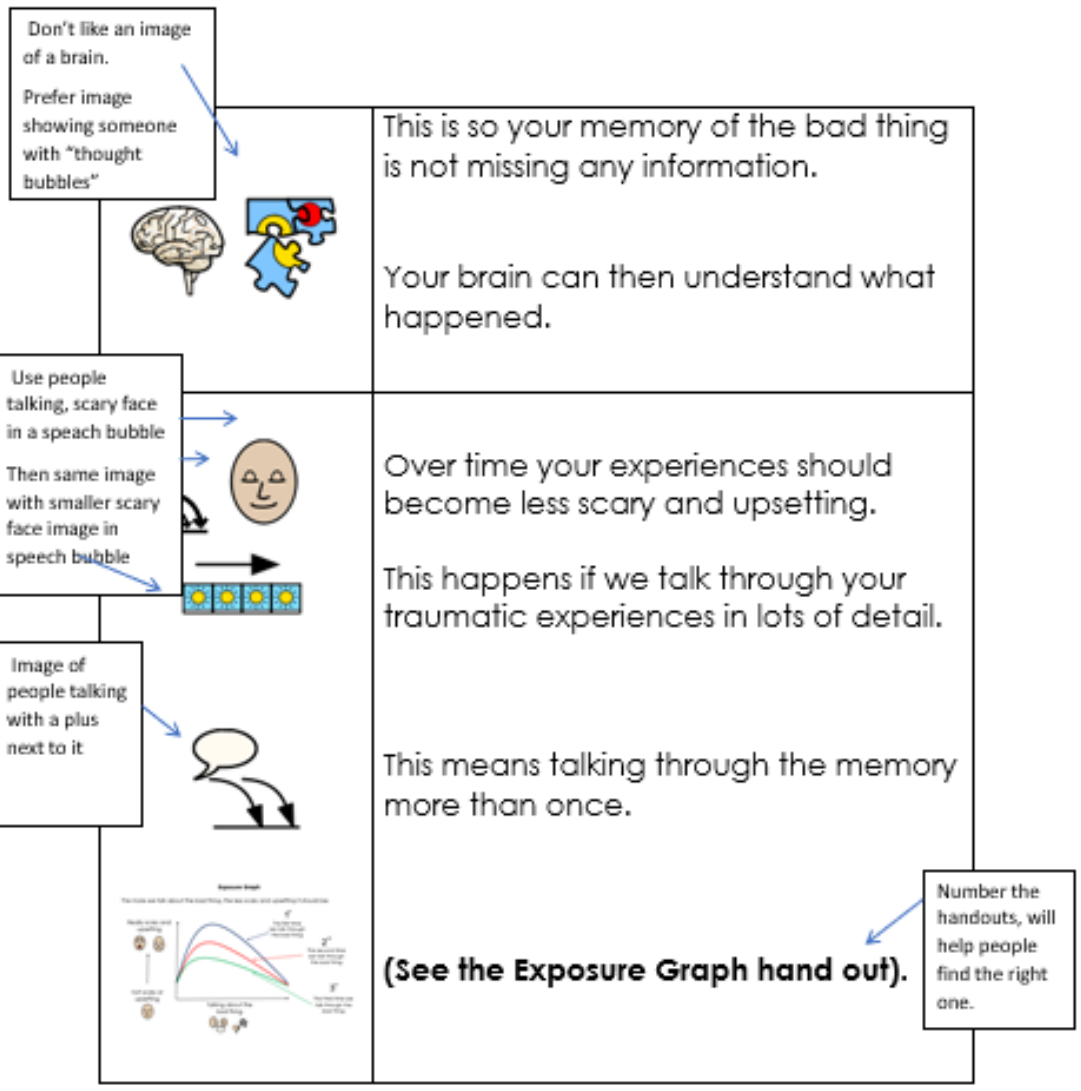
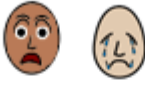







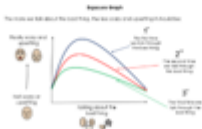


Figure 8

Example of how written feedback was incorporated into the 'easy read' materials

Why should I talk about the bad things?

 	<p>Thinking about the bad thing that happened to you can be really scary or upsetting.</p> <p>It makes sense that you try not to think about it. This is called avoidance.</p>
   	<p>We want to talk about the bad thing in lots of detail during therapy.</p> <p>This will include:</p> <ul style="list-style-type: none">• remembering what you were thinking at the time• remembering how you were feeling at the time• remembering what was happening in your body at the time <p>This is called exposure.</p>

	<p>This is so your memory of the bad thing is not missing any information.</p> <p>Your brain can then understand what happened.</p>
 	<p>Over time your experiences should become less scary and upsetting.</p> <p>This happens if we talk through your traumatic experiences in lots of detail.</p> <p>This means talking through the memory more than once.</p> <p>See HANDOUT 2 Exposure Graph.</p>

3.4 Written feedback from Clinical Psychologists

Written comments from each category of feedback are provided below in Table 6.

Table 6

Examples of feedback from CPs by category

Category of feedback	Comment from CP	What content it related to
Easy read materials: positive comments relating to accessibility	Mary: "This is worded very well".	Information sheet 1 'What is Narrative Exposure Therapy?'
	Alex: "I think this is a nice information sheet, clear, simple and helpful".	Information Sheet 2 'What will happen in therapy?'
Easy read materials: suggestions for alternative formatting	Mary: "Change to easy read format as per the information sheets?"	Handout 1 'Lifeline'
	Helen: "I think a graph might be too complex for people with a LD – they are unlikely to have got to the level of maths where	Handout 2 'Exposure'

Category of feedback	Comment from CP	What content it related to
	they learnt about graphs. Could you represent the level of distress with 3 cups – 1 full of stress, one medium and one with no stress in it?”	
Easy read materials: suggestions for alternative wording	Sam: “This seems like a good idea at the time could be changed to this helps us feel safe at the time, as seems like a good idea makes it seem as though it was a conscious decision”.	Information Sheet 1 ‘What is Narrative Exposure Therapy?’
	Hugo: “Perhaps the text could describe what will happen, rather than what won’t happen, for example, talking less or feeling fewer emotions could be reframed as being quieter or feeling the same all of the time”.	Handout 4 ‘What happens when we shut down?’
Easy read materials: suggestions for additional information	Sam: “Would it also be helpful to add some suggestions about what to do/not do after sessions? Have an activity to do, do something with other	Handout 9 ‘What might happen after sessions?’

Category of feedback	Comment from CP	What content it related to
	people, take a longer route home etc”.	Information Sheet 2
	Helen: “In the making your lifeline section – would it be worth clarifying here that you won’t be going into too much detail about the events and what you will do if people try to talk about things in too much detail?”.	‘What will happen in therapy?’
The adapted protocol: positive comments relating to the protocol	Alex: “These points all make sense and sound like sensible adaptations”.	The lifeline exercise
	Mo: “This looks great to me, very detailed. I think you have already included many of the adaptations and considerations which I might have suggested”.	Adapting the protocol for NET for adults with Mild ID generally
The adapted protocol: suggestions	Marcus: “Capacity and consent issues – including the right to withdraw and stop therapy”.	Adapting the protocol for NET for

Category of feedback	Comment from CP	What content it related to
for preparing clients for NET	Mo: "Dealing with outcomes and expectations? Explaining to clients and carers what is likely to change at the end of therapy and what might not change".	adults with Mild ID generally Same as above
The adapted protocol: suggestions for how carers are involved	Mo: "Should there be a carer session early on to discuss some practical strategies for the carer to help? And also what they shouldn't do? Perhaps develop a "support plan" with the carers to help them if/when issues arise? This should be written as many clients would have different carers during a week". Hugo: "Perhaps there could be more detail on how (and when) therapists discuss emotional reactions with carers. Also, consideration of the familiarity/consistency of carers – what if the client has no carers, these are infrequent, or the carer was involved in the	Adapting the protocol for NET for adults with Mild ID generally Same as above

Category of feedback	Comment from CP	What content it related to
	trauma in some way themselves (victim or perpetrator)?”	
The adapted protocol: suggestions for how the safety and well-being of clients is considered	Marcus: “Assessment of supportive and protective factors to ensure safety between sessions”.	Adapting the protocol for NET for adults with Mild ID generally
	Alex: “Perhaps in the initial sessions before the trauma work begins, this handout can be discussed and the therapist, client and carer can think about things that might help, or come up with a plan for how people will deal with the difficult times?”	Handout 9 ‘What might happen after sessions?’
The adapted protocol: suggestions for supporting the content of sessions	Lisa: “An alternative such as a ribbon could be used instead of a rope (especially if the client has negative/ trauma associations with a rope)”.	Adapting the protocol for NET for adults with Mild ID: The lifeline exercise
	Alex: “Many clients will struggle with open questions. They could be provided with the	Adapting the protocol for NET for adults with Mild ID:

Category of feedback	Comment from CP	What content it related to
	'feelings' handout and asked to choose from there".	Recognising a traumatic event
The adapted protocol: suggestions for adapting the structure of NET	Alex: "Realistically not all of our clients will be able to do this in one session, so will need some flexibility around this". Mo: "For some individuals, longer sessions with brief breaks might work. Twice per week might be better for some people".	Adapting the protocol for NET for adults with Mild ID: The lifeline exercise Adapting the protocol for NET for adults with Mild ID generally

3.5 Focus group discussion

3.5.1 *Optimism and motivation to adapt NET for people with ID*

The key concept of 'Optimism and motivation to adapt NET for people with ID' is presented here, which was not elaborated on in the main journal paper. This was developed as a result of the systematic application of FA to the transcript. The different themes within this concept are illustrated below with accompanying quotes from CPs.

Optimism about the suitability of NET for people with ID. CPs thought NET appeared feasible and worth trying among people with ID. They also highlighted many aspects of the approach that could be beneficial for this population including: the lifeline exercise which allows strengths and skills to be highlighted; the social justice element; and the focus on multiple traumas which people with ID can often face. In addition to this, one clinician, who had already used the lifeline exercise in practice with people with ID, shared positive experiences.

I think NET does seem feasible to me-Mary

I think it's definitely worth while giving it a go-Mo

that bit about sitting and being with somebody and allowing them that process of, of being in charge of naming and labelling all of those part of their life really felt like that would be a really useful thing-Sam

I know that it's recommended for people with multiple traumas whereas I think trauma-focused CBT often assumes just one or two, and for somebody, especially our clients who have faced multiple traumas, I think it can fit quite well for that-Lisa

a couple of other elements like I really like about NET . . . one is the social justice political side of it, because we know so many of our clients don't get social justice-Lisa

I use that [lifeline exercise] to sort of draw out the strengths and skills of somebody which makes it, you know for me, a much better place to tell the difficult story-Lisa

Furthermore, CPs thought NET appeared to be less complex and abstract than some of the other trauma-focused therapies, which meant it could be explained easily to the client and carers. It was also suggested that NET might match the expectations that clients have about trauma-focused therapy.

that's how I came across it in the first place because I was looking for something that was maybe a little bit more straight forward than some of the other things around-Mo

this feels to me, and I'm very new to NET, I've only come across it because I've been part of this, that it really is accessible, easy read, and respectful-Marcus

you're not looking to go in directly and address cognitions, or, or stuff that's slightly more abstract-Alex

if a client that you're working with has got carers, family members involved, you know core staff around them . . . it feels like this isn't alien, this approach can be described to those folks as well so they understand perhaps what their family member or client will be going through-Marcus

a helpful match between I guess what the therapy looks likes and what people are potentially going to expecting-Alex

Motivation to adapt NET for people with ID. CPs discussed the increased prevalence of trauma and adverse experiences among people with ID, when compared to the general population, and how this is being recognised and understood more. This included trauma among people who may have previously received diagnoses such as challenging behaviour.

I think nowadays we're recognising trauma a a lot more in people with, you know with learning disabilities-Mo

the rates of trauma and rates of you know difficult experiences in our client group are so much higher than the general population-Sam

I go back and think about all of the individuals I've worked with that were labelled with challenging behaviour, actually, probably that came from really traumatic experiences-Mo

In light of the above, CPs highlighted the mismatch between the levels of trauma among people with ID and the available evidence-based treatment options. They also discussed the lack of research and knowledge about how evidence-based treatments among the general population can be adapted for people with ID, which one CP labelled as discriminatory.

we're all sitting here talking about the prevalence of trauma and the prevalence you know of adverse experiences in our client groups and the lack of evidence base about what you do with that and it's that mismatch which just feels so wrong -Sam

we kept saying well how does this work [EMDR] with our client group and they just couldn't give us an answer-Lisa

it's discrimination all the way through, we, if its already in NICE guidelines as recommended evidence-based practice then it should be available to everybody, no matter what your IQ-Marcus

In addition to the increased prevalence of trauma among people with ID and the lack of evidence-based treatment options and adaptations, CPs also highlighted further motivations for adapting evidence-based approaches for people with ID. This included: the benefits of having more structured approaches to adapting therapies, as opposed to adaptations made by individual clinicians; validation for both clients and clinicians working with people with ID; and Trust requirements to ground interventions in evidence-based practice.

any attempt to do that in a structured way so it isn't just you know that, in [location] I'm cobbling it a bit together like this and in [location] you're doing it like that-Sam

the fact that effort has been put in to make the adaptations and to do it in a proper way is really validating for the client group and for the clinicians-Sam

we're expected to be doing things that have an evidence base, in terms of accountability and all sorts of things-Mo

3.5.2 Factors related to IDNET in practice

Additional quotes from CPs to illustrate the key concept of 'Factors related to IDNET in practice' are presented in Table 7.

