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Unwin, Gemma; Willott, Sara; Hendrickson, Stacey; Stenfert Kroese, Biza

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Eye Movement Desensitisation and Reprocessing for Adults with Intellectual Disabilities: Process Issues from an Acceptability Study

Authors
Gemma Unwin, University of Birmingham, School of Psychology*
Sara Willott, Birmingham Community Healthcare NHS Trust
Stacey Hendrickson, University of Birmingham, School of Psychology
Biza Stenfert Kroese, University of Birmingham, School of Psychology

*Corresponding author
University of Birmingham, School of Psychology, Edgbaston, Birmingham, B15 2TT
Email: G.L.Unwin@bham.ac.uk, Tel: 0121 414 7225

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Abstract

Background: Eye movement desensitisation and reprocessing (EMDR) is recommended for post-traumatic stress disorder (PTSD) and emerging evidence indicates that it is effective for people with intellectual disabilities (ID). However, acceptability from the perspectives of clients with ID, their therapists and other key people has not been formally evaluated. This study investigates process issues in the implementation of EMDR from perspectives of multiple stakeholders.

Method: Semi-structured interviews were conducted with two adults with ID and three clinical psychologists who had participated in EMDR as well as a key supporter (N=6) to provide information relating to three cases. The interviews were analysed thematically either directly from the audio recording or from transcripts.

Results: Five themes were identified: EMDR feels very different; EMDR is a technical process; the need to work with the present; talking is important; cautious optimism.

Conclusions: Whilst a range of client- and therapist-related factors served as barriers to using EMDR in this small-scale study, such as preferences in working with the present and inexperienced therapists, there was cautious optimism that EMDR may be useful for 'the right person at the right time'.

Introduction

Reported prevalence rates for post-traumatic stress disorder (PTSD) among people with intellectual disabilities (ID) vary widely from 2.5 to 60% (Mevissen & De Jongh, 2010), but are likely to be higher among people with ID as they are more likely to experience adverse life events than the general population (Hatton & Emerson, 2004; Sequeira & Hollins, 2003), in part because they are more likely to experience loss and are more vulnerable to abuse. Such experiences lead to trauma-related mental health problems and psychopathology (Wigham et al, 2014; Hulbert-Williams et al, 2011). People with ID may be more vulnerable to the effects of stressful and traumatic experiences due to impairments in stress appraisal, difficulties in appraising and processing information, difficulties in reasoning and adaptability, a need for a structured and predictable environment, and a limited behaviour repertoire leading to reduced successful avoidance of traumatic events (see Mevissen & De Jongh, 2010 for a review). As a significant number of adults with ID present to services with trauma-related mental health problems there is now increasing call for services to provide trauma-informed care (Kessler et al, 2005). Trauma-focussed cognitive behavioural therapy (TF-CBT) and eye movement desensitisation and reprocessing (EMDR) are both internationally recommended as first line interventions for PTSD (e.g. American Psychiatric Association, 2004; National Institute [England and Wales] for Health and Care Excellence, NICE; 2005; World Health Organisation, 2013), but there is currently a lack of empirically supported interventions for people with ID.

EMDR comprises a set of structured procedures and protocols delivered over eight phases (Shapiro, 2017). It is an eclectic therapy with a degree of overlap with TF-CBT (NICE, 2005). A key distinction is the use of bilateral stimulation (BLS), most commonly, rhythmic bilateral eye movements. Shapiro's (2017) Adaptive Information Processing Model (AIP) suggests that when an individual experiences a traumatic event, information processing may be incomplete, and the new information from the event may not be integrated with existing memory networks, resulting in this information being stored in its 'raw' form along with associated disturbed thoughts, sensations and emotions. In this way, the traumatic memory is not integrated with semantic knowledge and, if it

remains unprocessed can result in psychological distress. The aim of EMDR is to facilitate the client in fully processing the memory with the help of BLS.

EMDR has been shown to be effective among the general adult population (Chen et al, 2015) and emerging evidence indicates that it may be useful for people with ID who are experiencing trauma-related mental health problems (Jowett et al, 2016; Gilderthorp, 2015; Unwin et al, in preparation). However, existing studies do not use robust process evaluation and do not formally evaluate clients' or therapists' experiences of therapy. One small study has reported on three trauma-focused CBT groups (N=3, 5 and 4 respectively) for adults with ID presenting with complex PTSD (Stenfert Kroese et al, 2016). The quantitative findings suggest that this type of group work can be effective in reducing trauma-related symptoms and the qualitative analysis of data obtained through post-intervention interviews indicate that the clients considered this type of group therapy acceptable. Five main themes were identified: being listened to; it is nice to know you are not the only one; being in a group can be stressful; the importance of feeling safe; achieving and maintaining change.

In this paper we report process issues (such as obstacles and facilitative practices) related to the acceptability of EMDR from the perspectives of clients, those who support them, and therapists. The aim was to obtain personal reflections on the process of participating in EMDR from multiple perspectives and to triangulate these views to identify areas of convergence and divergence.

Method

Ethical approval was obtained from the National Research Ethics Service in England (Reference number 14/WM/0036).

