

Some observations on remote delivery of eye-movement desensitisation and reprocessing to people with intellectual disabilities

Unwin, Gemma; Stenfert-Kroese, Biza; Rogers, Gemma; Swain, Sophie; Hiles, Steve; Clifford, Clair; Farrell, Derek; Willner, Paul

DOI:

[10.1111/jppi.12452](https://doi.org/10.1111/jppi.12452)

License:

Creative Commons: Attribution (CC BY)

Document Version

Publisher's PDF, also known as Version of record

Citation for published version (Harvard):

Unwin, G, Stenfert-Kroese, B, Rogers, G, Swain, S, Hiles, S, Clifford, C, Farrell, D & Willner, P 2023, 'Some observations on remote delivery of eye-movement desensitisation and reprocessing to people with intellectual disabilities', *Journal of Policy and Practice in Intellectual Disabilities*, vol. 20, no. 2, pp. 205-215. <https://doi.org/10.1111/jppi.12452>

[Link to publication on Research at Birmingham portal](#)

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.



When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Some observations on remote delivery of eye-movement desensitisation and reprocessing to people with intellectual disabilities

Gemma Unwin¹ | Biza Stenfert-Kroese¹ | Gemma Rogers²  | Sophie Swain³ | Steve Hiles⁴ | Clair Clifford⁵ | Derek Farrell⁶ | Paul Willner⁷ 

¹School of Psychology, University of Birmingham, Birmingham, UK

²Kent and Medway NHS and Social Care Partnership Trust, Kent, UK

³Midlands Partnership NHS Foundation Trust, The Redwoods Centre, Shrewsbury, UK

⁴Swansea Trials Unit, Clinical Research Facility, Institute of Life Science, Swansea University, Swansea, UK

⁵Independent Researcher, Solihull, UK

⁶University of Worcester, Worcester, UK

⁷Department of Psychology, Swansea University, Swansea, UK

Correspondence

Paul Willner, Department of Psychology, Swansea University, Swansea SA2 8PP, UK.

Email: p.willner@swansea.ac.uk

Funding information

National Institute for Health Research (NIHR), Grant/Award Number: 17/125/04

Abstract

It is increasingly recognised that many people with intellectual disabilities suffer from post-traumatic stress disorder (PTSD). Eye-movement desensitisation and reprocessing (EMDR) has been proposed as a potentially helpful intervention that is less reliant on verbal skills than other effective treatments for PTSD and therefore could be more effective than verbal interventions for people with intellectual disabilities. The Trauma-AID project is a randomised clinical trial (RCT) evaluating the effectiveness of a bespoke EMDR protocol for adults with intellectual disability and PTSD, which incorporates a prolonged phase of Psycho-Education and Stabilisation (PES) prior to the trauma confrontation phase of EMDR. The COVID-19 pandemic struck during the feasibility phase of the Trauma-AID project, necessitating a second feasibility study to evaluate the acceptability and feasibility of remote or hybrid delivery of the PES + EMDR protocol. To this end, we conducted two online surveys of therapists followed by interviews with clients, carers and senior therapists. The surveys were analysed descriptively. Content analysis was used for client and carer interviews, and framework analysis for therapist interviews. All stakeholders reported positive experiences of EMDR; however, some challenges were identified. The majority of clients, carers and therapists interviewed reported that the intervention, whether PES alone or the full PES-EMDR package, had improved symptoms of PTSD and psychological well-being, and carers also reported decreases in challenging behaviour. A full account of the data is

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2023 The Authors. *Journal of Policy and Practice in Intellectual Disabilities* published by International Association for the Scientific Study of Intellectual and Developmental Disabilities and Wiley Periodicals LLC.

provided in four Supplementary Digital files. PES-EMDR therapy appears both feasible and acceptable for clients with intellectual disabilities and therapists, whether delivered face-to-face or in a remote or hybrid mode, though remote working appears easier for the PES phase than the EMDR phase of the intervention.

KEYWORDS

acceptability, eye-movement desensitisation and reprocessing, feasibility, hybrid delivery, intellectual disability, post-traumatic stress disorder, remote delivery

INTRODUCTION

Post-traumatic stress disorder (PTSD) is a common mental disorder that may develop following exposure to traumatic events. About 3% of the adult population in England suffers from current PTSD (McManus et al., 2008). Rates of PTSD are higher in people with intellectual disabilities than in the general population: a recent meta-analysis reported a prevalence of 10% (Daveney et al., 2018), with one study suggested that the prevalence of PTSD amongst in-patients with mild intellectual disabilities may exceed 40% (Nieuwenhuis et al., 2017). There is extensive evidence that people with intellectual disabilities are more likely to experience severe and prolonged bullying and/or sexual and other types of abuse (Beadle-Brown et al., 2010; Mevissen & de Jongh, 2010; World Health Organization, 2018) and that adverse life events are traumatising in this population (Hall et al., 2014; Wigham et al., 2011; Wigham & Emerson, 2015). A study of people with intellectual disabilities presenting for treatment of PTSD reported that almost all had experienced multiple traumatic events in adulthood and around half (probably an under-estimate) reported that they had also experienced traumatic events in childhood (Mason-Roberts et al., 2018). People with intellectual disabilities who have been traumatised typically show complex presentations of PTSD and display self-harm or other challenging behaviours (Kildahl et al., 2020; McCarthy, 2001; McNally et al., 2021; Mevissen & de Jongh, 2010), particularly when they are on the autistic spectrum (Rumball, 2019), and/or have physical and psychiatric co-morbidity (Mevissen & de Jongh, 2010). Frequently, PTSD is not diagnosed in this client group, and treatment focusses on the management of challenging behaviour (McNally et al., 2021). These clients can be extremely complex and challenging, requiring support from highly specialist intellectual disabilities services and considerable community support, and are at risk of admission to hospital. Their symptoms can also cause them and those around them significant distress.