Table 7

Additional quotes to illustrate 'Factors related to IDNET in practice'

Theme	Additional participant quotes
Challenges to overcome	the people who are presenting for trauma therapy are very rarely being presented as a neat package where you deal with the trauma and everything will be fine-Hugo
	I often get referrals for people where they're in a transition of some kind . . . and they're wanting these interventions to happen [trauma therapies] and sort of saying well we can't really provide that at the moment-Mo
	there would have been periods where I'd have been really cautious of using it [NET] because things were so close to break down that I think lots more resourcing was needed first, not just with the individual but the whole system around them-Alex

Theme	Additional participant quotes
	<p>trauma models can be very good for looking at a particular trauma event but once there happen to be multiple trauma events about, about say, say a person being a victim to a particular perpetrator, those models can break down quite quickly-Hugo</p> <p>you talked about people kind of shaking their heads when you talked about adapting it [NET] and I wonder what that's all about-Marcus</p> <p>we had to fight massively for me to be able to go on the course [NET training] because you know the people who control access to it were saying well why should we invest in you delivering it when you know there's no evidence for your client group-Sam</p> <p>well my vague memory is that they [trainers] were quite, not laid back exactly, [laughs] but I don't think you would have got shot down for suggesting that [an adaptation]-Lisa</p>
<p>The system around the client during therapy</p>	<p>it would be crucial to get that psychoed and the buy in from their main support network-Mary</p> <p>that need with our client group, to just always be thinking of that systemic picture-Alex</p> <p>it appears to be simple on a surface level or straight forward that people might misunderstand or misconstrue it and think that they can go away and do it-Mo</p>

Theme	Additional participant quotes
The practicalities of delivering and adapting NET	<p data-bbox="504 416 1334 667">it's really important that with any of these therapies there's proper supervision and I just wonder where we get supervision from for this type of thing and it's not just supervision in the approach but also in adapting it as well- Hugo</p> <p data-bbox="504 748 1334 999">who could potentially deliver this [NET] . . . we have art therapists in the service who are funded separately and budgeted from psychology . . . they are very good at using creative resources and doing that with some degree of technique and skill that I don't have-Hugo</p> <p data-bbox="504 1079 1334 1330">working with a few individuals with learning disabilities who are aware of the trauma and want to talk about it, they refer to quite specific episodes, even though, in one instance it was a very continuous situation . . . I'm guessing it's [NET] not that different-Mo</p> <p data-bbox="504 1411 1334 1554">we might just be describing another process that people in other areas use quite frequently, we're just helping somebody to order and make sense of life-Hugo</p> <p data-bbox="504 1635 1334 1823">it would be really good to review things, um, you know how much do people need that road map and scaffolding as they go through, because it's quite a big journey isn't it with NET to go through somebody's life story-Lisa</p>

Theme	Additional participant quotes
	<p>another real advantage of being involved in something like this, is finding out what other people are doing and what's being adapted-Hugo</p>
	<p>you sort of modify bits and pieces as you go, you try different things, you know, it's a developmental process isn't it trying to use a new, sort of approach-Mo</p>
	<p>we have to adapt stuff that's going on in mainstream . . . it's down to us as clinicians to make sure it is available-Marcus</p>

3.6 Feedback from NET clinicians and how it was actioned

A summary of the feedback from the expert panel discussion and how it was actioned by the research team is provided below in Table 8. Discussion points which resulted in future research questions to be explored when IDNET is trialled in practice are highlighted in italics.

Table 8

Feedback from NET clinicians and how it was actioned by the research team

Feedback	How it was actioned by the research team
<p>Psychoeducation</p> <p>Julia: Psychoeducation should not be broken up and discussed over a number of sessions as this delays treatment and can build avoidance. Psychoeducation should come after the diagnostics or lifeline session and relate to the client's problems, how these problems relate to their previous experiences and what NET can do about it. Small bursts of psychoeducation can be given during therapy when a big stone is processed or if avoidance comes up.</p> <p>Mia: People who are highly traumatised struggle to focus, which may be similar to those with ID, so psychoeducation should be kept short (for example, 15-20 minutes) and repeated throughout</p>	<ul style="list-style-type: none">• Delivering psychoeducation over a number of sessions was taken out of the protocol and instead the following was added: "the information sheets should be used flexibly depending on the cognitive ability of the client and any SALT guidance available, the client's current distress relating to PTSD symptoms, and what they are subsequently able to process during sessions".• The use of physical demonstrations to support psychoeducational explanations, such as how trauma memories are stored and how NET aims to help, was added to the protocol.• The need to revisit psychoeducation throughout therapy and in particular before processing stones, or at times of avoidance, was added to the protocol.

Feedback	How it was actioned by the research team
<p>therapy, rather than a “one off” session. If possible, physical demonstrations can support psychoeducation, such as about how trauma memories are stored and what therapy aims to do with the memories. Clients who are traumatised are not able to listen for a long time before therapy and language needs to be simple whatever the population.</p>	<ul style="list-style-type: none"> • <i>How psychoeducation is delivered in IDNET is something to be explored further in practice. This includes how much psychoeducation is given before commencing narration sessions, when the most appropriate time is to revisit psychoeducation during sessions, and what type of psychoeducation is most effective in increasing understanding, for example, visual information, physical demonstrations.</i>
<p>Handouts</p> <p>Julia: If handouts are used in sessions they should not be given as homework, clients should be left alone to rest and consolidate the new memory after sessions. However, handouts to support the client during sessions are a good idea and if they ask to take them home that is okay. The handouts may also be useful for carers to understand the therapy.</p>	<ul style="list-style-type: none"> • The following was added to the protocol: “Information sheets and handouts should never be given as “homework”. After NET sessions, the client is encouraged to rest”.

Feedback	How it was actioned by the research team
<p data-bbox="240 472 549 506">Involvement of carers</p> <p data-bbox="240 580 743 1384">Julia: Carers are not usually present during the lifeline and narration sessions of NET, even with very young children. If necessary, it may be appropriate to have a staff member who is known to the client, but this should never be the primary/secondary carer in everyday life or related to the client in an emotional way prior to the therapy. It may be useful to have a carer present just for the initial session who can help the therapist understand how best to communicate with the client.</p> <p data-bbox="240 1458 735 1989">Anna: When adults with ID have been asked their preference, they have chosen to do therapy alone. There is also the risk that if a carer is present during narration sessions that the client may want to continue working through the trauma with the carer outside of sessions. Whilst the carer can listen outside of sessions they</p>	<ul data-bbox="778 472 1342 1995" style="list-style-type: none"> <li data-bbox="778 472 1342 725">• Without any research exploring the impact of carers during IDNET, it would not be appropriate to exclude carers at this stage, which can be routine within ID services. <li data-bbox="778 752 1342 1666">• The following is already stated in the protocol: “Clients may choose to have a carer with them during NET sessions, however, there would need to be agreement between the client and therapist about who this is and consistency in who attends sessions. For example, it would not be appropriate to have a carer present who was a perpetrator or who may also be traumatised by the same event/s as the client”. However, the importance of considering the impact of the carer on the client’s willingness to talk about their traumatic experiences was added to the protocol. <li data-bbox="778 1693 1342 1995">• The following was also added to the protocol: “If carers are present during NET, it must be emphasised that work should not be continued outside of sessions with the therapist”.

Feedback	How it was actioned by the research team
<p>should not be enquiring more about the client's experience between NET sessions or continuing sessions.</p>	<ul style="list-style-type: none"> • <i>The impact of having carers present during IDNET is something to be explored further in practice. This would include exploring how carers can support during psychoeducation, lifeline, and narration sessions and how their presence impacts on both the client during therapy and how IDNET is delivered.</i>
<p>Understanding of NET</p> <p>Mia: Both the client and carers need to have an understanding of the therapy and possible reactions so that some distress is expected. However, this must be balanced with not deterring the client or carers from the client doing therapy.</p> <p>Anna: Psychoeducation should also be given to the staff team around the client about trauma symptoms (for example, dissociation) and about the method of NET.</p>	<ul style="list-style-type: none"> • The need for the client and carers to have an understanding about how NET may impact on the client is already included in the protocol. • The following was also added to the protocol: "The staff team involved with the client must also be informed about NET and possible reactions to the therapy, so these are expected and managed appropriately".

Feedback	How it was actioned by the research team
<p>Managing arousal</p> <p>Julia: In NET, the person who manages the arousal at all times is the therapist, the client should not be expected to have these skills beforehand and does not receive skills training. Breathing is never regulated in NET, only dissociation and flash backs are regulated. The therapist may comment on changes in breathing, and other physiological symptoms they notice and ask the client if it mirrors their experience at the time of the trauma. Labelling the experience in the here and now and relating it to the past trauma helps to regulate the arousal. Breathing exercises, mindfulness and grounding training may be part of rehabilitation after NET and are not a prerequisite of NET. NET is different to EMDR where the therapist may enquire with the client about their arousal, in NET the therapist and client are working so closely together that the therapist identifies and manages</p>	<ul style="list-style-type: none"> • Reactions to NET may have potentially devastating consequences for people with ID because of how their behaviour is interpreted by others. For example, an escalation in behaviour may be responded to by medication changes, and may result in placement breakdowns and inpatient admissions, which could have very long-term impacts. Therefore, either the client should have some ability to manage their arousal before starting NET or the team around the client should have an understanding of possible reactions to therapy and appropriate ways of responding which do not have long term and negative repercussions for the client. This has been added to the protocol. • <i>The level of ability required to manage their own arousal, prior to a client with ID engaging in IDNET, is something to be explored further in practice. This includes whether the client requires a stabilisation phase as completed in other TFCBT, but which contradicts current NET</i>

Feedback	How it was actioned by the research team
<p>arousal for the client and therefore only the therapist is required to know the skills of mindfulness, grounding etc. Treatment is effective when the client can be contained by the therapist at their highest level of arousal and continue to narrate through this.</p> <p>Mia: Learning how to manage arousal in NET should form a core part of the therapists training in order for them to feel confident when arousal is high in sessions.</p> <p>Mia: There is no need for a stabilisation phase before doing NET and research does not support the need for this phase. Therefore, insisting that a client is stable can delay treatment and reinforces the message that the client can't deal with their symptoms. When working with complex PTSD, arousal/emotional instability decreases as trauma is processed.</p>	<p><i>practice, or if this can be managed by the therapist and the system around the client.</i></p>

Feedback	How it was actioned by the research team
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Julia: Stabilisation may be increased by meeting the client regularly during NET, twice a week if possible.

<p>Checklists</p> <p>Julia: The checklists are a pillar of NET, even if patients are diagnosed prior to therapy, for example by a psychiatrist, the trauma checklist and the MACE should be completed. This is to gain a fuller picture of the trauma spectrum and to develop the bond between the therapist and client, focusing on trauma from the outset. Subsequently, when the lifeline is completed, the therapist can check whether content captured by the checklists is represented in the lifeline.</p>	<ul style="list-style-type: none"> • This appears to be a particular form of practice and has therefore not been incorporated into the protocol. If PTSD has been diagnosed before NET, it may not be necessary to do the checklists and the decision to do these can be made on a case-by-case basis. Furthermore, events can be remembered spontaneously during narration sessions that did not appear on either the lifeline or pre-treatment assessments. Therefore, no amendments were made to the protocol.
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Feedback	How it was actioned by the research team
<p>The lifeline exercise: duration</p> <p>Julia: There is research to suggest that prolonging the lifeline is not an effective treatment for PTSD, so there are no benefits to extending this session and it is expected that the lifeline is completed in one longer session (up to 2 hours).</p> <p>Mia: If the lifeline is taking too long then it is usually because the therapist is allowing the client to talk in too much detail about each event and starting exposure too early.</p> <p>Anna: If it is necessary to do the lifeline over more than one session, which may be the case within an ID population (one very complex patient with ID took 15 hours to complete the lifeline session), a photo can be taken so it can be laid out before the next session.</p>	<ul style="list-style-type: none"> • There is no research exploring the impact of extending the lifeline exercise when delivering NET with adults with Mild ID, however, there is evidence from the practice of one of the participants that the lifeline can take much longer with clients with ID, even when the NET protocol is followed correctly. Therefore, it would not be appropriate to state that the lifeline session cannot be extended at this stage. • The protocol states that “it may be that the lifeline is completed over two or more sessions, however, this decision should be made based on the abilities of the client and avoidance should be considered when planning to extend this activity into further sessions”. Therefore, this part of the protocol has not been amended. • The protocol has been amended to include the following: “If the lifeline takes more than one session to complete, a photo should be taken in order for the lifeline to be laid out prior to the next session. Sessions

Feedback	How it was actioned by the research team
<p>Mia: If the lifeline is over a number of sessions then these should be in quick succession, so it is not drawn out for the client.</p>	<p>should also be in quick succession so that narration sessions can proceed without too much delay".</p> <ul style="list-style-type: none"> • <i>The impact of extending the lifeline exercise over more than one session is something to be explored further in practice. This includes the impact on the client, in terms of level of distress, and on the delivery of NET, due to deviating from the standard protocol.</i>
<p>The lifeline exercise: symbols</p> <p>Julia: Sticks are an important part of NET and should be included if possible. For example, in relation to a situation where the client has done something/or not done something. Candles are also an important part of NET to symbolise loss and should also be included if possible.</p> <p>Anna: When doing the lifeline, it is also helpful to give each symbol a name, for example, 'bad time in my life', in order to get an initial</p>	<ul style="list-style-type: none"> • Whilst within an ID population it seems appropriate to limit symbols to stones and flowers to reduce complexity, sticks and candles may be used flexibly if they are meaningful to the client. The protocol has been amended to reflect this. • The following was added to the protocol: "If possible, the client should be encouraged to give each symbol a name to gain an initial understanding of its meaning for the client".