Recruitment

This process evaluation study was carried out as part of a study evaluating the effectiveness and acceptability of EMDR for adults with ID and trauma-related mental health problems. The study used a multiple baseline, case series design. The aim was to recruit a minimum of 6 client participants with ID who would participate in EMDR. Quantitative data were to be collected using a range of outcome measures before, during and after the intervention. Recruitment opened in March 2014. The study was halted at the beginning of 2016 as recruitment and progress with the intervention proved to be difficult (the psychologists were struggling to identify clients suitable for EMDR on their caseloads and were struggling to initiate EMDR with those who were suitable). At this stage, two participants with ID (client participants: C01 & C02) had been recruited and one client (C03) had been approached by their clinical psychologist. The latter took part in EMDR sessions but declined to take part in an interview. However, she agreed for her psychologist to be interviewed and information to be included as part of a case study. Two client participants were therefore interviewed as well as a key supporter (someone close to the client who could be involved in sessions, if required, and with whom the psychologist and client could liaise) of one of these client participants (KS01). The availability of a key supporter was not essential for participation in the study. The other client participant lived independently and did not have a key support worker). The two clinical psychologists of these clients were interviewed (CP01 & CP02), as well as the additional psychologist (CP03) to provide data relating to three cases.

Client participants were recruited from a specialist, community-based, ID health service in the West Midlands (UK). Clinical psychologists who had agreed to be part of the study and who had received training in EMDR (see intervention section) screened their current caseload and new referrals for potential participants who met the following criteria:

- Adults (>18 years)

- Receiving services from a specialist ID health service (therefore with administratively defined ID)
- With capacity to consent to take part in the study
- Evidence of current trauma-related distress (evidence of past traumatic experiences resulting in symptoms of PTSD or complex PTSD; trauma to have a broader meaning to include events not considered as major trauma; may be based on compassionate guesswork of the therapist (Barol & Seubert, 2010))
- Suitable for EMDR determined by clinical judgement taking into account of the psychological formulation, stability, circumstances, and any other relevant factors
- The decision to invite the client to participate was based on the best clinical interests of the client.

Potential client participants and their key support workers were first approached by their clinical psychologist. EMDR was introduced to potential participants using an accessible information leaflet supplemented by explanations from their psychologist. Those interested in using EMDR were asked whether they would like to join the study; those opting out were still eligible to receive EMDR. Those not wanting to use EMDR continued their therapy as usual. Following confirmation of interest and suitability, potential client and key supporter participants were approached by a researcher (GU) to go through the study information sheet, explain the project in detail and seek consent. All participants were given at least a week to examine the information sheet and discuss any queries, after which, consent was obtained and documented.

The Intervention

EMDR usually follows an 8-phase protocol: phases 1-2 include an exploration of history, alliance-building, preparation such as safety work and assessment/joint formulation; phases 3-8 (treatment) include desensitisation of trauma memories, installation of more positive thoughts, body scan, closure and re-evaluation. During the treatment the client is asked to focus on the most distressing parts of the target memory alongside thoughts and beliefs that have served to keep the memory in an unprocessed state. While keeping that memory in mind, the therapist introduces BLS. Client participants had regular (weekly or fortnightly) therapy sessions with the same EMDR-trained psychologist throughout.

Seven experienced, specialist ID clinical psychologists, working within the Trust received 3- or 4-part, accredited training in the adult protocol of EMDR. None had previous experience of using EMDR. During study group meetings, the psychologists decided that introducing both the study and EMDR at the same time to clients was too challenging and risky and therefore they were encouraged to concentrate on therapeutic work, using EMDR where appropriate, so that they could familiarise themselves with using this new therapeutic approach. Once they became familiar with using EMDR, they could then start approaching clients to include in the study. However, this approach still did not result in psychologists using EMDR with clients other than those mentioned in Table 1.

Over the 22-month recruitment period, regular updates were sought from the clinical psychologists. Of the seven, three did not have any clients who they felt were suitable for EMDR in this period and another had not progressed to using EMDR with any clients. The other three psychologists were interviewed. Attempts were made to interview all seven psychologists to discuss issues with recruitment and using EMDR, however it was not possible due to on-going service redesign, maternity leave and psychologists leaving the service.

Data collection for the Process Evaluation

The interviews were conducted after the EMDR intervention and aimed to explore personal accounts of clients', therapists', and key supporters' experiences of EMDR and to establish aspects of therapy that were important (beneficial or challenging). Interview schedules (one for each stakeholder group) were used to guide the interviews. Topics for discussion included what participants liked and disliked about EMDR, what they did in sessions, how they felt about it, whether they thought it helped, barriers and facilitative practices.

Individual semi-structured interviews were carried out by a researcher (GU) with experience of conducting qualitative research with people with ID and staff. In the interviews with participants with ID, simple, more concrete and focused questions were posed and a wider range of prompts were used. The interviewer provided further explanations and descriptions to help the interviewee respond and some closed questions were used; in these cases, follow-up questions asking the interviewee to explain their response were posed. All interviews were conducted in a private room either at the clinic base or a day service site. C01 was accompanied by a support worker at their request. Interviews lasted between 30 and 63 minutes and were audio recorded.

Data analysis

All three interviews relating to case 01 were transcribed verbatim. The other interviews were analysed directly from audio recordings. Data capture and analysis followed the method outlined by Halcomb and Davidson (2006). For all cases, field notes were made both shortly after the interview and upon listening to the audio recording or reading the interview transcript. These field notes were refined to ensure they were an accurate record of the interaction and then subject to content analysis to identify common themes within and then across the interviews. Candidate themes were listed and further defined by re-reading of the field notes. Themes were reviewed, refined and labelled by the research team to capture the meaning within the data set. The analytic process was cross-checked by the research team to ensure that the themes were a valid account of the dataset. Finally, the field notes were colour coded according to the themes to ensure they covered all key content of the interviews – any remaining text was examined in case an additional theme was required. Illustrative quotes were obtained from the transcripts or audio recording.