On the basis of evidence from systematic reviews and meta-analyses, the United Kingdom National Institute of

Clinical Excellence (NICE) and other clinical guidelines recommend trauma-focussed psychological therapies for PTSD (American Psychological Association, 2004; Bisson et al., 2019; National Institute for Clinical Excellence, 2005a, 2005b; Phelps et al., 2021), since therapies that do not require the patient to focus on traumatic memories are less effective (Bisson et al., 2013). The best-supported trauma-focussed interventions are trauma-focussed cognitive behavioural therapy (TF-CBT) and eye movement desensitisation and reprocessing (EMDR) (Bisson et al., 2013). There has been relatively little research on interventions for more complex presentations of PTSD, but what evidence there is suggests that phased approaches may be beneficial, in which the patient first undergoes psychoeducation and emotional stabilisation (PES) before undertaking any trauma-focussed intervention (Courtois, 2004; The Complex Trauma Taskforce, 2012). While there is little to choose between TF-CBT and EMDR in terms of their effectiveness in PTSD, they differ in the experience offered to the patient. TF-CBT is a highly verbal intervention that aims to identify and modify over-interpretations of the actual level of threat, and to modify beliefs and perceptions regarding the traumatic event. By contrast, EMDR is less reliant on verbal expression: the patient focusses on memories of past traumatic events while making controlled eye movements (or an alternative form of bilateral stimulation (Lalotiet et al., 2021)) that engage attention and enable the therapist to manage the intensity of the patient's distress (Shapiro, 1999).

Because EMDR is ostensibly less reliant than CBT on verbal expression, it could in principle, be considered more suitable for people with intellectual disabilities. The standard EMDR protocol is difficult to use with people with intellectual disabilities because the eye movement exercises (or alternative bilateral stimulation procedures) are unfamiliar, their purpose is difficult to explain, and clients often present with long-standing and complicated trauma histories that they may be reluctant to confront in therapy (Unwin et al., 2019). The approach can feel unfamiliar to therapists working in intellectual disabilities services and they may lack confidence in adapting

the standard protocol to suit their clients (Unwin et al., 2019). However, the procedure can be made more accessible to people with intellectual disabilities and acceptable to therapists by expanding the introductory PES phase in order to increase engagement and to ensure that participants have sufficient understanding of what they need to do and why, and by using some of the techniques developed for use with traumatised children (but adapted so as to be appropriate for adults (Barol & Seubert, 2010)). Some case study reports suggest that adapted EMDR protocols can be used to treat PTSD in people with intellectual disabilities (Gilderthorp, 2015; Jowett et al., 2016; Mevissen et al., 2011, 2017; Porter, 2022), and a small-scale controlled trial concluded that EMDR was 'feasible, acceptable and potentially effective' for people with intellectual disabilities (Karatzias et al., 2019). However, a recent review concluded that while EMDR appears acceptable and feasible 'no firm conclusions can be drawn regarding effectiveness due to small sample sizes, lack of standardised assessment, and a paucity of methodological rigorous treatment designs' (Byrne, 2022). Adaptations to the standard EMDR protocol that were found to be effective were the use of visual supports, frequent return to target and a focus on emotions and physical sensation rather than mental images or cognitions. Rigid adherence to the standard protocol is likely to result in less effective processing and engagement for this client group (Porter, 2022).

This paper reports initial data from the Trauma-AID project (full title: Eye movement desensitisation and reprocessing for symptoms of PTSD in adults with intellectual disabilities), which is a randomised controlled trial (RCT) of a PES + EMDR intervention adapted for people with intellectual disabilities that is currently recruiting participants (funded by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) programme). The project began with a feasibility study designed primarily to test the acceptability of the PES-EMDR intervention. A second feasibility study was subsequently initiated to examine the acceptability of remote or hybrid delivery, as a result of the COVID-19 pandemic and a move to a remote working model across the participating sites. This article presents the results of those feasibility studies. (A separate publication will present a detailed account of the protocol for the RCT.) We aimed to confirm the acceptability of the adapted PES-EMDR protocol implemented in the Trauma-AID study, and to evaluate the acceptability and feasibility of remote delivery of the intervention. As a result of the pandemic, remote delivery of interventions has become routine within many clinical psychology services. To the best of our knowledge, this is the first account of the remote delivery of EMDR to people with intellectual disabilities.

METHODS

Clinical context

The Trauma-AID trial uses a bespoke EMDR protocol that includes, as phase 1, a PES module that aims to install strengths and resources, stabilise emotional regulation, and build alliance and trust (Herman, 1997; The Complex Trauma Taskforce, 2012), and in phase 2 incorporates elements of the EMDR protocol based on a combination of adult (Shapiro, 1999), child (Lovett, 1999) and attachment-focussed (Parnell, 2013) EMDR. The PES module comprises 10 weekly session plans, and includes the first phase of the EMDR protocol (history taking and treatment planning) and aspects of phases 2 and 3 (preparation and assessment). In addition to those EMDR elements, the PES component includes a CBT-informed psychoeducational intervention previously trialled in a group format (Stenfert Kroese et al., 2016). The EMDR module involves up to 10 weekly sessions, but, in keeping with the NICE recommendation that the standard 8–12 sessions should be extended if multiple traumas and/or other comorbidities are present (National Institute for Clinical Excellence, 2005a, 2005b), the treating clinician may extend phase 2 by up to five sessions if clinically necessary, or more if this is considered clinically essential. The major adaptations (Barol & Seubert, 2010) are (i) making the stages, language and outcomes more accessible; (ii) not preferring side-to-side finger movements over other forms of bilateral stimulation such as tapping; (iii) encouraging creative use of expression (such as techniques from art and narrative therapy/storytelling (e.g., Lovett, 1999)); and (iv) involvement of carers where appropriate to support the patient within and/or between therapy sessions. The PES and EMDR modules were manualised (parts 1 and 2) before the start of the feasibility studies, and a supplement (part 3) covering issues relevant to remote delivery has been added.