Feedback	How it was actioned by the research team
<p>understanding of the meaning of the event for the client.</p>	
<p>Emotions</p> <p>Julia: There is research to suggest that people who are traumatised may not recognise emotions on facial expressions and so exaggerated pictures, for example, emojis, may be better for handouts. NET works with the five basic emotions: fear, anger, sadness, disgust, and joy.</p>	<ul style="list-style-type: none"> • The protocol states that “HANDOUT 7 ‘Feelings’ should be used as a guide for the therapist and adapted to suit the client. For example, the client may be able to describe emotions without any prompts, may prefer photos or to choose their own wording/images”. Therefore, the need to explore recognition and understanding of emotions on a client-by-client basis is already captured in the protocol. The handouts developed also use exaggerated pictures, rather than photos. • A basic emotions list, including the five basic emotions referred to by the NET clinicians, was developed as an alternative to the existing extended list.
<p>Distress scales</p> <p>Anna: The Subjective Units of Distress Scales are not usually</p>	<ul style="list-style-type: none"> • <i>Appropriate scales for measuring the client’s distress during IDNET are something to be explored further in</i>

Feedback	How it was actioned by the research team
<p>helpful within the ID population; other visual scales can be more useful, for example, something simpler with fewer categories that the client can rate, physically if possible.</p>	<p><i>practice. For example, whether scales should be verbal, visual, or physical tools and how many points on the scale are necessary to identify/discriminate changes in the client's arousal.</i></p>
<p>Use of language</p> <p>Julia: NET relies on language production and hippocampal functioning during exposure. Therapists can verbalise for the client, but the client also needs to produce language out loud around their experience. The client might also be taught more language during the narration, for example, around emotions. Pointing to emotions without verbalising experiencing may not be enough to reduce symptoms in line with NET theory.</p>	<ul style="list-style-type: none"> • The following is already included in the protocol: "Clients are required to have verbal ability to participate in this particular NET protocol". • The protocol was amended to include the following: "Clients should also verbalise feelings, as opposed to only pointing to emotions, in order to capture emotional experiences in the narration".

Feedback	How it was actioned by the research team
<p data-bbox="240 472 512 506">Types of questions</p> <p data-bbox="240 584 746 1111">Julia: Open questions should not be used to determine whether an experience was traumatic or not, as clients may not have the vocabulary. Instead, they should be asked “was that scary?” It is okay to make suggestions about their experience which can also help overcome avoidance if it is too difficult for them to verbalise.</p>	<ul data-bbox="778 472 1353 1167" style="list-style-type: none"> • If it is very clear to the therapist that the client is experiencing an emotion, such as sadness or fear, then it would seem appropriate to suggest this using a closed question. However, in instances where it is difficult to identify what emotion a client is experiencing, to avoid leading and due to the acquiescence observed among people with ID, an open question would seem more appropriate. The protocol has been amended to reflect this.
<p data-bbox="240 1301 395 1335">Visual aids</p> <p data-bbox="240 1413 746 1995">Julia: Visuals can be used to show the process of how events are exposed during the processing of a stone. During the narration, perception, cognition, emotion, body memories, and meaning making in the past are compared to the here and now, and how the past is now understood. The narration of what happened next is then continued and the cycle</p>	<ul data-bbox="778 1301 1262 1559" style="list-style-type: none"> • Visual prompts to support the processing of each symbol are already recommended in the protocol and therefore no amendments have been made.

Feedback	How it was actioned by the research team
<p>above begins again. This is useful for lay counsellors in the field to follow during sessions to ensure all aspects are explored.</p>	
<p>Contraindications</p> <p>Anna: If people are not able to distinguish between fantasy and reality, or if they can't distinguish between the past, the present and the future then NET would probably not be suitable.</p>	<ul style="list-style-type: none"> • The following has been added to the protocol: "It is unlikely that NET will be appropriate if the client is experiencing acute psychosis".

4.0 Extended discussion

4.1 Limitations

The current research was not without its limitations, and this applies to the order in which experts contributed to the research. Whilst this appeared logical during the design phase, and subsequent changes to IDNET including the 'easy read' materials were carefully considered before implementation, it is possible that the comments of either the service user group, or the CPs were unintentionally overridden during the following stages. The risk of this is particularly significant for the service user group where power imbalances may be more prevalent and clients with ID can often feel unheard (Hoole & Morgan, 2011). Therefore, an additional stage where service users were asked to re-review the 'easy read' materials may have been more in line with emancipatory research with disabled people, as defined by Zarb (1992), and could form a future research objective. Furthermore, CPs within the focus group expressed an interest in meeting with NET clinicians in order to discuss adaptations to the therapy. Perhaps a stage which involved representatives from all stakeholder groups coming together would have further countered the risk of the views of any group being overridden. However, the next stage in the research process is to trial IDNET in practice, rather than continue to seek the views of experts in different formats.

A further limitation of the current research is commonly cited in literature relating to the focus group method. This also applies to the expert panel in the current research and is regarding the presence of more dominant voices in groups. There were dominant voices in both the focus group and expert panel, however, the debate observed within both groups in relation to certain topics, such as the most appropriate profession to deliver NET in ID services within the focus group, and the need to extend the lifeline exercise for people with ID within the expert panel, suggests that some participants felt able to challenge each other appropriately. However, there may have been challenges that were left unspoken by other participants and which are impossible to quantify. This risk was countered somewhat by the opportunity for participants in the focus group to provide individual written feedback, however, this related only to

adaptations to IDNET including the 'easy read' materials, rather than topics which emerged during the focus group discussion.

4.2 The system around the client during therapy

It is usual practice within ID services for carers to be involved in psychological therapy, and carers are encouraged to support clients with ID in the assessment, care, and treatment of mental health difficulties (NICE, 2016). The involvement of carers is a recommended adaptation to psychotherapy with people with ID (Hurley et al., 1998; Jahoda, 2016) and systemic therapy which focuses on the family or group of people around the client, as opposed to the individual, is increasingly being offered in ID services (Kaur et al., 2009). This further highlights the importance of the system around the client in the treatment of mental health difficulties in ID services. It is therefore not surprising that the system around the client was identified as a theme during the focus group discussion between CPs and specifically, the support required from this system in order for therapy to be effective. This mirrors earlier research exploring the views of CPs, clients, and carers, where the wider system was generally perceived as a positive facilitator for change during psychological therapy (Ramsden et al., 2016).

Although NET is an individual approach to therapy (Schauer et al., 2011), Polyvagal Theory (Porges, 2018) may also indicate some significant advantages to the involvement of carers when delivering trauma-focused therapies. Polyvagal theory states that feelings of safety can counter the effects of trauma and that the absence of threat alone is not sufficient. The theory proposes that feeling safe, among other things, depends on the activation of the social engagement system which is an evolutionary response and a key mechanism in the co-regulation of physiological states. This system allows us to connect with others and feel safe by reading cues for safety in others, such as positive facial expressions. This therefore suggests that support from carers, who provide clients with ID with feelings of safeness, may have a specific benefit when delivering trauma-focused therapies such as NET, and further suggests that excluding carer involvement at this stage would not be appropriate.

4.3 Therapist Drift in the context of the current research

Therapist drift occurs when clinicians, consciously and unconsciously, deviate from evidence-based treatments in routine practice, and is cited as one of the reasons why treatments may be less effective (Waller & Turner, 2016). The focus group reported experiences of resistance from those trained in certain models to make adaptations to therapies and instances where access to training had been restricted/difficult because clinicians working in ID services were unable to fully adhere to the approach. It is a reasonable conclusion that this may be in an attempt to avoid 'therapist drift' and maintain treatment integrity. The literature base relating to 'therapist drift' largely focuses on CBT (Waller & Turner, 2016), which has relevance to NET as a TFCBT outlined by NICE (2018). In relation to the treatment of PTSD, imaginal exposure has been found to be underutilised in practice by trauma clinicians (van Minnen et al., 2010). This has clinical implications for NET, which uses imaginal exposure as a mechanism of change. The authors reported that factors related to underutilisation in practice were the amount of training clinicians received and clinician confidence in the approach, in addition to fears related to symptom exacerbation and dropout as a result of imaginal exposure. If we consider this in relation to the current research and avoiding 'therapist drift' when NET is adapted and delivered among adults with ID, clinicians must ensure that they are well trained and confident in the approach, and specifically in delivering the imaginal exposure component of NET. There is also the likelihood in NET that clients' symptoms will worsen temporarily during treatment, which is a normal part of the process of healing (Schauer et al., 2011), but also related to underutilisation of imaginal exposure in practice. It is therefore also vital that clinicians are aware of this possibility and prepared to manage this, which may further reduce the chances of 'therapist drift'. There is a lack of research exploring 'therapist drift' specifically among clinicians using TFCBT within ID populations, however, this issue highlights the importance of accurate reporting of interventions so that both 'therapist drift' and treatment integrity can be monitored, despite any adaptations made to the therapy. Furthermore, it

suggests that an adherence measure to be used when delivering IDNET is required, and future research should aim to develop this.

4.4 The multiple disadvantages of people with ID

The Equality and Human Rights Commission (2016) stated “some people in our society are being left further behind because they face particular barriers in accessing important public services and are locked out of opportunities” (p. 3); people with ID are included within this group. It is notable that the statement reads that some people are being left ‘further behind’, rather than ‘behind’, which alludes to not only the disadvantages that people with ID face first and foremost as a result of their disability, but also the subsequent barriers encountered when accessing services and opportunities. This reflects the issues raised within the focus group regarding the challenges faced when attempting to adapt and deliver trauma-focused therapies within ID services. If we consider the above further in the context of the current research and PTSD in people with ID; risk factors for developing PTSD following a traumatic experience include being female, prior trauma, and having a low educational level or socio-economic status (Tang et al., 2017). Not only are adults with ID at greater risk of exposure to adverse life events when compared to the general population (Wigham & Emerson, 2015), they are also disadvantaged in the areas of education and employment (Equality and Human Rights Commission, 2016) which will impact on socioeconomic status. This demonstrates the multiple disadvantages that people with ID face and which culminate in a greater risk of developing PTSD after a traumatic experience. This is further exacerbated by concerns about the quality of healthcare that people with ID receive (Equality and Human Rights Commission, 2016). With this in mind, and the lack of research into trauma-focused therapies for people with ID (Byrne, 2020; Dagnan et al., 2018; Mevissen et al., 2016), it is not surprising that the focus group reported many barriers to overcome with regards to delivering appropriate and adapted evidence-based approaches for treating PTSD within this population.

4.5 Future research

The current research raised a number of questions to be explored in future research when the adapted protocol is trialled in practice:

- How feasible is IDNET?
- How effective is IDNET in reducing symptoms of trauma in adults with Mild ID?
- What are the views of service users on the final IDNET therapy materials and how can they be incorporated?
- How effective are the 'easy read' materials developed in the current research, in increasing the understanding of NET among adults with Mild ID?
- What ability to manage their own arousal do clients with ID require prior to engaging in IDNET and how does this impact on the theory underpinning NET?
- How is psychoeducation in IDNET delivered with adults with Mild ID?
- What is the impact of having carers in the lifeline and narration sessions on both the client and the delivery of IDNET?
- What is the impact of extending the lifeline exercise over more than session on both the client and the delivery of IDNET?
- What scales are appropriate when delivering IDNET to measure current distress?
- How can adherence to the protocol be measured when delivering IDNET?

5.0 Reflections

Throughout the research process I kept a reflexive diary in order to reflect on my thoughts and feelings and consider the impact of these on the research. This was essential to the pragmatist approach I took, in order to ensure that research processes were guided by how best to answer the research questions, as opposed to any other motivations. The diary varied from brief sentences at certain points of the research process, to multiple paragraphs at more challenging stages, such as during the ethical approval phase of stage one and when the initial project design became unfeasible due to the COVID-19 pandemic. Below demonstrates some of the challenges faced throughout the research process, as well as how certain decisions were arrived at. My reflections were supported by regular supervision with my supervisors who had both clinical and research experience relating to the topics addressed by the current research. Quotations from the diary and supervision logs are included below.