Results

See Table 1 for a description of the cases.

Themes Identified in the Interviews

Five main themes were identified from the participants' accounts: EMDR feels very different; EMDR is a technical process; the need to work with the present; talking is important; cautious optimism. The following presents a narrative summary of the themes along with illustrative quotes from the interviews.

EMDR feels very different

All client and psychologist participants identified ways in which EMDR felt different to other ways of working; this was expressed most keenly by the psychologists. Differences were identified in how EMDR was preconceived, how it was actually experienced and the impact this had on the psychologists' sense of confidence and competence. This was balanced by acknowledgement of the overlap between EMDR and other approaches, especially in the early phases of therapy. The psychologists identified ways in which EMDR felt different, relating to the use of eye movements or other forms of BLS, reduced focus on talking and a mechanical approach. Owing to this, CP03 stated she would prefer to use EMDR with new clients who had not established expectations of therapy.

However, CP02 felt that working with an existing client was helpful as she knew the client and had established a therapeutic relationship. The psychologists reported that their clients also experienced EMDR as different resulting in them all preferring to return to previous ways of working with their psychologist.

> "Because it is such a different way of working, quite often if you're working and then you're having to introduce a different way of working, such as EMDR, they, they, struggle with that and it does sometimes hinder the therapeutic alliance that you've built over time, because it's a different way of working….For her, it almost felt as if, you know, this does not feel normal or doesn't feel comfortable, and it doesn't, she really struggled to relate to, erm, and her expectations of what therapy was, as very, very different, but if you set that expectation right from the beginning, then it's a lot easier." [CP03]

All psychologists expressed ambivalence and some cynical preconceived ideas about EMDR. They felt that it was a 'radically new and different approach' (including eye movements) and expressed some scepticism about its use with people with ID. This resulted in some anxiety and hesitancy to start using it with clients:

> "I think that, you know it is a very strange thing to be doing to somebody and even somebody without learning disabilities, you know, mixes up with hypnosis and other you know whacky looking things, so it's hardly surprising really." [CP01]

> "How I felt about going… I suppose a bit of anxiety, erm, because I hadn't used it before in clinical work. Yes, so, doing a bit of preparation around that reduced my anxieties, and I think doing it with [C02] , I felt more comfortable because I've known her quite a while, erm, and I knew some of the things that would be helpful to work on, and I wonder again if I put it off too though." [CP02]

Two of the psychologists highlighted how training had changed their attitude towards EMDR:

> "I was a bit cynical about EMDR before I took part in training, but I must say, I am more convinced after having worked through it myself." [CP02]

The psychologists expressed concerns that their clients would think that EMDR was too different, however, CP02 was surprised at how open C02 was to 'giving it a go'. C02 herself suggested that there was 'no harm in trying'. The other two clients were willing to try EMDR, however, all decided to return to their usual ways of working, as discussed later. CP02 also expressed concerns about how EMDR would be perceived by multi-disciplinary colleagues and how that could reflect on her. She acknowledged that it is not widely used and people have different levels of understanding about it and could therefore tend to have negative reactions to it.

Whilst the psychologists identified differences, they also identified a lot of overlap between EMDR and their usual ways of working, especially in the preparatory phases of EMDR which concern client history, emotional awareness, resource building and managing distress. All three clients used safe place techniques which the psychologists also used outside of EMDR.

The sense that EMDR was different to other approaches impacted on the psychologists' sense of competence and confidence. They felt that the training they received did not fully equip them for using EMDR with people with ID and that they had to adapt the protocol to suit their clients, but they did not feel confident in these adaptations and these adaptations further complicated the process of therapy.

> "Everything's an effort, and an effort when you don't really know what you're doing." [CP01]

However, the psychologists felt that with more experience their confidence would grow, especially with knowing what they can adapt in the protocol and with being more flexible in the approach. CP03 also spoke about how seeing the impact of EMDR first-hand with clients is essential for internalising and believing in its potential:

> "I'm yet to experience the, I suppose, the impact of the work in terms of its outcomes and how beneficial it is, erm, as with most therapeutic approaches, as you learn them, you understand and you, erm, you recognise how it can be beneficial, but you only begin to internalise that in a way, and have more belief and confidence in that approach, once you see the changes that take place with you working with a client, and as you're supporting them over time." [CP03]

EMDR is a technical process

EMDR was perceived by the psychologists to be a technical, mechanical, complex, structured and prescriptive procedure, requiring adherence to a detailed protocol and with less opportunity for an integrative approach. CP03 provided the examples of checking for non-verbal cues and signs of emotional processing and the approach to client-therapist interaction which are done in a more structured way in EMDR. The participants highlighted that, owing to the technicality of EMDR, some clients with ID may not be able to engage with the process of EMDR.