A decision was made at the outset to train experienced intellectual disability clinicians to deliver EMDR, rather than recruiting EMDR therapists and training them to work with people with intellectual disabilities. An initial cohort of 26 therapists was trained face-to-face in 2019, and a second cohort of 20 therapists was trained remotely during 2020 ($N = 46$). As a result of the loss of some staff, and the additional recruitment and top-up training of some clinicians already trained in EMDR, we are currently working with around 40 therapists in seven NHS Trusts across England. All trial therapists were trained to EMDR level 2 by an experienced and accredited EMDR trainer, including parts 1 and 2 of the Trauma-AID manual, followed by top-up training on remote working (part 3). Therapists are required to



compete a 'training case' before recruiting participants to the RCT. All therapists worked within UK NHS intellectual disability services, and clients undergoing therapy were judged by their treating clinician to have mild or moderate intellectual disabilities. This report is based on experiences gained during the delivery of those training cases.

Sources of information

Evidence of the acceptability of the PES-EMDR intervention arises from multiple sources: a survey of therapists' work with their EMDR training cases, interviews with clients, carers and therapists, discussions with a review group comprising senior clinicians from five of the seven participating Trusts and informal feedback from researchers and senior clinicians at fortnightly meetings of the research team. All participants in the formal studies provided informed consent. The number of participants was deemed sufficient for a qualitative study. A small team of senior researchers designed the interview schedules (the topic guides are in Appendix S5) and their content was informed by the on-going discussions during the wider fortnightly team meetings regarding remote delivery. All interviews were conducted by two research assistants (GR and SS) employed on the project. The first interview for each informant group was considered to be a pilot and only included in the data set if the interviewer and at least one senior researcher deemed the interview to have been successful.

All studies received ethical approval through the UK Integrated Research Application System (IRAS: project 260514). Most of the data were collected in June–July 2021.

Study 1: Client interviews

Semi-structured interviews were conducted in June–July 2021 with 10 (seven male and three female) therapy participants (Appendix S1). Three had completed the PES phase only, four were in the EMDR phase and three had completed both PES and EMDR. Five of the clients had experience of remote therapy. Two received face-to-face therapy and remote therapy over an online video platform on alternate weeks, while the other three had only worked remotely, two using an online video platform and one using a phone (audio only). Four of these clients were still at the PES stage, but one had completed EMDR reprocessing. All participants had been screened to establish they had a significant intellectual disability yet had the ability to provide informed consent and engage in 1:1

talking therapy. They were therefore considered suitable informants for this qualitative study with sufficient receptive and expressive verbal communications skills to take part in a 1:1 interview.

Data were subjected to a content analysis using the Halcomb and Davidson (2006) method for data analysis which does not require transcription of the interview recordings; rather, it involves making field notes during interviews, reviewing them and repeatedly listening to the interview recordings. The content is reported under headings that reflect the questions asked during the interview. Halcomb and Davidson (2006) have argued, after weighing up the pros and cons of verbatim transcription of interview recordings, that their method is a valid and cost-effective means of data management when using thematic or content analysis. Their assertions are supported by other authors who have indicated that verbatim transcription is only one method of capturing verbal data (e.g., Denscombe, 2014; van Teijlingen & Ireland, 2003). The analysis process was guided, supervised and audited by GU and BSK, both experienced in qualitative research methods and the Halcomb and Davidson method of analysis.

Study 2: Carer interviews

Semi-structured interviews were also conducted, in June–July 2021, with four female carers, three mothers and one paid residential carer (Appendix S2). The people they cared for were at different points in their treatment pathway: one was in the early stages of therapy, one at mid-point, one was near completion, and one had already completed therapy. One mother was present at nine out of the 11 therapy sessions; none of the other carers attended any therapy sessions. Only one of the carers we interviewed had experience of remote (online) delivery. Data were subjected to a content analysis using the Halcomb and Davidson (2006) method, as above.

Study 3: Therapists surveys

As part of their EMDR training, therapists were required to administer EMDR to a client with an intellectual disability. An online survey was circulated regarding progress with these training cases (November 2020–January 2021). The survey comprised mainly fixed options with a few free text fields where clarification might be needed. Of the 32 respondents, only eight reported using remote EMDR: this survey was conducted only shortly after—or in some cases, before—therapists attended training sessions on remote delivery of EMDR.

Around 6 months later (June–July 2021), all therapists involved in the study at the time ($N = 40$) were emailed a link to an online structured free-text based interview form, and sent two reminders to complete the survey. The main focus of the interview was remote delivery of the PES-EMDR intervention. Online interviews were returned by 13 (33%) therapists, with representation from six out of seven participating sites (Appendix S3). Unlike the earlier survey, use of remote EMDR was a major focus of the interview. Seven of the 13 therapists interviewed reported using remote EMDR, one of whom provided a case report describing dramatic clinical improvements with remote reprocessing. Of the six therapists who were not working remotely, two were not currently using the PES-EMDR intervention, two implicated IT issues, one client chose to work face-to-face, and one therapist did not feel comfortable using remote therapy with clients with intellectual disabilities.