Developing the research

From the outset of training, I knew that I wanted to conduct my research in the field of ID and recruit Anna to the research if possible, given what I knew about Anna from working in the ID team as an assistant. However, it took time to find a specific focus for the research, which felt like a lifetime in comparison to some of my peers who had chosen topics from the handbook and seemed to be well away with their plans. This was extremely frustrating; out of all the challenges I was expecting to face throughout my training, I did not foresee developing my thesis project idea as one of these:

Diary: I can't believe how difficult it is to pin down a thesis project. I want my research to be something I am genuinely interested in that will keep me motivated over the next three years, but it's harder than I thought. I know I have been advised to go back to the research manual to look at topics suggested already but I want to do my research with people with ID and there aren't any topics suggested in the manual. I also really want to contribute to the idea.

As advised, I did go back to the research topics which had been suggested by different supervisors on the course and this is where everything quickly fell into place. Thomas had shared his interest in NET, something I had not come across before. However, I did have an understanding of the increased prevalence of trauma among people with ID and Winterbourne View was still fresh in my mind from working in ID services. A quick literature search found nothing on the use of NET with adults with ID and Thomas welcomed the idea of combining the two ideas, which could follow a similar design to a current third year project:

Supervision log: Trainee's interest in ID was discussed early in the meeting and how this interest could be combined with interest in NET. Possible research question 1 – How can NET be adapted for an ID population? Possible research question 2 – Are there benefits of NET for an ID population?

Anna was on board with the research idea and just like that, after what had felt like forever trying to pin down a question, the research project came together and did well at the research proposal panel a few weeks later. By this point, we had also discussed the benefits of involving service users in the adaptations and had made the decision to consult with a service user group on the accessibility of both the research and therapy materials we would develop:

Supervision log: Adaptations made to NET will be evaluated by consulting with a service user panel on the accessibility of the adaptations for people with ID. This, and consultation with a speech and language therapist throughout the adaptations, will allow for triangulation.

Shortly after developing the research design, the BBC show Panorama released their documentary uncovering the abuse of people with ID at Whorlton Hall. This further highlighted the need to find effective evidence-based treatments that are appropriately adapted for people with ID. My motivation for this project has remained unchanged throughout this whole process, despite the

challenges, and I believe this is largely due to instances like the above never being far from my mind.

Gaining ethical approval

I again did not expect to face the challenges I did when attempting to gain ethical approval for the project. I also did not anticipate the huge differences in time scales between gaining HRA approval for a project, as opposed to solely from the University, and how this would affect me:

Diary: I'm starting to panic; I feel like I'm falling behind my timescale and my peers already. I do really love this project though and it will be worth it to work directly with clients in the NHS. There is such a lack of research into trauma-focused therapies for adults with ID and I wonder whether these lengthy processes to gain ethical approval are why.

It was extremely time consuming completing everything for the sponsor at the university and then moving on to complete the forms for HRA approval. Lots of the forms were so alien to me and took up lots of valuable time on study days which I needed for other assignments. I travelled to Solihull ethics committee and found the experience daunting; however, I was generally prepared and able to answer the questions raised by the panel. However, I did find some of the feedback frustrating:

Diary: It's been suggested that I put a smiley face on the consent form if the person wants to be involved in the research and a sad face if they do not, instead of the tick or cross I have suggested. This is frustrating - it should be a positive decision for the client whether they choose to take part in the research or not and this feels like it could be leading.

The service user group were going to offer feedback on the consent form in the first stage of the research and so I felt confident that this issue would be resolved. However, just as I had received ethical approval from HRA and was ready to approach the NHS, the pandemic hit, which threw the biggest spanner

in the works for the research plan. I was advised straight away by the NHS that they would not be reviewing any research which was not COVID-19 related. After some negotiation, they did agree to review the study, however, there were now even more hoops to jump through. This was frustrating, but understandable given the increased pressure on the service and the need to ensure that they had the capacity to support the research. Eventually I received confirmation to go ahead with the first stage of the project and hoped that by the time I got to the case study phase, we would be seeing clients face to face again.

Changing the project design

Along with many others, I was naïve as to how long the pandemic would last. I thought by the time we had completed stage one of the research project; business would be back to normal. We now know how overly optimistic this was. At a meeting in September 2020, it was decided that the original plan for the research was no longer feasible, and we couldn't even be sure that a single case study could be completed due to the likelihood of further lock downs. Early on in the development of the research design, it had been suggested by some of the course research team that adapting the NET protocol for people with ID could be a project in itself and it was decided that extending the adaptation phase was the most appropriate way forward:

Supervision log: We discussed the next phase of the project (case study series); it was decided due to time and COVID restraints that this phase is no longer feasible. Instead, we plan to conduct two focus groups; one group of ID psychologists and one group of NET clinicians, to gain feedback on the adapted protocol and resources produced in phase one.

I was initially quite upset about this. It felt like all of the hard work and time spent gaining approval from HRA had been for nothing and I was having to start all over again. The comparison with my peers, which occurred throughout the process of the research, was highlighted once again as some projects were unaffected by the pandemic or were more easily amended to an online format. During the redesign of the research, I attended a research clinic where other

research tutors queried whether focus groups were the most appropriate way forward. This was also frustrating because at that point I was under pressure to finalise the next stage of the project and it felt like I didn't have the time to consider anything else. I approached my supervisors and suggested whether the Delphi method would allow more structured implementation of feedback from the professionals into the adapted protocol, however, we decided to continue with the focus group method due to reasons already outlined in the methodology section. We also discussed how we would ensure that feedback was implemented in a structured and predetermined way, which were the advantages of the Delphi method:

Supervision log: The focus group comprised of ID psychologists will be sent the NET adaptations prior to a focus group and asked to provide written feedback, these will then be integrated into the documents and marked up before being sent back to the group to review. During the focus group, suggested changes will be discussed, and psychologists will be asked to reach a majority decision on whether the change is appropriate or not. If a majority decision cannot be reached, the researchers will attempt to integrate all viewpoints and will decide final wording.

A later challenge emerged when we were unable to recruit more than three NET clinicians to the second focus group. This was another moment of panic during the research, as I did not want to extend the recruitment stage. The research timeline had already been extended substantially by this point, and potential dates for this focus group to occur had already been suggested to participants in order to comply with this new timeline. We knew that between four and eight participants were the norm for focus group research (Kitzinger, 1995; Wilkinson, 2004) and therefore it was decided that the format of this group would change to an expert panel. This was discussed within supervision, and it was felt that the aims of involving NET clinicians in the research could still be achieved with three participants.

Analysing the focus group data

I was apprehensive about the data analysis stage; it had been around eight years since I had last done any qualitative analysis and I could barely remember the process. I was also conscious that there had been a reflective group within the cohort involving those who were completing qualitative analysis, but I had not had any data at that time, and they had now all submitted their theses. I did approach this group, who welcomed me into their WhatsApp group and were really helpful in supporting me during the data analysis and in developing my thinking:

Diary: So thankful to have such a good cohort – Hayley offered to read through a bit of my coding, and I feel much more confident sending it to Thomas and Anna now to review. It's been really helpful talking to Hayley about the initial codes and has got me thinking about some potential themes in the data already and some topics for my discussion.

Fortunately, I was pleasantly surprised when I started the data analysis stage and I found the book by Ritchie et al. (2014) extremely helpful. Due to having only one focus group to analyse, I did not find the data overwhelming and familiarised myself with it quickly. I was aware of some of the biases and assumptions I had when going into the focus group, such as my beliefs about what barriers the CPs might raise regarding the delivery of NET with people with ID. Therefore, when it came to coding and generating themes, I was careful not to exaggerate barriers which I was expecting to find, unless of course they were clearly grounded in the data. I also reflected on some of my thoughts and feelings in the diary which arose as a result of the focus group discussion and which might have influenced my analysis:

Diary: I can't believe the resistance people have talked about when it comes to trying to access and adapt therapies for people with ID. One person was asked why they should be allowed on the NET training when there isn't any evidence for people with ID... I understand that there needs to be a good rationale for training which is expensive, but how can we get any evidence for people with ID

if no one working in those services is trained?! So frustrating - another time where people with ID draw the short straw!

During the analysis, I was therefore also careful to ensure that I didn't ignore any data which challenged my own assumptions. For example, one of the CPs talked about a positive experience where they felt the trainer of a therapy model was open to making adaptations for people with ID and I ensured to include this in the final write up. This also highlighted the need for qualitative analysis to be reviewed by other researchers in order to assess the quality of themes developed and avoid the analysis being influenced by any strong emotions which might be evoked.

Final reflections

Although the research project has been challenging and stressful at times, I am now able to reflect on how beneficial the process has been. The pandemic meant that there was no other choice but to extend the adaptation phase of the project and I am so very grateful that this happened. Including CPs and NET clinicians in the adaptation phase enhanced the adaptations hugely and identified many issues that needed to be considered when the adapted protocol is trialled in practice. Furthermore, the project is being continued by another trainee and so my efforts to gain ethical approval from HRA have not been in vain and the case study stage will go ahead. I am also entering employment in ID services on qualification and so hope to remain involved in the project and see how it progresses. I really believe NET could benefit people with ID, who deserve efforts to be made to find effective evidence-based treatments for trauma, just like efforts are made among the general population, and my passion for and commitment to this project continues.

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Appendices

Appendix A: Journal submission guidelines

British Journal of Learning Disabilities

<https://onlinelibrary.wiley.com/page/journal/14683156/homepage/forauthors.htm>

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Appendix B: Stage one - University of Nottingham Sponsorship Statement



Our reference: R&I: 19101
IRAS Project ID: 273021

0115 8467906
sponsor@nottingham.ac.uk

**Health Research Authority
Research Ethics Committee**

Research and Innovation
University of Nottingham
East Atrium, Jubilee Conference Centre
Triumph Road
Nottingham
NG8 1DH

21st January 2020

Dear Sir or Madam,

Sponsorship Statement

Re: Narrative Exposure Therapy for traumatic stress in adults with Intellectual Disabilities: A sequential measurement single case study series

I can confirm that this research proposal has been discussed with the Chief Investigator and agreement to sponsor the research is in place.

An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.*

Any necessary indemnity or insurance arrangements will be in place before this research starts. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

Wording has been included in the participant information sheets to address the requirements of GDPR for transparency information and has been drafted by the sponsor to ensure consistency and compliance with the University's privacy notice, HRA guidance and the expectations of other organisations, therefore the HRA template wording has not been used verbatim.

Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

The duties of sponsors set out in the UK Policy Framework for Health and Social Care Research will be undertaken in relation to this research.**

* Not applicable to student research (except doctoral research).

** Not applicable to research outside the scope of the Research Governance Framework.

Yours faithfully

A handwritten signature in black ink, appearing to read "A. Shone".

Angela Shone
Head of Research Governance
University of Nottingham



Appendix C: Stage one - Research Ethics Committee Approval Letter


**Health Research
Authority**
West Midlands - Solihull Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS
Telephone: 0207 1048191

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

15 April 2020

Professor Thomas Schröder
Professor of Clinical Psychology and Psychological Therapies, University of Nottingham;
Co-Director (Academic & Research), Trent DClinPsy Programme;
University of Nottingham
Trent Doctorate in Clinical Psychology, Division of Psychiatry and Applied Psychology
University of Nottingham, Jubilee Campus, Wollaton Road
Nottingham
NG8 1BB

Dear Professor Schröder

Study title: Narrative Exposure Therapy for traumatic stress in adults with Intellectual Disabilities: A sequential measurement single case study series
REC reference: 20/WM/0048
Protocol number: 19101
IRAS project ID: 273021

Thank you for your letter of , responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Approvals Manager.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales) NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

Appendix D: Stage one - Health Research Authority Approval letter



Professor Thomas Schröder
Professor of Clinical Psychology and Psychological
Therapies, University of Nottingham; Co-Director
(Academic & Research), Trent DClinPsy Programme;
University of Nottingham
Trent Doctorate in Clinical Psychology, Division of
Psychiatry and Applied Psychology
University of Nottingham, Jubilee Campus, Wollaton
Road
Nottingham
NG8 1BB

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

15 April 2020

Dear Professor Schröder

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Narrative Exposure Therapy for traumatic stress in adults with Intellectual Disabilities: A sequential measurement single case study series

IRAS project ID: 273021

Protocol number: 19101

REC reference: 20/WM/0048

Sponsor: University of Nottingham

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

Appendix E: Stage one - Confirmation of capacity and capability from local NHS Foundation Trust

From: [REDACTED] - Research & Evaluation Assistant <[REDACTED]>
Sent: 19 June 2020 21:38
To: Katie Marlow <msxkm16@exmail.nottingham.ac.uk>
Subject: Study review: Narrative Exposure Therapy for adults with Intellectual Disabilities. IRAS ID: 273021

Dear Katie,

Re: Study Title: Narrative Exposure Therapy for adults with Intellectual Disabilities. IRAS ID: 273021

We have now had the opportunity to review the study together with supporting documents.

Please accept this email as formal confirmation that [REDACTED] NHS Foundation Trust have the capacity and capability to conduct this research **as outlined in the 1st part of the study in line with current COVID guidelines.** (Please find the signed Agreement attached).

Please note that before the second part of the study can start, we need confirmation from the Service and nominated study PI, that everything is in place for the 2nd part of the study to start. This is a new process specifically set up to support portfolio restart work.