> "So, I think just finding clients where you think you could actually work with, and you think that they would actually be able to engage with that process. So even though you think 'absolutely, yes, this client would be absolutely superb and it could work', getting them on board and being able to engage with the process is another issue." [CP03]

The need for adaptation and flexibility to suit client needs was highlighted leading to a sense of conflict and concern over deviation from the core approach. However, the psychologists felt that more experience would build their confidence to know which elements of the standard protocol to preserve and which could be adapted. CP01 felt that everything had to be adapted and thought about in terms of the suitability for her client; CP03 reported making many adaptations to language and tools; whereas CP02 felt that little adaptation was required outside of simplification and prompting.

BLS was regarded by the psychologists as a mechanical/technical feature of therapy which differentiated EMDR from other types of therapy. The standard format for BLS (eye movements) required adaptation. C02 was able to use eye movements and suggested that it was "easy", however, CP02 felt that C02 struggled at times and needed prompting to follow her fingers and that the difficulty in eye tracking may have contributed to her decision to stop EMDR. Both C01 and C03 were unable to use eye movements and instead used auditory or tactile stimulation. This led to conflicts for the psychologists who became aware of the limited evidence of effectiveness for other modalities, but were unable to use the most evidence-based approach (eye movement) with their clients. C01 provided a description of her experience of BLS. Here C01 explains that she found the eye movements too difficult and that this dual attention task was too taxing:

> "I: Right. Excellent. And you said earlier about the eye movements that you tried doing. Did you try and follow [therapist]'s hand, like that?
> C01: Yeah.

I: And you didn't like that?
C01: Nah.
I: Why was that?
C01: 'Cos I couldn't think when she was doing it. When she was doing it, she asked the questions, but I couldn't think while she was doing it.
I: Sure. So it's quite hard to follow with your eyes, the hand movement?
C01: Yeah.
I: And so you preferred the music?
C01: Yeah.
I: Did you ever hold on to buzzers, things that? Did you try that as well?
C01: Yeah.
I: How did you find that?
C01: Didn't like it.
I: Didn't you? Why didn't you like that?
C01: It was too fast."

All the psychologists felt that their clients need prompting and direction to facilitate engagement with EMDR in sessions, for CP02, this was a key theme in EMDR sessions. Furthermore, CP02 and CP03 simplified the distress and positive cognition scales that are used as part of EMDR by using physical or visual analogue ratings rather than verbal reporting of the numeric scales

The need to work with the present

All participants emphasised the need to work with current as well as past problems. All participants talked about current issues for clients such as problems with family, instability in living circumstances, poor health of relatives and changes to day service, with which they were struggling to cope. The psychologists felt that stabilising the client was the primary aim at the start of therapy and was a prerequisite for reliving work. Both CP01 and CP02 had worked on stabilising their clients for over a year before starting to use EMDR and found resource building to be useful. CP01 commented on the various techniques she used to build resources to recognise strengths, develop self-management techniques and improve emotional awareness and resilience. All cases used 'a safe place' as a way to manage present distress which was installed using BLS, however two psychologists queried the added value of using BLS with safe place techniques.

"And so I think that kind of work around looking at people's strengths and resources can be very powerful especially with this group." [CP01]

"She found that quite helpful in terms of when she was feeling angry or distressed or if there had been difficult things going on with the family." [CP02]

Both client participants were positive about the safe place techniques and confirmed that they used these techniques outside of therapy sessions to help manage their emotions. C02 suggested that installation of her safe place through eye movements helped her to think about it.

"I: Have you used safe place outside of sessions?
C02: Yeah
I: You have?
C02: Yeah
I: And how do you find that?
C02: Peaceful really, peaceful."

I: Right. And so how often do you do that?

C01: Only when I go to bed.
I: Right. Every night, do you look at your safe place and—? Or not every night?
C01: If I haven't had a good day, or if I'm at home and I don't feel good at home.
I: And do you think that – does it help?
C01: Sometimes it does.
I: How does it help you?
C01: Cos I can imagine going onto the beach, imagining going onto the beach."

There was resistance to working with the past from clients, families (reported by psychologists) and psychologists. Clients found talking about the past hard, it made them feel worse and they did not like doing it, but they recognised that it was 'good to get it off your chest'.

"I: Was there anything that was really hard, anything you didn't like throughout all your sessions with [therapist]?
C01: Talking about the past and talking about my dad and my nan."

CP01 and KS01 also expressed concerns over the perceptions of family members who were not supportive of 'dragging up the past'. C01 also identified the lack of family support. Both KS01 and CP01 felt that the lack of family support contributed to C01's decision to stop EMDR and KS01 implicated issues around guilt, blame and shame owing to the nature of C01's trauma. CP01 talked about the cost:benefit ratio of reliving and how, after long-term therapy, C01 was perhaps not troubled enough by her past to want to undertake any reprocessing. The participants felt that it was the combination of these factors (reluctance to bring up the past, talking about the past being upsetting/destabilising, lack of support from family, and limited present problems with the past) that led to her deciding to stop therapy.

"I think there was guilt there. I think there was a lot of covering up. I think maybe they've you know, I think they've, in a way they were a bit torn, they acknowledged it needed to be dealt with but they wanted to push it under the carpet, this behaviour isn't related to that, this behaviour is all [C01]. That's the way she is. So I think there is a lot, there was a lot of barriers there and I think, it could have influenced [C01's] maybe, willingness to work well within that type of therapy." [KS01]

The psychologists were wary of the destabilising potential of reliving work and highlighted that some clients with ID would find it too upsetting and would not want to undertake this work and that it is important to respect client's wishes. CP01 felt particularly cautious about this, especially in light of long-standing clients with whom she had worked with to stabilise over time.