Study 4: Clinical review panel

A review panel consisting of six senior clinicians, representing six of the seven participating sites, discussed the experiences of therapists working with the PES-EMDR intervention within their respective Trusts (July 2021). Remote working with the PES-EMDR intervention was the major focus of the review panel (Appendix S4). One group panel session, facilitated by two members of the study team, was conducted with four senior clinicians from different NHS Trusts and lasted an hour. Two further individual sessions, lasting 30 min, were conducted with senior clinicians from different NHS Trusts one and 3 weeks later. The interviews were recorded and transcribed. The data were analysed using framework analysis (Ritchie & Spencer, 1994) to screen for relevant material relating to each of the topics covered in the topic guide. The material relating to each topic was then analysed and interpreted to produce themes and descriptions.

RESULTS

The results are reported in relation to three broad issues: acceptability of the PES-EMDR intervention, acceptability of remote working and feasibility of remote working. The data reported are selected as appropriate from the various sources of information, as described below. Full details of the qualitative analyses of the two sets of interviews (studies 1–2), the second therapist survey (study 3) and the clinical review group (study 4) are provided, for the benefit of the interested reader, as online Supporting Information Appendices.

Acceptability of the PES-EMDR intervention

Clients

A number of participants reported that they had reservations about taking part in EMDR therapy when it was first offered to them. Specifically, the physicality of EMDR (the bilateral stimulation techniques such as finger waving and buzzers) had been off putting. The participants who had experienced reprocessing had found that stage of therapy particularly tough as difficult emotions were evoked and they had felt overwhelmed. One participant had found it all too much but planned to revisit this stage again at a later date. All participants spoke of how challenging some of the sessions had been but also how helpful, and that hard and helpful could co-exist. With one exception, participants stated that the therapy had had a positive impact on them with a decrease in PTSD symptoms and an increase in psychological well-being and positive life changes.

Carers

Overall, carers were satisfied with the therapy. Some carers noticed negative changes in the clients during the processing stage but reported positive outcomes subsequently, namely decreases in challenging behaviours and improvements in psychological well-being. They were concerned about long-term maintenance of these positive outcomes.

Therapists

Therapists were generally very positive about the intervention: they are all committed to its evaluation and can see a real value in providing this therapy to clients with intellectual disabilities. They said that it will be an asset to have EMDR as a part of their therapeutic repertoire and acknowledged the importance of working in a trauma-focussed way with clients with intellectual disabilities. They found the PES stage is comprehensive and may be enough for some clients, who have benefited from working in a trauma-informed way without reprocessing. A number of therapists were confident that for some clients, EMDR reprocessing can bring about dramatic changes: some talked about a ‘light bulb moment’ when therapists can see that the approach will work and for some clients at least can be transformational. Some therapists have seen this first hand for clients with intellectual disabilities, although experiences of completed



reprocessing remain in the minority with most therapists still working through the PES stage with their clients. Alongside this optimism amongst the therapists, however, some challenges were also identified, typically relating to the client group, in terms of readiness to work on trauma and complex trauma histories.

The PES stage was received well by clients and therapists and was reported to provide a good opportunity to build therapeutic rapport, trust and safety, which are essential to proceed to reprocessing. Therapists reported that some clients feel that PES is enough and are satisfied with the outcome of this stage, having developed coping skills, and therefore may decide not to proceed with reprocessing. Therapists commented favourably on the therapy manual, but noted that it may take some clients more than 10 sessions to work through the PES material because in addition to working on trauma they need space to address issues that the client brings to sessions. As a result, the length of the PES phase can vary widely; and some clients may not succeed in developing all the skills or understanding all the material.

Therapists noted that clients may not have clear and defined trauma memories which can make goal setting and maintaining attention to specific traumas more challenging. They also noted that clients' goals for therapy may not be trauma-focussed, leading to a reluctance to address traumatic experiences that can result in disengagement from therapy. Some clients need time to tell their story and others may want to work on their trauma but might not be ready. Engaging with trauma memories is distressing, and the transition from PES to reprocessing can be difficult for clients because of fear of this distress. However, when clients present with a clear trauma memory and are ready to work on it, EMDR can proceed quickly and produce a good outcome.

Therapists reported having felt anxious about using a new therapeutic model. They stated that they felt unconfident in their skills rather than pessimistic about the approach as a whole and they anticipated that their confidence would grow with experience. (In light of this feedback, the research team now provides top-up training to therapists.)

Almost all clients, carers and therapists reported consistently that the intervention, whether PES alone or the full PES-EMDR package, had improved symptoms of PTSD and psychological well-being, and carers also reported decreases in challenging behaviour.

Acceptability of remote working

Clients

All five clients who had worked remotely spoke positively about their therapy, albeit that the two who were using

the hybrid model both expressed a preference for face-to-face sessions and said they found them easier. Conversely, one of the three clients who only received remote therapy expressed a preference for remote delivery. However, clients also mentioned that they sometimes encountered technical difficulties such as an unstable internet connection.

Carers

Two clients also mentioned that working remotely was convenient for their carers. The one carer we interviewed who had experience of remote (online) delivery spoke positively about how it saved time and gave her easy access to the therapist (Appendix S2).