Therefore, prior to the start of the 2nd part of the study, please complete and return the attached CHECK and ASSESS form, in order that we can review the form prior to approval for the start-up of the 2nd part of the study.

As this is a new process, we would also welcome any feedback on the portfolio process.

In the meantime, we wish the study well for the start up of Part 1 and look forward to hearing from you when you are ready to prepare for the 2nd part of the study to open.

Kindest regards

[REDACTED]
Research Compliance Facilitator

Appendix F: Stage two - University of Nottingham approval letter



DPAP Committee

18/01/2021

Supervisor: Thomas Schroder

Applicant : Katie Marlow

Project: Project Id Adapting the protocol for Narrative Exposure Therapy for adults with Mild Intellectual Disability

A favourable opinion is given to the above named study on the understanding that the applicants conduct their research as described in the above numbered application. Applicants need to adhere to all conditions under which the ethical approval has been granted and use only materials and documentation that have been approved.

If you need to make any any changes (for example to the date or place of data collection, or measures used), an Amendment Form should be submitted. This can be done by the Supervisor in 'Create Sub Form' in the Actions Menu on the left hand side of the page on the on-line system: Select 'Amendment Form'

yours

Professor David Daley

Co-Chair of DoPAP Ethics Subcommittee

Professor Amanda Griffiths

Co-Chair of DoPAP Ethics Subcommittee

Appendix G: Stage two - University of Nottingham amendment approval letter



DPAP Committee

09/03/2021

Supervisor:

Applicant : Katie Marlow

Project: Project Id Adapting the protocol for Narrative Exposure Therapy for adults with Mild Intellectual Disability

A favourable opinion is given to the above named study on the understanding that the applicants conduct their research as described in the above numbered application. Applicants need to adhere to all conditions under which the ethical approval has been granted and use only materials and documentation that have been approved.

If you need to make any any changes (for example to the date or place of data collection, or measures used), an Amendment Form should be submitted. This can be done by the Supervisor in 'Create Sub Form' in the Actions Menu on the left hand side of the page on the on-line system: Select 'Amendment Form'

yours

A handwritten signature in black ink that reads "David Daley". The signature is written in a cursive style.

Professor David Daley

Co-Chair of DoPAP Ethics Subcommittee

A handwritten signature in black ink that reads "Amanda Griffiths". The signature is written in a cursive style.

Professor Amanda Griffiths

Co-Chair of DoPAP Ethics Subcommittee



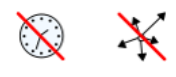
Appendix H: Example feedback provided by SALT on easy read materials

Psychoeducational example of trauma reactions given in the NET manual

No matter how hard we try to avoid the memories of the traumatic experience, they keep coming up again. All of a sudden you may feel upset, anxious, or detached from reality and not know why. During a traumatic experience, your mind cannot comprehend what is happening and you become overwhelmed by the body's alarm system and anxiety. You become highly aroused in order to act fast, but you have no time to process the information. However, your brain has a tendency to want to complete things and so brings up pieces of information in the future in order to try and understand them. Reliving feelings, images and bodily sensations shows that your mind is trying to process and understand the event. They keep coming back into consciousness again and again but because they are so painful, you try to avoid them. We want to give them time during therapy and give your mind chance to process and integrate these parts of your memory.

Easy read format developed by the lead researcher with feedback from SALT


Why do I feel this way?

	When the bad thing happened to you, your body went into flight or fight to try and help you manage it.
	This meant your brain focused on your senses - what you could see, smell, hear, taste and touch, to help you manage what was happening.
	You didn't focus on other things like what day it was and where you were. These things were less helpful for you at the time.


RJ Renton Jessica - Highly Specialist Speech & L...
Why do I feel like this?

RJ Renton Jessica - Highly Specialist Speech & L...
Think about other things.

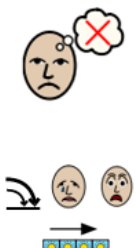
RJ Renton Jessica - Highly Specialist Speech & L...
This is because your brain didn't think they were helpful at the time.


	<p>After the bad thing, your brain brings up the memory to try and understand what happened to you.</p> <p>This is hard because you didn't focus on things like what day it was and where you were at the time.</p>
---	--

RJ Renton Jessica - Highly Specialist Speech & L...
Your brain thinks about what happened to try and understand what happened.

	<p>You might have thoughts and images of the bad thing popping up in your head.</p> <p>You might have nightmares about the bad thing. Your body might feel the way it felt when it went into fight or flight.</p> <p>These things show us that your brain is trying to make sense of what happened.</p>
---	--

RJ Renton Jessica - Highly Specialist Speech & L...
pictures

	<p>It is really upsetting when these things happen, and you might try and not think about the bad thing.</p> <p>This seems like a good idea at the time but can make us more upset and scared in the future.</p>
---	--

	<p>During therapy, we want to focus on the memories so that your brain can understand what happened.</p> <p>This means putting together the information about our senses with the information about what day it was and where we were at the time.</p>
---	---



RJ Renton Jessica - Highly Specialist Speech & L...
think about

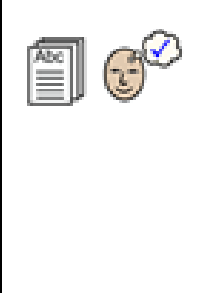
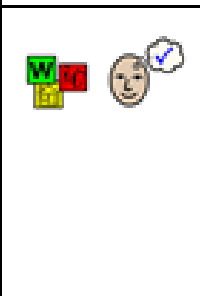
Appendix I: Example feedback sheet for service user group

5

Feedback sheet: Is this normal?

Is this normal?

	<p>When we are in danger, things happen to our bodies. This is to try and keep us safe.</p> <p>This is called the fight or flight response (see the fight or flight response booklet).</p> <p>This makes sure that our bodies are ready to fight or run away from the danger.</p> <p>When this happens, we become more aware of things that might hurt us.</p>
	<p>It is normal for our bodies to stay in fight or flight. This might happen even when we are not in danger anymore.</p>

	<p>Does the writing make sense?</p>	
	<p>Do the symbols make sense?</p>	



Was there anything you didn't understand?



What are the main things you liked about it?



What are the main things you would change about it?

Appendix J: Participant Information Sheet ID Clinical Psychologists

PARTICIPANT INFORMATION STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

Project Title: Adapting the protocol for Narrative Exposure Therapy for adults with Mild Intellectual Disabilities

Researcher/Student: Katie Marlow msxkm16@exmail.nottingham.ac.uk

Supervisor/Chief Investigator: Professor Thomas Schröder

lwzts@exmail.nottingham.ac.uk

Ethics Reference Number: 1668

We would like to invite you to take part in a research study about adapting a short-term therapy for traumatic stress disorders, called Narrative Exposure Therapy (NET), for people with Intellectual Disabilities (ID). Before you begin, we would like you to understand why the research is being done and what it involves for you.

What is the purpose of this study?

The aim of the study is to identify how NET can be adapted for adults with Mild ID. This includes both the materials used during the therapy and the way in which it is delivered. The study also aims to explore whether specialists in the field of ID and NET believe the adapted version of NET, developed throughout the research process, is appropriate for adults with Mild ID and remains consistent with the NET treatment manual. The study's findings may therefore inform clinicians about how to adapt a recommended treatment for post-traumatic stress disorder (PTSD) for adults with Mild ID and the appropriateness of delivering this type of therapy.

The study is also for educational purposes and will form part of my Doctorate in Clinical Psychology.

Why have I been invited?

You have been invited because you are a Clinical Psychologist who has experience of working with adults with ID and have replied to our advert in the British Psychological

Society's Division of Clinical Psychology Faculty for People with ID. We are inviting 4-8 participants to take part in the study.

Do I have to take part?

It is up to you to decide whether to take part or not; it is entirely voluntary. If you do decide to participate, you will be asked to sign a consent form and complete a demographics questionnaire.

You are free to withdraw at any point before or during the study without giving a reason.

What will I be asked to do?

1. You will be asked to electronically sign a consent form and complete a demographics questionnaire via email.



1. You will be sent, via email, NET materials which have been adapted for adults with Mild ID and recommendations which have been developed, regarding the delivery of NET for adults with Mild ID. These have been developed by the researchers and a Speech and Language Therapist. The therapy materials have also been reviewed by a service user group.



2. You will be asked to provide written feedback on the accessibility of these materials and recommendations for delivering NET with adults with Mild ID and suggest possible amendments you believe would improve the adaptations. You can structure your feedback in a way to suit you and there is no predetermined form; you may decide to write specific feedback throughout the documents, or you may prefer to write general feedback. You will be asked to provide your feedback within two weeks of receiving these documents and a reminder email may be sent if a response has not been received within 10 days. We anticipate that it will take you between 1-2 hours to review and provide feedback on the materials and recommendations for delivering NET with adults with Mild ID.



3. The researchers will subsequently integrate the suggested amendments into the documents and return these to participants to read prior to being invited to a focus group; which will be at least one week later. The suggested amendments will be clearly marked throughout the documents; however, the origin of these suggestions will not be disclosed, unless participants choose to identify their suggestions during the focus group.



4. The focus group will be held online over Microsoft Teams at a time convenient for all participants and will be recorded using the facility available through Microsoft Teams. The researcher facilitating the group will share their screen and read through each suggested amendment, facilitating a discussion around the amendment and asking for a majority decision on whether the amendment should be incorporated. If a majority decision cannot be reached, the researchers will aim to incorporate both views into the documents.



5. Following this, a discussion will be facilitated during the focus group around adapting trauma-focused therapies within ID services, the appropriateness of NET with adults with Mild ID and foreseeable advantages and disadvantages of using this type of therapy, rather than other trauma-focused therapies. It is anticipated that this focus group will last no longer than 2 hours.

Will the research be of any personal benefit to me?

Participating in the study may not benefit you directly, however, it will give you the opportunity to reflect on your skills and experience of delivering trauma-focused therapies with adults with ID. It is hoped this will help to inform how NET can be adapted for adults with Mild ID and the appropriateness of delivering this type of therapy with adults with Mild ID experiencing traumatic stress. Your participation therefore has the potential to positively impact on service users by determining whether NET could be a useful therapy and what adaptations would be appropriate.

Are there any possible disadvantages or risks in taking part?

Taking part in this research will take up approximately 4 hours of your time, however, this is dependent on how long it takes you to review the documents sent prior to the focus group. It is highly unlikely that you will experience any distress during the focus groups, as you will be asked to speak about your professional skills and experience.

What will happen to the information I provide?

The written feedback you provide prior to the focus group will be made known to other participants in the focus group, however, it will remain anonymous unless you choose to identify it as your own within the focus group discussion.

The focus group will be recorded, using the facility available through Microsoft Teams, therefore by consenting to this study, you are consenting to the recording of the focus group discussion. All data collected from participants including consent forms, information about demographics and focus group recording will be kept **strictly confidential**. Data will be stored in a secure and locked office, and on a password protected database at the University of Nottingham which only the research team will have access to. Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. Please be advised that whilst we will ask all participants to respect the privacy of fellow participants by treating focus group discussions as confidential and not sharing information outside of the group, the researchers cannot guarantee that others will adhere to this.

Participants will be given a pseudonym, which will remain confidential during and after the study completion. The focus group discussions will be transcribed by the research team and anonymised, and information that could identify participants will be removed. Direct quotations may be used from the focus group discussions in the final report and in subsequent publications, though these will remain anonymous. This includes my thesis, which forms part of the Doctorate in Clinical Psychology that I am currently working towards.

Your contact information will be kept by the University of Nottingham for 1 year after the end of the study so that we are able to contact you about the findings, unless you have chosen to opt out of this in the consent form. Your contact information will be kept separately from the research data collected and only those necessary will have access to it. All other data (research data) will be kept securely by the University for 7 years

under the terms of its data protection policy. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

Data Protection

We will follow ethical and legal practice and all information will be handled in confidence.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

<https://www.nottingham.ac.uk/utilities/privacy.aspx>

We would like your permission to use anonymised data in future studies, and to share our research data (e.g. in online databases) with other researchers in other Universities and organisations both inside and outside the European Union. This would be used for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the email addresses above.

What if there is a problem?

If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee adrian.pantry@nottingham.ac.uk who will pass your query to the Chair of the Committee.

If you remain unhappy and wish to complain formally, you should then contact the Faculty of Medical and Health Sciences Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk

We believe there are no known risks associated with this research study; however, as with any online activity the risk of a breach is always possible. We will do everything possible to ensure your involvement in this study will remain anonymous.

What will happen if I don't want to carry on with the study?

Your participation in the study is entirely voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, we will no longer collect any information from you, however, we will keep the information that we have already obtained as we are not able to tamper with study records. This information may have already been used in some analyses and may be included when the study is written up. Once you have taken part in the focus group, we will not be able to remove your data from the study as this will form part of a group discussion which will be analysed as a whole, however, you will remain anonymous.

What will happen to the results of the research study?

Participants will be contacted via email about the results of the study when it has been finalised, and with details of any subsequent publications, unless you state you do not want to be contacted. Alternatively, the results can be obtained by emailing the researchers using the details provided at the end of this participant information.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded as part of my Doctorate in Clinical Psychology, by NHS Health Education East Midlands (HEEM).