"I think that some clients just wouldn't want to go there. I think it would be too upsetting and destabilising, and it may be that there is never a good time for them to do this so it just doesn't happen." [CP02]

CP02 also felt that it was inappropriate to ignore what C02 brought to each session so that she could undertake some reprocessing and highlighted how her client prioritised working on present issues herself, suggesting that a key reason for C02 deciding to stop reprocessing was because she valued the opportunity to bring current issues to sessions and work on those. This was identified by all psychologists as a barrier to moving onto reprocessing as they had to stabilise the client and work with what had happened between sessions, leaving no space to work on the past.

"I think with erm, you'd plan to start the desensitisation and then there'd be some issue at home that would need dealing with. So, sometimes it felt like it was being put off… It

> doesn't feel particularly therapeutic to say 'Oh, we can't talk about that 'cos we've planned to do EMDR'" [CP02]

Talking is important

Therapy as a platform to share and engage was valued by all. All participants highlighted the importance of talking and the client participants identified this as the most important aspect of therapy which helped them with their problems and left them feeling better after sessions:

> "Talking to [CP02] gets rid of it [anger]." [C02]

> "I: Why do you think – why do you think it's helpful to talk about things, even though it's hard?
> C01: 'Cos I don't wanna get stuck inside."

> "Also, there would be an outlet for her to, I don't know, to share some of her feelings, to share what happened in the past and have somewhere to filter them… I think she was quite, she was quite eager that somebody was listening to her. I think she was quite happy that she would have that 1.1 interaction." [KS01]

The psychologists felt that their clients really valued the opportunity to talk and be listened to, and felt that the reduced focus on talking in EMDR affected their client's engagement with therapy and their decisions to revert to other talking therapies. CP02 suggested that there was 'something missing, in terms of the interaction, with EMDR'. The psychologists felt that this was a key difference between their usual way of working and working with EMDR and derived positives and negatives from this. They felt more confident about talking being the mechanism of action of therapy and did not feel comfortable with shifting away from talking. Talking was a means to develop a therapeutic relationship and trust. The psychologists spoke about the trusting relationship they had built with their clients and how they feared that reducing the potential for talking in sessions could compromise this relationship. CP03 was especially cautious and suggested that EMDR felt invasive as she had not anticipated the disruption to the therapeutic relationship.

> "…'cos [C02], after the first session, we talked about whether she found it helpful, and she said she'd prefer to go back to just her normal psychology sessions and I think that was part of that, because she likes talking about things, and EMDR's quite non-verbal. So I think she found the EMDR helpful, but I think there was something missing, in terms of the interaction." [CP02]

> "Okay, we're now at the stage we're going to do the eye movements really, and so we stop talking! And it is the stop talking bit that is a big disruption to the therapeutic alliance and the therapeutic processes that are taking place and that's the bit that feels quite difficult and I know that when I, I was doing the training it was very easy for us to get back into talking about it because that's what we got so used to doing to, to actually say, no, no, we need to stop and focus on the eye movements and work with that, was, was a bit of an adjustment, a significant adjustment really." [CP03]

Cautious optimism

Whilst the process of EMDR could be challenging, the participants identified ways in which they felt therapy had helped and could help others, and all three psychologists were optimistic about using EMDR in the future. They saw EMDR as another tool to be used with appropriate clients and in combination with other approaches as it could be helpful to "sandwich it in amongst more

traditional stuff, helpful to have that as a tool." (CP02) CP02 highlighted the prevalence of trauma among clients who present to the forensic team and how it could be "narrow-minded" to just work on the offending rather than working on broader issues that might lead to offending such as trauma. However, she acknowledged that not everyone wants to work on past traumatic experiences. Both CP02 and CP03 highlighted the importance of "the right person at the right time" but that for some, there might never be a right time, especially in light of instability in the lives of people with ID and the challenges of bringing up past trauma.

> "I did find it helpful 'cos I think you can get wrapped up in a lot of the emotional stuff erm, when you do, kind of, traditional therapy, but there's something about the finger movements that stops you focussing too much on that." [CP02]

All clients and psychologists were positive about 'safe place'. However, the psychologists commented on needing more time and prompting to help clients to develop and practice their safe place and were doubtful about how much it was used outside of sessions. They also acknowledged that this is not unique to EMDR.

C02 talked about how she stopped eye movements because she did not think that they were working but, on reflection during the interview, felt that EMDR may have helped, however, she mainly identified that talking helped with her anger. CP02 reflected on whether she felt EMDR had helped C02 to reprocess her traumatic experiences: at the time, C02 reported that it had helped, ratings of distress reduced and validity of positive cognition increased along with C02 providing verbal feedback which seemed appropriate to what they were working on. She reflected on why, given the good response, C02 wanted to discontinue after three sessions and she queried whether she found the eye tracking too challenging or missed the opportunity to talk about current issues.