Therapists

Therapists adopted the hybrid model of EMDR delivery at various stages of their work with clients. Some clients started work remotely, others transferred from face-to-face to remote, and vice versa. For most clients, a blended approach was used to move between remote and face-to-face therapy based on factors relating to service restrictions, practical constraints, client preference and clinical need/content of sessions. The majority of therapists were positive about delivering the PES stage remotely and identified a range of helpful aspects such as improved attendance at sessions, better engagement and ability to offer more consistent session times. Therapists reported that some clients preferred to work remotely, especially at the outset, as they welcomed the physical and psychological distance provided by video work. Indeed, it was reported that some clients would not have engaged in the work had it been face-to-face.

Therapists also identified some issues with remote working. Commonly, therapists were concerned about engagement and rapport building and reported a preference amongst a majority of clients for face-to-face work. Other common concerns related to problems with maintaining safety and boundaries, and managing distress. This was especially pertinent when considering remote trauma confrontation work. Similarly, monitoring non-verbal communication and signs of distress was challenging when working remotely and therapists were concerned that non-verbal cues could be missed. Therapists felt more confident in helping the client to manage distress associated with trauma confrontation when working face-to-face. Some resource and skill building activities proved more difficult for some clients, especially where these involved therapists modelling behaviour, for example, breathing exercises. Clients' limited

access and ability to use IT equipment was cited by some; however, this could be overcome, to some extent, by support from carers. Therapists also reported practical issues such as sharing resources on screen, connection problems and interruptions to remote therapy.

Therapists reported that overall, the majority of clients preferred face-to-face therapy; however, a significant minority preferred to work remotely (although most were working on the PES stage only). For respondents to the online survey of training cases in late 2020/early 2021, the decision on mode of therapy delivery was largely determined by service restrictions due to the national COVID-19 regulations. At this point, some clients opted to wait for face-to-face therapy as this was their preference or they had limited access to IT facilities. Decisions around mode of therapy for respondents to the online interview and clinical review panel in summer 2021 were based more on client preference and clinical need. Therapists identified a range of benefits to remote PES work and found this was an acceptable way to work, but were more cautious about remote trauma confrontation. Therapists reported a range of criteria that need to be met in order to undertake remote work including client preference, client engagement, robust IT facilities, supportive physical and social environment, and the client's ability to manage distress.

Feasibility of remote delivery

A number of factors are relevant to the ability of participants to work remotely, including their access to and confidence with IT facilities, and the availability of a safe space and support if distressed. Our observations about the feasibility of the PES-EMDR intervention are derived informally from the data sources described above.

Therapists reported that inpatients, who represent around 10% of our likely participants (based on the settings in which our therapists work) potentially have access to good support when using remote platforms, though this is dependent on fluctuating staffing levels and level of individual risk. Less support is typically available for community-based participants, but we nevertheless estimate that up to two-thirds would be able to use platforms such as Zoom or Microsoft Teams (based on feedback from seven of the 11 therapists interviewed about their remote work with clients during lockdown). However, a somewhat greater proportion of people with intellectual disabilities who are sufficiently able to participate in this study use a smartphone. We have therefore negotiated with some (though not all) of the participating Trusts to permit delivery of the intervention via WhatsApp or Facetime, which run on

smartphones and do not involve the barrier of following a link or logging in. Overall, we estimate that a majority of community-based potential participants could in principle engage remotely in the PES-EMDR intervention if it was strictly necessary to do so and if appropriately supported.

Therapists indicated that some aspects of PES-EMDR, for example, breathing exercises, may be more difficult to implement remotely with people with intellectual disabilities, and as a result, these elements may take longer to deliver. We are not in a position to estimate the extent to which this issue might impact on the number of sessions needed to complete the intervention. Bilateral stimulation using eye movements is also more difficult to implement remotely, though our therapists have access to remote EMDR software, which simplifies the process. This said, most participants prefer to implement bilateral stimulation using tapping, which is much less affected by remote working, and can even be delivered over an audio-only phone connection.

In relation to safety and support, while the PES-EMDR intervention has significant potential to cause participants distress, this is also the case for many other interactions that clinical psychologists have with their clients, and all community-based therapists have had to learn to manage this issue in their day-to-day practice. We were also made aware by both clients and therapists that some clients (particularly those with autism), undertaking both PES-EMDR and other psychological interventions, may prefer a remote interaction to face-to-face contact. Indeed, some participants commented that remote contact was preferable because a carer could be present to provide emotional support.

DISCUSSION

The COVID-19 pandemic forced clinical services to develop remote modes of delivery, and there are many publications describing how intellectual disability services have faced this challenge (e.g., Buono et al., 2021; Hwang et al., 2022; Sheehan et al., 2021; Wos et al., 2021; Zaagsma et al., 2020). However, there are few studies of the delivery of specific mental health interventions, and to the best of our knowledge, this is the first report dealing with remote delivery of EMDR to people with intellectual disabilities.

From the responses of clients, carers and therapists, the PES-EMDR intervention appears to be acceptable to the majority of clients, albeit that some may choose to stop treatment after the PES phase and not progress to engagement with trauma confrontation. There are a number of previous publications reporting outcomes of



EMDR for people with intellectual disabilities, suggesting that the procedures used were acceptable (Gilderthorp, 2015; Jowett et al., 2016; Karatzias et al., 2019; Mevissen et al., 2011, 2017; Porter, 2022). Those studies did not comment on whether there were also clients who did not complete the full course of therapy. Our novel observation is that remote delivery of the PES-EMDR intervention also seems acceptable to both clients and therapists, albeit that most—but not all—clients prefer face-to-face working. However, most of the remote experience has been with the trauma stabilisation phase; therapists were less confident about remote trauma confrontation, though some striking successes were reported. Therapists and clients also drew attention to a number of technical issues that can sometimes arise.