Who has reviewed the study?

All research in healthcare is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the University of Nottingham Faculty of Medicine & Health Sciences Research Ethics Committee.

Further information and contact details

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Email: msxkm16@exmail.nottingham.ac.uk

Professor Thomas Schröder

Division of Psychiatry and Applied Psychology

University of Nottingham

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Appendix K: Participant Information Sheet NET Clinicians

PARTICIPANT INFORMATION

STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

Project Title: Adapting the protocol for Narrative Exposure Therapy for adults with Mild Intellectual Disabilities

Researcher/Student: Katie Marlow msxkm16@exmail.nottingham.ac.uk

Supervisor/Chief Investigator: Professor Thomas Schröder

lwzts@exmail.nottingham.ac.uk

Ethics Reference Number: 1668

We would like to invite you to take part in a research study about adapting a short-term therapy for traumatic stress disorders, called Narrative Exposure Therapy (NET), for people with Intellectual Disabilities (ID). Before you begin, we would like you to understand why the research is being done and what it involves for you.

What is the purpose of this study?

The aim of the study is to identify how NET can be adapted for adults with Mild ID. This includes both the materials used during the therapy and the way in which it is delivered. The study also aims to explore whether specialists in the field of ID and NET believe the adapted version of NET, developed throughout the research process, is appropriate for adults with Mild ID and remains consistent with the NET treatment manual. The study's findings may therefore inform clinicians about how to adapt a recommended treatment for post-traumatic stress disorder (PTSD) for adults with Mild ID and the appropriateness of delivering this type of therapy.

The study is also for educational purposes and will form part of my Doctorate in Clinical Psychology.

Why have I been invited?

You have been invited because you have an active interest and practical experience of delivering NET and have contacted the researchers, after having been informed about the study by another NET clinician. We are inviting 4-8 participants to take part in the study.

Do I have to take part?

It is up to you to decide whether to take part or not; it is entirely voluntary. If you do decide to participate, you will be asked to sign a consent form and complete a demographics questionnaire.

You are free to withdraw at any point before or during the study without giving a reason.

What will I be asked to do?

1. You will be asked to electronically sign a consent form and complete a demographics questionnaire via email.



2. You will be sent, via email, NET materials which have been adapted for adults with Mild ID and recommendations which have been developed, regarding the delivery of NET for adults with Mild ID. These have been developed by the researchers and a Speech and Language Therapist. The therapy materials have been reviewed by a service user group, and the therapy materials and recommendations for delivering NET with adults with Mild ID, have been reviewed by Clinical Psychologists who have experience of working with adults with ID. You will be given at least one week to read through these documents before being invited to a focus group.



3. The focus group will be held online over Microsoft Teams at a time convenient for all participants and will be recorded using the facility available through Microsoft Teams. Discussions will be facilitated around how consistent the

revised materials and recommendations for delivering NET are with the NET manual and how appropriate you believe NET is for adults with Mild ID. There will also be opportunity for you to provide recommendations for how NET could be adapted for adults with ID, should you have experience of delivering NET with adults with cognitive impairment. It is anticipated that this focus group will last 1-2 hours.

Will the research be of any personal benefit to me?

Participating in the study may not benefit you directly, however, it will give you the opportunity to reflect on your skills and experience of delivering Narrative Exposure Therapy. It is hoped this will help to inform how NET can be adapted for adults with Mild ID and the appropriateness of delivering this type of therapy with adults with Mild ID experiencing traumatic stress. Your participation therefore has the potential to positively impact on service users by determining whether NET could be a useful therapy and what adaptations would be appropriate.

Are there any possible disadvantages or risks in taking part?

Taking part in this research will take up approximately 3 hours of your time depending on how long it takes you to review the documents sent prior to the focus group. It is highly unlikely that you will experience any distress during the focus groups, as you will be asked to speak about your professional skills and experience.

What will happen to the information I provide?

The focus group will be recorded, using the facility available through Microsoft Teams, therefore by consenting to this study, you are consenting to the recording of the focus group discussion. All data collected from participants including consent forms, information about demographics and the focus group recording will be kept **strictly confidential**. Data will be stored in a secure and locked office, and on a password protected database at the University of Nottingham which only the research team will have access to. Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. Please be advised that whilst we will ask all participants to respect the privacy of fellow participants by treating focus group discussions as confidential and not sharing information outside of the group, the researchers cannot guarantee that others will adhere to this.

Participants will be given a pseudonym, which will remain confidential during and after the study completion. The focus group discussions will be transcribed by the research team and anonymised, and information that could identify participants will be removed. Direct quotations may be used from the focus group discussions in the final report and in subsequent publications, though these will remain anonymous. This includes my thesis, which forms part of the Doctorate in Clinical Psychology that I am currently working towards.

Your contact information will be kept by the University of Nottingham for 1 year after the end of the study so that we are able to contact you about the findings, unless you have chosen to opt out of this in the consent form. Your contact information will be kept separately from the research data collected and only those necessary will have access to it. All other data (research data) will be kept securely by the University for 7 years under the terms of its data protection policy. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

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included when the study is written up. Once you have taken part in the focus group, we will not be able to remove your data from the study as this will form part of a group discussion which will be analysed as a whole, however, you will remain anonymous.

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This research is being organised by the University of Nottingham and is being funded as part of my Doctorate in Clinical Psychology, by NHS Health Education East Midlands (HEEM).

Who has reviewed the study?

All research in healthcare is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the University of Nottingham Faculty of Medicine & Health Sciences Research Ethics Committee.

Further information and contact details

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Appendix L: Consent form ID Clinical Psychologists

Participant Consent

Interactive form for online/remote/social media/internet-based interview studies

STUDENT RESEARCH PROJECT ETHICS REVIEW Division of Psychiatry & Applied Psychology

Project Title: Adapting the protocol for Narrative Exposure Therapy for adults with Mild Intellectual Disabilities

Researcher: Katie Marlow msxkm16@exmail.nottingham.ac.uk

Supervisor: Professor Thomas Schröder lwzts@exmail.nottingham.ac.uk

Ethics Reference Number: 1668

- Have you read and understood the Participant Information? Yes No
- Do you agree to take part in a focus group, that will be recorded, about adapting Narrative Exposure Therapy for adults with Mild Intellectual Disabilities? Yes No
- Do you know how to contact the researchers if you have questions about this study? Yes No
- Do you understand that you are free to withdraw from the study, at any time, without giving a reason? Yes No
- Do you understand that once you have been involved in the focus group discussion, it will not be possible to withdraw your data from the analysis? Yes No
- Do you agree to maintain the confidentiality of the information discussed by all participants and researchers during the focus group? Yes No
- Do you give permission for your data from this study to be shared with other researchers in the future, provided that your anonymity is protected? Yes No
- Do you understand that non-identifiable data from this study, including quotations, might be used in academic research reports or publications? Yes No
- I confirm that I am 18 years old or over Yes No

If you would like a summary of the research findings please insert your email address in this text box

By ticking the button below, I indicate that I understand what the study involves, and I agree to take part. I consent to take part in this research study Yes

Appendix M: Consent form NET Clinicians

Participant Consent

Interactive form for online/remote/social media/internet-based interview studies

STUDENT RESEARCH PROJECT ETHICS REVIEW Division of Psychiatry & Applied Psychology

Project Title: Adapting the protocol for Narrative Exposure Therapy for adults with Mild Intellectual Disabilities

Researcher: Katie Marlow msxkm16@exmail.nottingham.ac.uk

Supervisor: Professor Thomas Schröder lwzts@exmail.nottingham.ac.uk

Ethics Reference Number: 1668

- Have you read and understood the Participant Information? Yes No
- Do you agree to take part in an expert panel, that will be recorded, about adapting Narrative Exposure Therapy for adults with Mild Intellectual Disabilities? Yes No
- Do you know how to contact the researchers if you have Questions about this study? Yes No
- Do you understand that you are free to withdraw from the study, at any time, without giving a reason? Yes No
- Do you understand that once you have been involved in the Expert panel discussion, it will not be possible to withdraw your data from the analysis? Yes No
- Do you agree to maintain the confidentiality of the information discussed by all participants and researchers during the expert panel? Yes No
- Do you give permission for your data from this study to be shared with other researchers in the future, provided that your anonymity is protected? Yes No
- Do you understand that non-identifiable data from this study, including quotations, might be used in academic research reports or publications? Yes No
- I confirm that I am 18 years old or over Yes No

If you would like a summary of the research findings please insert your email address in this text box

By ticking the button below, I indicate that I understand what the study involves, and I agree to take part. I consent to take part in this research study Yes

Appendix N: Interview schedules

Focus group: ID Clinical Psychologists

Question	Prompts
How feasible do you think NET is with adults with Mild ID?	<p>Can you tell me a bit more about that?</p> <p>What barriers do you think therapists might need to overcome?</p>
NET is one of several therapies recommended for treating trauma. What might be the advantages of delivering NET within ID services, rather than other trauma therapies?	<p>For the client?</p> <p>For the therapist?</p>
NET is one of several therapies recommended for treating trauma. What might be the disadvantages of delivering NET within ID services, rather than other trauma therapies?	<p>For the client?</p> <p>For the therapist?</p>
What might be the advantages of adapting trauma-focused therapies within ID services, rather than delivering non-adapted therapies?	<p>For the client?</p> <p>For the therapist?</p>
What might be the disadvantages of adapting trauma-focused therapies within ID services, rather than delivering non-adapted therapies?	<p>For the client?</p> <p>For the therapist?</p>
Based on your experience, what further recommendations would you make for adapting and delivering trauma-focused therapies for adults with ID?	<p>Can you give any specific examples from your practice?</p>

Expert panel: NET clinicians

Question	Prompts
How appropriate do you think this NET is for adults with Mild Intellectual Disability?	What barriers do you think therapists might need to overcome?
We have attempted to ensure that adaptations and recommendations maintain consistency with the theory underpinning NET. To what extent do you think this has been achieved?	What recommendations do you have for making the adaptations more consistent with the NET manual?
If you have experience of delivering NET with adults with cognitive impairment, what recommendations would you suggest for adapting NET?	If you have experience, can you give any specific examples from your practice?

Appendix O: Examples of indexing

Example one:

Sam: You know it's the things that [Mo] was just talking about there that you, the feeling of kind of a **lack of other options, that work with our clients and other kind of structured approaches and evidence base for therapeutic approaches for trauma for people with learning disabilities is so bad**, given that the **rates of trauma and rates of you know difficult experiences in our client group are so much higher than the general population**. That, that mismatch between what people experience and what we can effectively do to help them with it is such a stark thing for me that just during the training I was really, I felt that yes it was, you know for a very specific part of the client group, but that it would be a very helpful approach, but yeah I haven't actually been able to do it because I haven't felt like doing a brand new therapeutic approach virtually during a pandemic would have been a very sensible thing to do, so yeah [laughs].

Lack of treatments for trauma in people with ID

Recognising and understanding trauma in people with ID

NET as potentially useful for people with ID

Example two:

Hugo: Yeah, errr, and our Trust are really pushing forward with the idea of us taking laptops into sessions and you know doing our clinical notes at the same time, clearly that's a broad-brush approach to everybody within a large mental and physical health Trust but, yeah, you know there are these things that are the kind of contextual factors that hold these therapies and hold these approaches and how much time is there to do things afterwards. **Can we break with the manual**, the manual is designed, well it sounds like from hearing the conversations for war zones, [laughs] where you know you've just got to do it and get on with it and **how does that apply to me working in [Hugo's location] [laughs], slightly different from a war zone.**

Practical considerations of NET + Potential challenges of delivering NET

Thinking about adaptations and the need to learn more about NET

Example three:

Lisa: Working in learning disabilities, we know we need to be so creative and adapting all the time and its part of our bread and butter isn't it adapting and you know, when you come across, a body goes no no, and I guess it's about getting into the NICE guidance, erm, having something that they think is you know if you go from a specific protocol then it more likely to be gold standard, you know evidence, but it doesn't sit very nicely does it with the messiness of, of real life, especially people who have got very complex lives and presentations.

Adapting approaches for people with ID generally

Resistance from others to adapt therapies for people with ID

Complexities of working with people with ID

Poster



Adapting Narrative Exposure Therapy for Adults with Intellectual Disabilities

Katie Marlow, Prof Thomas Schröder, Dr Anna Tickle & Jess Renton
Trent Doctorate in Clinical Psychology

Background

Adults with Intellectual Disabilities (ID) are more vulnerable to developing post-traumatic stress disorder (PTSD) than the general population (Fletcher, 2016). Narrative Exposure Therapy (NET; Schauer et al., 2011) is recommended by the National Institute for Health and Care Excellence (2018) to treat PTSD. However, there is a lack of research exploring firstly, the effectiveness of NET among adults with ID and secondly, what adaptations are required for this population. The aim of this study was therefore to adapt the NET protocol for delivery with adults with Mild ID.

Research questions

- How can NET be adapted for adults with Mild ID to create a new protocol (IDNET) for further investigation in clinical practice?
- What are the views of service users on the IDNET therapy materials developed and how can they be incorporated?
- What are the views of professionals on using NET in ID services and on the adapted protocol (IDNET), and how can they be incorporated?