> "She [C02] said that she found it helpful and she fed back to her community nurse that she found it helpful… so it's interesting that she didn't want to continue with it." [CP02]

Discussion

This paper investigated the acceptability of EMDR as a therapy for adults with ID and trauma-related mental health problems from the perspectives of clinical psychologists providing the therapy, clients with ID and their key supporters. Five themes were identified from the analysis of the interviews, namely *EMDR* feels very different; EMDR is a technical process; the need to work with the present; talking is important; cautious optimism. An important limitation of the present study is the modest experience of desensitisation and reprocessing across the participants, given that only one client-psychologist pair undertook desensitisation and reprocessing of past traumatic experiences, this is despite stabilisation/preparation phases of over a year in two cases. However, the analysis elucidates some of the issues in using this kind of re/processing with clients with ID, especially in terms of client expectations of and preferences for therapy. Furthermore, whilst the number of client participants is relatively low, an in-depth analysis of the perspectives of clients with ID about EMDR is unique and triangulation of views from multiple perspectives provides the opportunity to identify convergence and divergence in those perspectives, which is another novel feature of the present study. However, the findings must be considered with reference to the overall small sample size and therefore findings may not be generalizable.

Currently, people with ID do not have access to empirically supported trauma-focused therapies. Nascent evidence indicates that EMDR may be useful for people with ID and trauma-related mental health problems in terms of symptom reduction and improvements in daily functioning (Gilderthorp, 2015; Jowett et al, 2016; Unwin et al, in preparation). Only one study has evaluated TF-CBT for people with ID which suggests this approach is also feasible (Stenfert Kroese et al, 2016). The

present study also suggests cautious optimism that EMDR may be useful, but might not be acceptable to all parties involved – there is a need to 'find the right client at the right time'. Client experience and treatment acceptability are crucial factors when selecting appropriate treatments (Crawford et al, 2002). Treatment acceptability is defined as the degree to which an individual person perceives a treatment to be appropriate, reasonable and unobtrusive (Kazdin, 1980). Despite its importance, client experience and treatment acceptability are often overlooked in the evaluation process (Manary et al, 2013). In addition, the experience and views of the therapists are rarely sought, despite research demonstrating that treatments which are experienced as difficult, complex or intrusive are selected less frequently by clinicians, regardless of the clinical efficacy (Ruzek et al, 2014). The participants here experienced elements of EMDR to be difficult, complex, and intrusive and this affected engagement with the therapy. Whilst this is not insurmountable, some work may be required to encourage clients with ID and their psychologists to undertake EMDR.

All three clients chose not to pursue desensitisation and reprocessing of their identified traumatic life events and to return to their previous, non-trauma focused way of working. The clients and therapists gave several reasons for this, most notably, there was a preference to work on the present. Clients with ID experience more disturbing life events than the general population (Hatton & Emerson, 2004; Martorell & Tsakanikos, 2008) requiring work on present issues in therapy and little opportunity to work on the past. The clients in this study had chaotic lives and experienced ongoing issues with family and living circumstances with which they wanted help. The therapists were required to work on presenting issues such as interpersonal conflicts, emotional problems and fears (symptom management, which may relate to current or past experiences) rather than trauma treatment.

Clients with ID may also have long-standing and complex trauma and, therefore may not present with a single, relatively recent index experience to be re/processed, as with 'simple' PTSD (Buhler, 2014). Working on present problems may reduce distress to a point where the client does not feel it necessary to work on historical trauma: one of the participants implicated that the cost-benefit ratio of reliving was not positive, despite her psychologist's clinical assessment suggesting that EMDR would still be of benefit. Failure to target the touchstone memory, as required in EMDR may result in unresolved and therefore ongoing issues. These may abate in the short-term, with therapy, but may re-emerge later. There may be reluctance from the client to bring up the past and clients with ID may have difficulties in understanding the complex mechanisms involved in EMDR and therefore lack the impetus for reliving. Furthermore, they may be more susceptible to the views of family members who may also be worried about bringing up the past and/or trying out a new kind of therapy.

In the present study, therapy focused more on managing present distress and all clients used safe place techniques about which they spoke positively. Whilst these coping strategies are not exclusive to EMDR, previous research has also demonstrated the positive effect of incorporating this preparatory work into EMDR. Barol et al (2010) reported significant difficulty in participants identifying and processing past memories and therefore therapy sessions focussed heavily on developing self-management strategies and interpersonal skills such as 'safe place' and other self-calming techniques. Similarly, Dilly (2014) reported that a client experienced a high level of arousal during sessions and therefore sessions focussed on safe place visualisation techniques. The psychologist participants in this study commented on the overlap between the preparatory phases of EMDR and other therapies. Combined with working with existing clients and lengthy stabilisation phases, it makes it difficult to isolate the effects of EMDR as it is difficult to determine when the unique EMDR component of the therapy starts. Further research should consider this overlap and could consider recruiting new referrals only. This would also alleviate issues around introducing a different way of working with existing clients. Furthermore, future research should investigate the

potential 'added value' of installing safe place and other resources with BLS. The techniques used in a 12-week TF-CBT group intervention greatly overlap with the initial phases of EMDR (e.g. safe place and relaxation techniques) and resulted in significant symptom reduction after fewer sessions and without the one-to-one BLS/ reprocessing work that were attempted in the current study (Stenfert Kroese et al, 2016).