We had considered that, for the purposes of the Trauma-AID trial, it would be necessary to develop formal procedures in relation to the choice of remote, face-to-face or hybrid working. However, over the course of opening up therapy services as the country emerges from the pandemic, the question of a client's ability to undertake a remote intervention has become one that therapists now face routinely in their clinical practice. As a result, therapists have been required to acquire the competence to assess clients' suitability for remote working. In light of this experience, we now take the view that therapists can be relied on to exercise their ongoing clinical judgement in respect of a client's ability to undertake the PES-EMDR intervention remotely, drawing on their knowledge of the technical and safeguarding factors that apply to their client, and using clinical supervision as appropriate. We note that this is how therapists will work when the intervention is rolled out for routine clinical use.

We had also envisaged that it would be necessary to develop criteria to determine how to deal with the situation of participants who cannot continue to work face-to-face but would be unable to switch to remote working if this became necessary. However, because of the roll-out of the vaccination programme it now appears unlikely that there would be further general lockdowns that could affect a significant proportion of our trial participants. There may be periods when NHS Trusts mandate a shift to remote working, and sporadic cases of COVID-19 or contact with COVID-19 infection will arise that would preclude face-to-face contact. Some of the clients affected might be unsuitable for continuation of therapy using a remote platform. However, this inability to conduct therapy sessions would not differ in principle between COVID-19 and many other illnesses, and in the case of someone testing positive but remaining asymptomatic, the interruption to therapy would be brief. Indeed, given that prolonged lockdowns are unlikely to reoccur, we

think it unlikely that there will be more than a handful of cases where it would not be possible to continue therapy after a brief delay without the use of a remote platform. We have therefore decided not to create special provisions to deal with this eventuality. We also note that the availability of remote platforms means that it could be possible to continue therapy with a participant who moves home—for example, to an out-of-county placement—who in other circumstances might be lost to the trial.

Conclusions

The qualitative data collected from clients, carers and therapists during the preliminary phase of a RCT evaluating the effectiveness of a bespoke PES-EMDR protocol for adults with intellectual disabilities and PTSD support the following conclusions with regard to this intervention and its remote delivery:

Acceptability and feasibility of the PES-EMDR intervention

- i. The majority of clients, carers and therapists interviewed reported that the intervention, whether PES alone or the full PES-EMDR package, had improved symptoms of PTSD and psychological well-being, and carers also reported decreases in challenging behaviour.
- ii. The intervention is acceptable to the majority of clients, albeit that some may choose to stop treatment after the PES phase and not progress to engagement with trauma confrontation.
- iii. For unavoidable clinical reasons, it may sometimes be necessary to extend PES session plans beyond a single session, resulting in a prolonged preliminary (PES) phase.

Acceptability and feasibility of remote delivery

- iv. While it is possible that the ongoing pandemic will produce situations in which clients cannot continue with face-to-face therapy but are unable to switch to remote working, these situations are likely to be brief and do not require special arrangements.
- v. Remote or hybrid delivery of PES-EMDR therapy appears both feasible and acceptable for clients with intellectual disabilities and therapists, though remote working appears easier for the PES phase than the EMDR phase of the intervention.

- vi. Therapists are hesitant to practice remote trauma confrontation unless there is good support present for the client during and after the therapy session.
- vii. Face-to-face delivery is generally preferable to remote therapy but there may be exceptions where remote therapy is preferred by clients. (A protocol to ascertain clients' wishes, in relation to the choice of face-to-face, remote or hybrid working, has been incorporated into the main trial protocol.)
- viii. Therapists can be relied on to exercise their ongoing clinical judgement regarding a client's ability to undertake the PES-EMDR intervention remotely, drawing on their knowledge of the technical and safeguarding factors that apply to their client, and using clinical supervision as appropriate.

Strengths and limitations

The design of this study was constrained by its main purpose: to evaluate the acceptability and feasibility of a specific intervention for use in a large-scale RCT. The time constraints imposed by this pragmatic context meant that some of the participants had limited experience of the full PES-EMDR procedure, and only some of them had experience of remote working. Despite these limitations, we were able to collect sufficient convergent data, from a variety of sources, to reach clear conclusions, as listed above, to guide clinical practice. And although the context of the study was the needs of a specific clinical trial, we would expect the conclusions to apply to other EMDR protocols for people with intellectual disabilities. The Trauma-AID trial, incorporating the conclusions of the feasibility study reported here is now open for recruitment.

Our overall conclusion is that, with some reservations, the PES-EMDR therapy appears both feasible and acceptable for clients with intellectual disabilities and therapists, whether delivered face-to-face or in a remote or hybrid mode, though remote working appears easier for the PES phase than the EMDR phase of the intervention.

ACKNOWLEDGEMENT

The team would like to thank the participants and all who assisted in the facilitation of this study; without you this would not have been possible.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

FUNDING INFORMATION

This study is funded by the National Institute for Health Research (NIHR) [Health Technology Assessment project

17/125/04]. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

ETHICS STATEMENT

The ethics statement is at the end of the Methods section Sources of Information.