Method

Stage one: The NET protocol was systematically adapted for adults with ID in collaboration with a service user group (acknowledged below). This was informed by guidance relating to adapting therapies for people with ID, making information accessible, and developmentally appropriate adaptations to NET already documented in the literature.

Stage two: Professionals' views on the adapted protocol and on the use of NET in ID services were sought, to inform subsequent amendments to the protocol. This comprised a focus group of Clinical Psychologists (CPs) working in ID services and an expert panel of NET clinicians. The Framework Approach (FA; Ritchie & Spencer, 1994) was conducted on the focus group data.

Results

Stage one: A new protocol was developed (IDNET) which comprised recommendations for how NET could be adapted for adults with Mild ID. This included six information sheets and nine handouts in 'easy read' format which mapped onto the psychoeducational examples in the NET manual.

Stage two: Eight CPs and three NET clinicians were recruited to the research. Feedback from professionals led to amendments to IDNET. Two key core concepts were developed as a result of applying FA to the focus group: '**Optimism and motivation to adapt NET for people with ID**' and '**Factors related to NET in practice**'. Issues raised by professionals regarding the delivery of IDNET highlighted further research questions for when the adapted protocol is trialled in practice.

Discussion

- This research is the first attempt to systematically adapt NET for adults with ID, in collaboration with a number of different expert groups including service users.
- Professionals were optimistic about IDNET, however, they highlighted a number of issues which require further consideration. In addition to practical considerations, these include the impact of adaptations to the NET protocol (e.g. extending the lifeline exercise, involving caregivers) on the client, the way NET is delivered and the theory underpinning NET.
- Future research should aim to trial IDNET in practice to explore feasibility and effectiveness in reducing symptoms of PTSD among adults with ID.



References: Fletcher, R. J., Barnhill, J., McCarthy, J., & Strydom, A. (2016). From DSM to DM-ID. *Journal of Mental Health Research in Intellectual Disabilities*, 9(3), 189-204; National Institute for Health and Care Excellence. (2018). Post-traumatic stress disorder. <https://www.nice.org.uk/guidance/ng116/chapter/Recommendations#management-of-ptsd-in-children-young-people-and-adults>; Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. G. Burgess (Eds.), *Analysing Qualitative Data* (pp. 173-194). Routledge; Schauer, M., Neuner, F., & Elbert, T. (2011). *Narrative exposure therapy: A short-term treatment for traumatic stress disorders* (2nd ed.). Hogrefe Publishing.

Acknowledgements: The research team would like to thank the Learning Together Northwest Ltd for their involvement in the first stage of the research.

Small Scale Research Project

An audit of the implementation of NICE recommended psychological interventions for post-traumatic stress in one service for adults with Intellectual Disability

Katie Marlow^{1,2} and Dr Anna Tickle^{1,2}

¹ Trent Doctorate in Clinical Psychology, Division of Psychiatry and Applied Psychology, University of Nottingham, UK

² Nottinghamshire Healthcare NHS Foundation Trust, Nottingham, UK

Abstract

Purpose Adults with Intellectual Disability (ID) appear more likely to develop post-traumatic stress disorder (PTSD) than the general population, yet research into appropriate therapies and adherence to relevant National Institute for Health and Clinical Excellence (NICE) guidance is lacking. This report describes an audit of recent practice within one ID service within the Midlands, England, to determine convergence with NICE guidance for psychological interventions for mental health problems in adults with ID and specifically PTSD.

Design/methodology/approach Eleven Clinical Psychologists and Trainee Clinical Psychologists were asked to identify clients with whom they had completed individual trauma-focused therapy since 2016. A retrospective audit of electronic client files was subsequently completed.

Findings Ten clients were identified. Results demonstrated that practice was largely consistent with current NICE guidance, however, there were important omissions in clients' electronic records including: components of trauma-focused cognitive behavioural therapy; aspects of communication; collaboration with clients on measuring progress and support to practice and apply new skills. This points to recommendations for the service regarding treatment and how this is documented in clients' files.

Research limitations The sample is limited and may not represent all work being completed in the service. There are also limitations regarding the method of data collection used to assess practice against NICE guidelines.

Originality This appears to be the first attempt to audit practice in ID services against NICE guidelines for the treatment of PTSD in adults.

Background

The rise of trauma informed care within mental health services in the UK has highlighted the need for patients to receive care that considers trauma and includes referral for specific trauma-focused treatment where appropriate (Sweeney, Clement, Filson and Kennedy, 2016). This includes the treatment of post-traumatic stress disorder (PTSD). Adults who have an Intellectual Disability (ID) are at greater risk of exposure to adverse life events (Hughes *et al.*, 2012; Wigham and Emerson, 2015) and experience a substantially higher prevalence of mental health conditions (Mevisen, Didden and de Jongh, 2016; Hughes-McCormack *et al.*, 2017) when compared to the general population. With this in mind, and the potential impact of ID on coping resources, it appears adults with ID are at greater risk of developing PTSD than the general population (Mevisen and de Jongh, 2010; Fletcher, Barnhill, McCarthy, and Strydom, 2016; Cowles, Randle-Phillips, and Medley, 2018).

In the UK, the National Institute for Health and Clinical Excellence (NICE) provides guidance for clinicians in the health service, including mental health treatment (Dagnan, Jackson, and Eastlake, 2018). Guidelines such as these enable research into different clinical presentations to be “carefully interpreted and translated to ensure its appropriate application to routine clinical care” (Forbes *et al.*, 2010, p.552). Whilst the guidelines have been formulated to facilitate optimal standards of care, their implementation in clinical practice is variable and may depend on a number of factors including support amongst professionals in the field and an environment where clinicians are not isolated (Sheldon *et al.*, 2004). NICE (2018) recommends individual trauma-focused cognitive behavioural therapy (TFCBT) to treat PTSD, or clinically important symptoms of PTSD in adults, and Eye Movement Desensitization and Reprocessing (EMDR) for non-combat related

trauma, “if the person has a preference for EMDR”. For those who prefer non-face to face psychological intervention, computerised TFCBT is recommended. There are no NICE guidelines specific to the treatment of PTSD in adults with ID; the NICE (2016) guidelines for mental health problems in people with ID advise that guidance relating to specific mental health problems should be referred to in the first instance when delivering psychological interventions with people with ID. This is advised in conjunction with generic recommendations regarding communication, tailoring interventions to suit individual needs, collaboration on decision making and the provision of additional support. The lack of ID specific guidelines is not surprising, considering that until 2015, there were no guidelines at all published by NICE relating to the health care of people with ID, despite this population having a higher risk of developing health difficulties (Murphy, 2017). However, NICE (2018) do make additional recommendations regarding the care of people with PTSD and complex needs, including those with comorbid depression and/or substance misuse issues. Whilst the guidelines do not explicitly refer to adults with ID, they specify that interventions for PTSD for people with additional needs should build in extra time to develop trust, consider the safety and stability of the individual’s circumstances, provide support to manage barriers to engagement in therapy and plan ongoing support after treatment has ended, if appropriate.

A review of the literature regarding individual TFCBT for the treatment of PTSD in adults with ID found just eight case studies; the quality of reporting of these studies varied, as did adherence to NICE (2018) guidelines for TFCBT (Marlow, Schröder and Tickle, 2019). Mevissen *et al.* (2016) identified more research into EMDR with adults with ID, however, this included multiple publications from the authors themselves and information about reliable and valid methods of measuring

change was often lacking. Therefore, whilst research suggests that people with ID have an increased risk of developing PTSD, there is a lack of robust research into NICE recommended trauma-focused interventions for this population (Mevisen *et al.*, 2016). There is also an absence of any published research into adherence to NICE guidelines for the treatment of PTSD when delivering psychological interventions with people with ID, despite this being the only specific guidance available to guide clinicians when people with ID present with symptoms of PTSD. This is particularly concerning, given that people with ID have previously been excluded from research examining the effectiveness of recommended mental health interventions (Taylor, Lindsay and Willner 2008). Concerns about the inequalities in the way in which people with ID are supported by mental health services, when compared to the general population, are ongoing and the quality of mental health care for people with ID requires improvement so that this group have equal access to evidence based treatments (Foundation for People with Learning Disabilities, 2014).

The above suggests that firstly, there is a need for research exploring the effectiveness of NICE recommended treatments for PTSD among the ID population and secondly, that measures should be taken to ensure that people with ID, presenting to psychological services with symptoms of PTSD, are receiving treatment in line with NICE recommendations. This is particularly pertinent given the existence of the NICE (2016) guidelines for involving people with ID in mental health assessment and treatment and the further guidance available elsewhere for how psychological therapy should be adapted for adults with ID (for example Hurley, Tomasulo and Pfadt, 1998; Beail, 2016). Whilst the NICE guidelines for PTSD were not updated until 2018, previous guidance existed (NICE, 2005), and prior to the update, there was already an increasing emphasis on trauma informed care within

mental health services, including the provision of trauma-focused treatment. Given the NICE (2016) guidance to refer to recommendations regarding specific mental health problems for people with ID, prior to 2018, the NICE (2005) guidance would have been the starting point for clinicians when adults with ID presented with PTSD or clinically important symptoms. Therefore, it is important to explore whether psychological interventions for PTSD delivered by both Clinical Psychologists and Trainee Clinical Psychologists within recent years, converges with current guidance and highlight any recommendations which do not appear to have been met and which may have been additions to the 2018 NICE guidance. Therefore, this audit aims to answer the following questions:

- To what extent does recent practice within one clinical psychology service for adults with ID, converge with updated NICE (2018) guidelines for psychological interventions for the treatment of PTSD, or clinically important symptoms of PTSD?
- To what extent does the psychological therapy completed meet the NICE (2016) guidelines for involving people with ID in mental health treatment and specifically, delivering psychological interventions?

Method

The audit questions were addressed using a retrospective design targeting one ID service within a National Health Service (NHS) Trust in the Midlands, England. Approval to complete the audit was gained from the relevant Research and Development Department, ethical approval was not required due to this being an audit of existing care records.

Procedure

Eleven Clinical Psychologists and Trainee Clinical Psychologists within the ID service were asked to identify clients who were currently accessing or who had previously accessed the service and completed individual trauma-focused therapy between 1st January 2016 and the present day (3rd June 2020). Clinical Psychologists who may have delivered this type of therapy within the time frame, but who had subsequently left the service, were not approached. The audit had initially aimed to capture work completed since the NICE guidelines for the treatment of PTSD had been updated in 2018, however, there was a lack of response to this initial request. The reasons for this were unclear, but it may have indicated a lack of this type of work being completed in the service within the specified time frame and therefore this was adjusted to include therapy completed since 2016. This was to instead capture work completed since the introduction of the first NICE guidelines for assessing and treating mental health problems, such as PTSD, in people with ID in 2016, which coincided with an increasing emphasis on trauma informed care within the UK and the presence of relevant publications (for example Sweeney *et al.*, 2016). Therefore, an audit of therapy delivered since 2016, against current recommendations, was deemed appropriate. Clients were not required to have a diagnosis of PTSD or for this to be the reason for referral to the service; given that PTSD is “largely underdiagnosed and undertreated in people with ID” (Mevisen *et al.*, 2016, p.12). However, clinically important symptoms of PTSD were required to be a feature of their presentation. There was no specification regarding the type of trauma-focused therapy delivered and therapy could have been completed from any psychological modality, provided this was individual work with clients.

Data collection

To categorise the components of the 2016 and 2018 NICE guidelines, a data collection form was compiled. From the 2016 guidelines, this comprised fields relating to communication throughout assessment and treatment and delivering psychological interventions for individuals with ID. From the 2018 guidelines, this comprised fields relating to the psychological treatment of adults and specifically, care for people with PTSD and complex needs. The NHS Trust under which the service audited falls, states that the Trust is required to review and implement NICE guidance, where appropriate, and that implementation forms part of the Trust's compliance with Care Quality Commission requirements (reference redacted to protect anonymity). It can therefore be reasonable assumed that the target adherence to NICE guidelines is 100%, unless deemed inappropriate, and this was the standard set for this audit. Data were collected retrospectively from the NHS patient electronic notes system by the first author and were not cross-checked independently. The details of trauma-focused therapy delivered to each client were reviewed within case notes entered by Clinical Psychologists, correspondence from Clinical Psychologists to clients and others involved in the client's care and clinical psychology reports and discharge letters.

Results

Participants

Ten clients were included in the audit which consisted of seven males and three females, who at the time of receiving therapy had an average age of 34 years. All clients had a diagnosis of Mild Intellectual Disability and were of White British origin, except for one client who identified as 'other ethnic group'. All therapy was

completed in the community and included therapy delivered by six male and female Clinical Psychologists and one female Trainee Clinical Psychologist. The decision was made to include therapy completed by Trainee Clinical Psychologists given that they would be considered trained in the therapy they delivered, and their practice subject to ongoing supervision; the requirements specified by NICE regarding practitioners (NICE, 2018). However, it is acknowledged that this therapist may have had less experience working with adults with ID than the Clinical Psychologists included in this audit.