A prominent reason for clients' limited re/processing was the value placed by both parties on talking and that EMDR felt very different because of the reduced focus on talking. It could be asserted that, owing to the reduced requirement to verbalise distress, EMDR may be more suitable for clients who have problems with communication. However, the present findings indicate that clients with ID appreciate the opportunity to talk about their current problems (also a theme identified by Stenfert Kroese et al, 2016) and that this is fundamental in developing an empathetic therapeutic relationship. Indeed, the move away from this approach was suggested as a reason for two of the clients deciding to cease re/processing and return to more traditional talking therapy. Studies of the acceptability of cognitive behavioural therapy have reported the same perspectives from clients with ID (Unwin et al, 2016) and other studies have highlighted this with the general population (Keijsers et al, 2000; Lambert & Barley, 2001). It is important to note that all three client participants had mild-moderate ID and were relatively able in terms of verbal communication. Further research should investigate how clients with more severe communication impairments experience therapy. A case series with four adults with severe ID has shown promising results in terms of symptom reduction but did not investigate the experience of therapy from the perspectives of clients (Mevissen et al, 2012).

The clinical psychologists struggled to adapt to a different therapeutic approach and were reticent to use EMDR with their clients. They felt that EMDR was radically different, were worried that their clients would not be able to adapt to working in different ways and felt that their lack of experience in using EMDR impacted on their confidence in the approach and their sense of competence. All three psychologists used more traditional talking therapies and had only received training in EMDR. They felt that their training had not fully prepared them for using EMDR with this client group and that adaptations were required to the standard EMDR protocol, however they did not feel confident to make these adaptations at the outset. The psychologists were cautious about using a reliving therapy which would destabilise and distress their clients, especially in light of its different mechanism of action, with which they were unfamiliar. Therapists and researchers have also expressed this concern regarding other vulnerable groups, such as those with psychosis, however, research has shown that EMDR is well tolerated by those with psychosis and did not lead to an exacerbation in symptoms (de Bont et al, 2013).

Using clinical psychologists who were newly trained in EMDR is a limitation of this study and may help explain why recruitment to the study was problematic as clinicians were required to make the first approach to clients. The therapists needed supervision and support from an experienced clinician in both EMDR and ID, however, as EMDR is new to the field in the UK, this may not be available. It would have been helpful if the psychologists had access to examples where EMDR had been used successfully as well as reassurance that the adaptations they were using still maintained fidelity to the approach. An alternative approach could be to use therapists who are more experienced in EMDR, but not ID. However, therapists have emphasised the importance of experience of working with clients with ID for the development of the therapeutic relationship (Jones, 2014) and it is not clear whether such therapists would have the skills necessary for working with clients with ID.

EMDR was experienced as a technical and fairly rigid procedure, however flexibility in the application of the standard EMDR protocol was considered necessary to meet clients' level of comprehension

and communication style. For example, the ratings of distress and cognitions in the standard protocol were too complex for the clients and therefore simplified ratings were used. Only a minority of clients with ID in other studies have been able to use the standard ratings and all studies of EMDR for people with ID report making some adaptations (Unwin et al, in preparation). Other studies have used the children's EMDR protocol with adults with ID, which uses simpler language and ratings (Mevissen et al, 2011a; 2011b). Clinicians could consider utilising the children's EMDR manual when comprehension or communication difficulties arise, however, clinicians would need to ensure that the protocol is age-appropriate. Further research into adaptations for clients with varying severity of ID could lead to the development of a specialist protocol specifically for this client group. This could ensure suitable language, adaptations, tools and techniques are readily available for use which would save time and provide standardised methods for EMDR which could then be used in research. Furthermore, research should systematically evaluate adaptations to the standard protocol and the effect on treatment fidelity and efficacy. Such research could consider the distinction between an 'adaptation' and 'reasonable adjustments' made to make the therapy more suitable for clients. Kendall et al (2008) use the phrase 'flexibility within fidelity' to make a distinction between flexible use of therapy and adherence to a therapeutic modality, making room for adjustments to be made to therapeutic protocols, for example, to match cognitive ability and mental age, whilst maintaining adherence to an approach.

All three clients were reported to have had difficulties with eye tracking resulting in two using other forms of BLS. In the third case, the psychologist reported difficulties in eye tracking and suspected that this contributed to her client's decision to stop reprocessing, however the client did not report any problems. The psychologists were aware of the limited evidence to support the use of alternative forms of BLS and this made them cautious to use other forms. Indeed, researchers have failed find a beneficial effect of auditory stimulation on memory retrieval (Nieuwenhuis et al, 2013). Difficulties using eye movements with clients with ID have been reported in other studies (Mevissen et al, 2011a; 2011b; Barol & Seubert, 2010) therefore therapists should consider the views and preferences of clients when selecting the method of BLS, whilst further research should investigate the impact of alternative methods on efficacy, especially in people with ID.

Conclusions

To the authors' knowledge, this is the only systematic study of the experience of EMDR from clients' and therapists' perspectives. Useful insights are provided into the experiences of providing and receiving this therapy, however, the extent to which these experience apply to other contexts needs further investigation. We found that a combination of factors served as barriers to using EMDR with this client group such as trying to adapt the protocol without prior experience of using the model, client preferences for talking and working with present issues. However, the psychologists were still optimistic about using EMDR with clients in the future. Whilst the present study provides insight into the issues involved in initiating and early-phase EMDR, no conclusions can be drawn about the experience of reprocessing as only one client-therapist pair undertook three sessions of desensitisation and reprocessing. Further research should therefore seek to understand more about the process of reliving and reprocessing in EMDR. Furthermore, future research with robust process evaluation should compare EMDR with other trauma-focussed therapies to attempt to delineate the mechanism of action, especially owing to the overlap between EMDR (early phases) and more traditional therapies. Future research would be aided by the development of an adapted EMDR protocol for people with ID.