ORCID

Gemma Rogers  <https://orcid.org/0000-0003-0211-6085>

Paul Willner  <https://orcid.org/0000-0001-5576-5260>

REFERENCES

- American Psychological Association. (2004). *Clinical practice guideline for the treatment of post-traumatic stress disorder*. APA Retrieved from <http://www.apa.org/ptsd-guideline/>
- Barol, B. I., & Seubert, A. (2010). Stepping stones: EMDR treatment of individuals with intellectual and developmental disabilities and challenging behaviour. *Journal of EMDR Practice and Research*, 4(4), 156–169.
- Beadle-Brown, J., Mansell, J., Cambridge, P., Milne, A., & Whelton, B. (2010). Adult protection of people with intellectual disabilities: Incidence, nature and responses. *Journal of Applied Research in Intellectual Disabilities*, 23, 573–584.
- Bisson, J. I., Berliner, L., Cloitre, M., Forbes, D., Jensen, T. K., Lewis, C., Monson, C. M., Olf, M., Pilling, S., Riggs, D. S., Roberts, N. P., & Shapiro, F. (2019). The international society for traumatic stress studies new guidelines for the prevention and treatment of posttraumatic stress disorder: Methodology and development process. *Journal of Traumatic Stress*, 32, 475–483.
- Bisson, J. I., Roberts, N. P., Andrew, M., Cooper, R., & Lewis, C. (2013). Psychological therapies for chronic post-traumatic stress disorder (PTSD) in adults. *Cochrane Database of Systematic Reviews*, 12, CD003388.
- Buono, S., Zingale, M., Città, S., Mongelli, V., Trubia, G., Mascali, G., Occhipinti, P., Pettinato, E., Ferri, R., Gagliano, C., & Greco, D. (2021). Clinical management of individuals with intellectual disability: The outbreak of COVID-19 pandemic as experienced in a clinical and research center research in developmental disabilities. *Research in Developmental Disabilities*, 110, 103856.
- Byrne, G. (2022). A systematic review of treatment interventions for individuals with intellectual disability and trauma symptoms: A review of the recent literature. *Trauma Violence Abuse*, 23, 541–554.
- Courtois, C. (2004). Complex trauma, complex reactions: Assessment and treatment. *Psychotherapy: Theory, Research, Practice, Training*, 41, 412–425.
- Daveney, J., Hassiotis, A., Katona, C., Matcham, F., & Sen, P. (2018). Ascertainment and prevalence of post traumatic stress disorder (PTSD) in people with intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, 12, 211–233.
- Denscombe, M. (2014). *The good research guide for small-scale social research projects*. McGraw-Hill Education.
- Gilderthorp, R. C. (2015). Is EMDR an effective treatment for people diagnosed with both intellectual disability and post-traumatic stress disorder? *Journal of Intellectual Disabilities*, 19, 58–68.