Psychological interventions for the treatment of PTSD in adults

There was no requirement, from an audit perspective, for the clients to have received TFCBT, however, all clients received therapy which appeared to be integrative and included techniques from CBT and third wave CBT approaches that focus on the process of thoughts, rather than content (Hunot *et al.*, 2013). There was no evidence of the use of EMDR or non-face to face interventions in any of the clients' records. Circular questioning was demonstrated with one client; a technique used within systemic approaches (Tomm, 1987) and life story work was evident in the work with two clients, which is common in multiple psychological approaches. Due to all clients receiving therapy which included techniques from CBT or third wave approaches, the audit considered the evidence of components of TFCBT specified by NICE (2018). Although completion of TFCBT was not a specific requirement of the audit, there was evidence of at least one example in each client's file of 80% of the components of TFCBT (see Table 9). Of the 20% of components that were not evidenced in records, 9% was accounted for by the absence of reference, in any of the clients' records, to the use of a validated manual. The

remaining 11% was due to a lack of evidence in some of the clients' files of: at least 8 sessions being provided; processing trauma-related emotions; restructuring trauma-related meanings; help to overcome avoidance; and preparation for the end of treatment (however, this was due to COVID-19 and other services continued support).

Table 9

NICE (2018) components of TF-CBT

Client	Based on a validated manual	Provided over 8-12 sessions	Delivered by trained practitioners	Includes psychoeducation about reactions to trauma, strategies for managing arousal and flashbacks, safety planning	Includes elaboration and processing of trauma memories	Includes processing trauma-related emotions, including shame, guilt, loss and anger	Includes restructuring trauma-related meanings	Includes support to overcome avoidance	Includes focus on re-establishing adaptive functioning, for example work	Includes preparation for the end of treatment	Includes planning booster sessions if needed
1	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
2	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
3			✓	✓	✓	✓		✓	✓	✓	✓
4	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
5			✓	✓	✓	✓	✓	✓	✓		✓
6	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
7	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
8	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
9			✓	✓	✓				✓	✓	✓
10	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

With regards to the NICE (2018) recommendations relating specifically to the care of people with PTSD and complex needs, where there was evidence that clients presented with both PTSD and depression (five clients), trauma work was the focus

of intervention in 100% of the work completed. NICE recommends that PTSD should be treated first, unless the depression will likely interfere with trauma work, or there are significant concerns regarding risk to self and others. The guidelines also state that clients should not be excluded from psychological treatment on the basis of substance misuse; this is difficult to establish within a sample where receiving treatment formed part of the inclusion criteria and there is no permission held within the specific ID service to contact people who were referred, but who did not receive a service. However, where substance misuse was identified (one client), this did not preclude them from psychological intervention. Routine screening regarding substance misuse was not completed for three of the ten clients and therefore we can only be certain this recommendation was followed for 70% of cases. NICE (2018) also specifies that interventions for people with PTSD and additional needs should build in extra time to develop trust, consider the safety and stability of the individual's circumstances, provide support to manage barriers to engagement in therapy and plan ongoing support after treatment has ended, if appropriate. These were considered and actioned where necessary for 100% of clients reviewed in the audit. Where it was not obvious that the duration or number of therapy sessions had been increased to develop trust, specific reference was made in clients' files to how this was developed, for example, by including individuals who the client trusted in sessions and completing sessions at a place in the community where the client preferred.

Involving people with an ID in mental health treatment

NICE (2016) makes eleven recommendations for communication with people with ID regarding mental health assessment and treatment. There was evidence of

at least one example in each client's file of 65% of these recommendations. These included: speaking to the client directly; use of clear and unambiguous language; assessing whether communication aids or someone familiar with the client's communication was needed; adjustments for sensory impairments where necessary; and use of either concrete examples, visual imagery, practical demonstrations and role play to explain concepts. As with all data collected during this audit, it is not possible to assess whether the elements were incorporated consistently across sessions, however, there was at least once instance of each of these components explicitly stated in all clients' files. For example, evidence that the client was seen alone and therefore spoken to directly, written communication to the client which demonstrated clear and unambiguous language and documentation of a role play which was completed within the session to explain a concept.

There was also evidence in nine of the ten files that different methods of communication were used depending on the client's preference; where only verbal communication was evident for one client, this may have been their preference, however, this was not explicitly stated. Regardless, this accounted for less than 1% of recommendations that were not evidenced. The remaining recommendations not shown to be met were: explaining the content and purpose of every session (eight clients); communicating at a pace that was comfortable for the client (six clients); regularly checking the client's understanding (seven clients) and summarising the conclusions of every session (seven clients). None of the clients' files included reference to checking that the client had communicated everything that they wanted to say before ending sessions. For these recommendations, the researchers were again looking for at least one example of the component being documented in the client's file, such as "the purpose of the session was explained".

There was evidence of at least one example recorded in each client's file of all of the adaptations to psychological interventions recommended by NICE (2016) and therefore this met the 100% target adherence. This included: tailoring the intervention to the client's preferences, understanding, strengths and needs; considering the client's physical, neurological or sensory impairments and communication needs; considering the client's need for privacy; and agreement with the client on how the intervention should be delivered. This involved identifying examples of these documented in clients' files, such as "we discussed how to adapt the intervention to suit the client" and "the client was offered an appointment without their carers or away from home". NICE (2016) recommends that if possible, the client and/or carers should be collaborated with to decide on goals, how the person expresses emotion, structure and flexibility of sessions, and how progress will be measured. There was evidence of at least one example of each of these recommendations in 86% of clients' files; the remaining 14% was due to a lack of reference to how progress would be measured in seven out of ten files audited.

Lastly, NICE (2016) guidelines state that when delivering psychological interventions, people with ID might need more structured support to practise and apply new skills. There was evidence in all of the clients' files of family members or professionals attending at least one session, however, it was not explicit in three of the ten files whether this person supported the adult with ID to practice and apply new skills. Therefore, this recommendation was met in 70% of the files audited.

Discussion

This audit aimed to explore the extent to which recent practice within one ID service for adults with ID converges with updated NICE (2018) guidance relating to

psychological interventions for the treatment of PTSD, or clinically important trauma symptoms. The results suggest that, in the majority of cases, practice from 2016 to the present day was largely consistent with these guidelines, however, this did not reach the 100% target adherence. Whilst there are manuals for working with adults with ID regarding other difficulties (for example Hassiotis *et al.*, 2012), there are no manuals specific to adults with ID who have PTSD. Clinical Psychologists may have adapted existing manuals for the treatment of PTSD, but not recorded this in clients' files, which may account for this lack of reference in any of the files audited. This suggests a need for applied clinical research to be undertaken and disseminated to support practice within ID services, including the adaptation of existing treatment manuals. There was no evidence in half of the files audited that work was completed to restructure trauma-related meanings, despite evidence that adults with ID can engage with cognitive work in relation to other presentations (Vereenoghe and Langdon, 2013). Exposure work was also not evident in all cases; research has demonstrated that this can be an effective technique even with clients with Moderate levels of ID (for example Jones and Banks, 2007). Furthermore, almost a third of clients did not receive the minimum amount of sessions recommended by NICE (2018); we would expect the number of sessions to be increased within an ID population, rather than reduced. The results therefore suggest that whilst practice was consistent with the majority of guidelines in the current audit, questions are raised about why certain components of TFCBT were not demonstrated, which appear feasible within an ID population. However, the fact that data were not cross-checked independently and therefore could be subject to some researcher biases, should be held in mind when considering the results of the audit, as should other limitations which are outlined below.

This audit also aimed to explore the extent to which the work completed met the NICE (2016) guidelines for involving people with ID in mental health treatment. The results suggest that these were met to some extent, however, this again did not reach the 100% target adherence. As with the above, the guidelines were assessed on the basis of client files alone and it is not possible to assess whether this is a valid representation of what actually occurred during therapy sessions. Session case notes, which were largely relied upon to complete the audit, are based on retrospective accounts from therapists and may be subject to biases, such as social desirability, considering that this documentation can be viewed by other professionals in the client's care team. The audit therefore highlights a difficulty in assessing therapy against these specific NICE guidelines; even if the researchers had been given access to session observations to assess consistency with recommendations, this could still be problematic given that the clients themselves would be best positioned to provide feedback on certain criteria, such as whether the session was paced correctly. This is a consideration which should be incorporated into further research which aims to assess the consistency of current practice within ID services against NICE guidelines. Therefore, whilst some of the recommendations for communication were not evidenced in clients' files, it is unclear whether this was due to a lack of recording; for example, it might be assumed that understanding is checked regularly throughout sessions within an ID service and it would be impractical to suggest that Clinical Psychologists should document every single NICE guideline followed during a therapy session. However, without this being explicitly recorded, it was not possible in the current audit to compare practice against NICE guidance, which may underestimate the consistency of the work being completed.

The lack of collaboration with clients on how progress would be measured is also an area to be addressed, especially in a population where power imbalances may be more prevalent and clients with ID can often feel unheard (Hoole and Morgan, 2011). However, therapists may be under pressure to use routine outcome measures within services, which may reduce opportunities to be collaboratively. It was also unclear whether all clients received support from carers to practice and apply new skills, where necessary. This is particularly important when working with adults with ID who may need extra support to ensure therapy is transferred into real life (Jahoda, 2016). Therefore, whilst there are some aspects of NICE guidance which do not appear to have been met during therapy, other aspects may not have been captured due to limitations regarding the methods of data collection used during this audit and other methods may be better suited to capturing information about the process of therapy, such as session observations and interviews with Clinical Psychologists and clients. Furthermore, the cases identified for the audit by Clinical Psychologists may have been based on prior assumptions of which cases were likely to perform well and more objective methods of identifying relevant cases would be preferable in future audits.

In addition to the above limitations, the audit reviewed the trauma-focused therapy delivered by a small proportion of the number of Clinical Psychologists and trainees who have worked within this specific ID service since 2016. This raises questions about to what extent the selected cases are representative of all trauma-focused therapy completed within this service, especially considering that Clinical Psychologists and trainees who may have delivered this type of therapy within the time frame audited, but who had subsequently left the service, were not approached. The audit also took place during the COVID-19 pandemic, which may have impacted

the response rate, as Clinical Psychologists experienced changes to their job roles and responsibilities. However, it is possible that other Clinical Psychologists had not received relevant referrals since 2016.

The number of clients included in this audit may also be an underrepresentation of the amount of adults with ID who have presented with symptoms of PTSD to this ID service since 2016, given that approximately three quarters of adults with Mild to Moderate ID are likely to have experienced trauma (Martorell *et al.*, 2009). Whilst there may be barriers to adults with ID presenting to services, considering that they are often referred by someone else (Ramsden, Tickle, Dawson, and Harris, 2016), it raises further questions about: whether there may have been additional cases of individual trauma-focused therapy that were not identified for the audit; whether there is under-identification of trauma in those referred to services; and whether there may be a proportion of clients where trauma was identified but where individual trauma-focused therapy was not deemed appropriate. Whilst the symptomology of PTSD in adults with Mild ID does not necessarily differ from the general population (Wieland, Wardenaar, Dautovic and Zitman, 2013), PTSD in individuals with more severe ID can often be misinterpreted as challenging behaviour or misdiagnosed as a feature of another psychiatric disorder (Bakken *et al.*, 2014). This is particularly significant for those adults with ID who may be unable to communicate their trauma symptoms. Alternatively, it may be that whilst trauma was identified, individual therapy was not considered appropriate due to barriers such as those reported previously when implementing psychological interventions, such as communication and memory difficulties (Ramsden *et al.*, 2016). Therefore, the Clinical Psychologist may have chosen a consultancy role advising those supporting the individual, rather than completing individual therapy.

Future research should actively screen clients for trauma symptoms and determine the proportion of those presenting with trauma symptoms who are offered individual therapy, compared to those offered indirect therapy or other means of working, and explore the decision-making processes behind this, as well as adherence to NICE (2018) guidance. This was not possible in the current audit due to the sampling method adopted.

Unfortunately, there are no comparable audits against which to compare these results. However, despite the limitations outlined, the audit points to some clear recommendations for this ID service. The NICE guidelines which have not been evidenced in clients' files in the current audit, for involving people with ID in mental health treatment and specially the treatment of PTSD, should be reviewed. This includes:

- Components of individual TFCBT
- Routine screening for substance misuse
- Aspects of communication for adults with ID
- Collaboration with clients on how progress in therapy is measured
- Support to practice and apply new skills, if necessary

It would perhaps be useful to collaborate with the Trust's NICE guidance implementation team (who were not involved in the current audit) in order to identify how best to implement and capture the level of adherence to NICE guidelines, given clinicians are unlikely to record information relating to every guideline after each therapy session completed, the limitations identified above regarding the auditing of NICE guidelines using client files alone, and the apparent need to incorporate service user feedback to accurately assess some of the guidance. It may also be

useful to draw on relevant literature, such as Sheldon *et al.* (2004), to identify any further barriers to implementing NICE guidance. This process may highlight a need for practice-based research to explore and promote understanding of the barriers to adhering to NICE guidelines for therapy for adults with ID and PTSD, or clinically important symptoms. By engaging with the above recommendations, this would help to ensure that the ID service is working within a trauma informed framework which includes the delivery of treatments for PTSD, and clinically important symptoms, in line with NICE recommendations.

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