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Conflicts of Interest
None.

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Table 1: Case description

	Case 1	Case 2	Case 3
Clients (C)			
Interview length (minutes)	58	30	N/A
Timing of interview (months after final EMDR session)	3	3	N/A
Age at recruitment	23	40-50	42
Sex	Female	Female	Female
ID	Mild-moderate	Borderline-mild	Mild-moderate
Traumatic experiences	Numerous traumatic events including physical and sexual abuse, bullying and harassment as well as neglect. C01 was sexually abused by a family friend from the age of 6 to 12 years.	Trauma relating to abandonment as a child as she was given up for adoption by her birth mother and subsequently fostered. More recently, she had suffered physical abuse by her son.	Historical and recent experience of abuse: there were suspicions that C03 was sexually abused as a child; more recently she was physically restrained in a physical assault.
Presenting symptoms/complaints	Presenting symptoms included changeable mood, self-harm and frequent periods of significant distress characterised by shouting and crying. C01 reported intrusive imagery when she was trying to go to sleep or when stressed. C01 was referred by a staff member at her day service because of problems at home with stealing and lying and issues at the day service around divulging sensitive information about her abuse. Staff felt that C01 needed to do some work around boundaries and managing her own emotions.	C02 was referred to the forensic team after she was convicted of committing fraud towards a family member. Later, she presented with problems with anger and anxiety, especially towards family members.	After this event, C03 deteriorated with marked loss of function and regression. C03 could no longer travel independently, walked using a stick, stopped using the toilet, feared going out, rarely left the house and lived in fear of being attacked. This led to C03 moving out of her flat to live with her mother. C03 presented as being very anxious and tearful and she struggled to focus and engage. She used self-talk to try to manage her distress.
Description of EMDR	C01 engaged in EMDR approximately 12	C02 engaged in EMDR approximately 13	C03 engaged in EMDR shortly after her

therapy	months after being referred to the service. C01 participated in phases 1 to 3 of EMDR which included developing a safe place and resource building including installation through (slow) auditory and tactile BLS; but did not attempt any reprocessing of traumatic experiences. Some work was undertaken around identifying targets (to label some of C01's worst memories), but most information relating to C01's traumatic experiences came from referral information. CP01 did not work directly with P01 to identify and prioritise targets for EMDR. C01's key support worker attended some parts of her sessions to aid information sharing and to facilitate a consistent approach. At the point that reprocessing was being discussed, C01 advised that she felt that she no longer needed therapy and she was subsequently discharged from the service after 18 months of therapy. At the same time, there were destabilising events at C01's day service as a key member of staff, of whom C01 was very fond, was leaving.	months after being referred to the service and was interviewed 3 months after her final EMDR session. She was still seeing her psychologist. She participated in all phases of EMDR after drawing up a time line and identifying targets which C02 felt were still problematic: being 'abandoned' as a child, when she was that told she had ID and that she would have to go to a special school, abusive relationship with son, and loss of employment after being bullied and a period of sickness. During the preparation phase, C02's safe place was installed through slow eye movements. C02 then had 3 sessions of desensitisation and reprocessing to target issues of abandonment and self-blame, after which, C02 decided that she wanted to revert to her previous way of working with CP02.	referral to the service. Her mother attended all sessions with her. Her first session involved a thorough assessment and resource development, including progressive muscle relaxation. The second session incorporated a brief taster session of EMDR to install a safe place using tactile BLS. A further session focused on C03 returning to her flat, as that was what she found most distressing – C03 was very distressed and anxious about being alone in her flat and thought that people were watching her and waiting to take advantage of her. Tactile BLS was used to desensitise and reduce the anxiety around thoughts of moving back to her flat and being alone in her flat and a future template of a successful move back to her flat was installed. After this session, CP03 was no longer able use EMDR with C03 as she had an unsuccessful trial at moving back to her flat, which had been arranged by her mother and support workers. C03 had become very distressed and presented in clinic as very tearful and upset. CP03 therefore felt it was not appropriate to attempt any further EMDR until C03 was more stable and instead focused on de-arousal and helping C03 to feel safe. Subsequently, C03 wanted to continue with this way of working and declined to engage further in EMDR.

Clinical Psychologists (CP)			
Interview length (minutes)	63	42	38
Timing of interview (months after final EMDR session)	4	3	24 (case discussed and notes recorded at time of EMDR and 5 months afterwards)
Experience	An experienced clinical ID psychologist, specialised in trauma work. She had received accredited training in EMDR, adult protocol, but had no prior experience of EMDR before the study. At the time of the interview, CP01 had used EMDR with C01 only, but was preparing to introduce EMDR to another client.	An experienced clinical ID psychologist, working as part of the forensic team. She had received accredited training in EMDR, adult protocol, but had no prior experience of EMDR before the study. At the time of interview, CP02 had used EMDR with C02 only.	An experienced clinical ID psychologist. She had received accredited training in EMDR, adult protocol, but had no prior experience of EMDR before the study. CP03 had used EMDR with C03 and one other client. Neither had progressed onto reprocessing memories.
Key Supporter (KS)			
Interview length (minutes)	36	-	-
Timing of interview (months after final EMDR session)	3	-	-
Experience	Operations Manager at the day centre the client attended on a regular basis. She had known C01 for a number of years.	-	-