- Halcomb, E. J., & Davidson, P. M. (2006). Is verbatim transcription of interview data always necessary? *Applied Nursing Research*, *19*, 38–42.
- Hall, J. C., Jobson, L., & Langdon, P. E. (2014). Measuring symptoms of posttraumatic stress disorder in people with intellectual disabilities: The development and psychometric properties of the impact of event scale-intellectual disabilities (IESIDs). *British Journal of Clinical Psychology*, *53*, 315–322.
- Herman, J. L. (1997). *Trauma and recovery*. Basic Books.
- Hwang, I. T., Hallock, T. M., Schwartz, A. E., Roth, S., Pfeiffer, B., & Kramer, J. M. (2022). How people with intellectual and developmental disabilities on collaborative research teams use technology: A rapid scoping review. *Journal of Applied Research in Intellectual Disabilities*, *35*, 88–111.
- Jowett, S., Karatzias, T., Brown, M., Grieve, A., Paterson, D., & Walley, R. (2016). Eye movement desensitization and reprocessing (EMDR) for DSM-5 posttraumatic stress disorder (PTSD) in adults with intellectual disabilities: A case study review. *Psychology of Trauma*, *8*, 709–719.
- Karatzias, T., Brown, M., Taggart, L., Truesdale, M., Sirisena, C., Walley, R., Mason-Roberts, S., Bradley, A., & Paterson, D. (2019). Mixed-methods, randomized controlled feasibility trial of eye movement desensitization and reprocessing (EMDR) plus standard care (SC) versus SC alone for DSM-5 posttraumatic stress disorder (PTSD) in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disability*, *32*, 806–818.
- Kildahl, A. N., Oddli, H. W., & Helverschou, S. B. (2020). Potentially traumatic experiences and behavioural symptoms in adults with autism and intellectual disability referred for psychiatric assessment. *Research in Developmental Disabilities*, *107*, 103788.
- Lalot, D., Lubert, M., Oren, U., Shapiro, E., Ichii, M., Hase, M., La Rosa, L., Alter-Raid, K., & Jammes, J. T. S. (2021). What is EMDR therapy? Past, present, and future directions. *Journal of EMDR Practice and Research*, *15*, 186–201.
- Lovett, J. (1999). *Small wonders: Healing childhood trauma with EMDR*. Free Press.
- Mason-Roberts, S., Bradley, A., Karatzias, T., Brown, M., Paterson, D., Walley, R., Truesdale, M., Taggart, L., & Sirisena, C. (2018). Multiple traumatisation and subsequent psychopathology in people with intellectual disabilities and DSM-5 PTSD: A preliminary study. *Journal of Intellectual Disability Research*, *62*, 730–736. <https://doi.org/10.1111/jir.12505>
- McCarthy, J. (2001). Post-traumatic stress disorder in people with learning disability. *Advances in Psychiatric Treatment*, *7*, 163–169.
- McManus, S., Meltzer, H., Brugha, T., Bebbington, P., & Jenkins, R. (Eds.). (2008). *Adult psychiatric morbidity in England, 2007: Results of a household survey*. The NHS Information Centre.
- McNally, P., Taggart, L., & Shevlin, M. J. (2021). Trauma experiences of people with an intellectual disability and their implications: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, *34*, 927–949.
- Mevissen, L., & de Jongh, A. (2010). PTSD and its treatment in people with intellectual disabilities: A review of the literature. *Clinical Psychology Review*, *30*, 308–316.
- Mevissen, L., Didden, R., Korzilius, H., & De Jongh, A. (2017). EMDR therapy for PTSD in children and adolescents with mild to borderline intellectual disability: A multiple baseline across subjects study. *Journal of Applied Research in Intellectual Disabilities*, *30*, 34–41.
- Mevissen, L., Lievegoed, R., & de Jongh, A. (2011). EMDR treatment in people with mild ID and PTSD: 4 cases. *The Psychiatric Quarterly*, *82*, 43–57.
- National institute for Clinical Excellence. (2005a). Post-traumatic stress disorder: Management. Retrieved from www.nice.org.uk/Guidance/cg26
- National institute for Clinical Excellence. (2005b). Post-traumatic stress disorder (Update). Retrieved from www.nice.org.uk/guidance/indevelopment/gid-ng10013
- Nieuwenhuis, J. G., Noorthoorn, O. E., Llewellyn, H., Nijman, I., Naarding, P., & Mulder, C. L. (2017). A blind spot? Screening for mild intellectual disability and borderline intellectual functioning in admitted psychiatric patients: Prevalence and associations with coercive measures. *PLoS One*, *12*(2), e0168847.
- Parnell, L. (2013). *Attachment-focused EMDR: Healing relational trauma*. Norton.
- Phelps, A. J., Lethbridge, R., Brennan, S., Bryant, R. A., Burns, P., Cooper, J. A., Forbes, D., Gardiner, J., Gee, G., Jones, K., Kenardy, J., Kulkarni, J., McDermott, B., McFarlane, A. C., Newman, L., Varker, T., Worth, C., & Silove, D. (2021). Australian guidelines for the prevention and treatment of post-traumatic stress disorder: Updates in the third edition. *The Australian and New Zealand Journal of Psychiatry*, *56*(3), 230–247.
- Porter, J. L. B. (2022). EMDR therapy with people who have intellectual disabilities: Process, adaptations and outcomes. *Advances in Mental Health and Intellectual Disabilities*, *16*, 32–43.
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In B. Bryman & R. Burgess (Eds.), *Analyzing qualitative data* (pp. 173–194). Routledge.
- Rumball, F. (2019). A systematic review of the assessment and treatment of posttraumatic stress disorder in individual with autism spectrum disorders. *Review Journal of Autism Developmental Disorders*, *6*, 294–324.
- Shapiro, F. (1999). Eye movement desensitization and reprocessing (EMDR) and the anxiety disorders: Clinical and research implications of an integrated psychotherapy treatment. *Journal of Anxiety Disorder*, *13*, 35–67.
- Sheehan, R., Dalton-Locke, C., Ali, A., Vera San Juan, N., Totsika, V., & Hassiotis, A. (2021). Effects of the COVID-19 pandemic on mental healthcare and services: Results of a UK survey of front-line staff working with people with intellectual disability and/or autism. *British Journal of Psychiatry Bulletin*, *12*, 1–7.
- Stenfert Kroese, B., Willott, S., Taylor, F., Smith, P., Graham, R., Rutter, T., Stott, A., & Willner, P. (2016). Trauma-focussed cognitive-behaviour therapy for people with mild intellectual disabilities: Outcomes of a pilot study. *Advances in Mental Health and Intellectual Disabilities*, *10*, 299–310.
- The Complex Trauma Taskforce. (2012). The ISTSS Expert Consensus Treatment Guidelines For Complex PTSD In Adults. Retrieved from http://www.istss.org/AM/Template.cfm?Section=ISTSS_Complex_PTSD_Treatment_Guidelines&Template=%2FCM%2FContentDisplay.cfm&ContentID=5185.
- Unwin, G. L., Willott, S., Hendrickson, S., & Stenfert Kroese, B. (2019). Eye movement desensitisation and reprocessing for

- people with intellectual disabilities: Process issues from an acceptability study. *Journal of Applied Research in Intellectual Disabilities*, 32, 635–647.
- van Teijlingen, E., & Ireland, J. (2003). Research interviews in midwifery. *RCM Midwives Journal*, 6(6), 260–263.
- Wigham, S., & Emerson, E. (2015). Trauma and life events in adults with intellectual disability. *Current Developmental Disorders Reports*, 2, 93–99.
- Wigham, S., Hatton, C., & Taylor, J. (2011). The effects of traumatizing life events on people with intellectual disabilities: A systematic review. *Journal of Mental Health Research in Intellectual Disabilities*, 4, 19–39.
- World Health Organization. (2018). *ICD-11 implementation version*. WHO.
- Wos, K., Kamecka-Antczak, C., & Szafranski, M. (2021). Remote support for adults with intellectual disability during COVID-19: From a caregiver's perspective. *Journal of Policy and Practice in Intellectual Disability*, 18, 279–285.
- Zaagsma, M., Volkers, K. M., Swart, E. A. K., Schippers, A. P., & Van Hove, G. (2020). The use of online support by people with

intellectual disabilities living independently during COVID-19. *Journal of Intellectual Disability Research*, 64(10), 750–756.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Unwin, G., Stenfert-Kroese, B., Rogers, G., Swain, S., Hiles, S., Clifford, C., Farrell, D., & Willner, P. (2023). Some observations on remote delivery of eye-movement desensitisation and reprocessing to people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 20(2), 205–215. <https://doi.org/10.1111/jppi.12452>