

Stepping Stones: EMDR Treatment of Individuals With Intellectual and Developmental Disabilities and Challenging Behavior

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Trauma and its ensuing accommodations, including challenging behaviors, have been a growing consideration for practitioners working with people with intellectual and developmental disabilities (IDD). Recognizing the importance of one's client's trauma history, practitioners are seeking effective methods of providing therapy to IDD clients with posttraumatic stress disorder (PTSD) and other trauma-related diagnoses. In this exploratory study, using a multiple single case study design, six individuals with IDD and known trauma histories were treated with eye movement desensitization and reprocessing (EMDR). The researchers employed the standard EMDR protocol, adapting it when necessary to accommodate the needs of each participant. Outcomes provide preliminary evidence that EMDR may be an effective method of trauma treatment for clients with intellectual abilities, pointing to EMDR as a treatment with potential for facilitating healing from trauma with IDD clients.

Keywords: intellectual and developmental disabilities; autism; PTSD; EMDR; trauma treatment

Practitioners have been seeking more effective means to support clients with intellectual and developmental disabilities (IDD) and to replace challenging behavior with more effective coping strategies. Challenging behaviors in the context of this article refer to behaviors that interfere with the client's ability to interact successfully with their physical and social environment, and to live a fulfilling life. Examples of challenging behaviors include verbal and physical aggression, self-abuse, property destruction, and inability to participate in positive social interactions.

The authors of this paper recognize that many people with IDD have trauma as a significant root cause of their challenging behavior, but lack an effective means to recover from the underlying trauma. This article presents six case studies exemplifying how eye movement desensitization and reprocessing (EMDR) therapy can be adapted to meet the needs of individuals with IDD, to help them heal from traumatic experiences and overcome their challenging behaviors.

Results indicate that using adaptations to the EMDR protocol makes the treatment model more effective with people with IDD and challenging behavior. These findings have implications for practitioners from multiple disciplines seeking to support clients who have experienced trauma and who have IDD.

Overview

Until recent times those with the dual diagnosis of IDD and mental health issues were deemed inappropriate candidates for counseling or psychotherapy (Prout & Nowak-Drabik, 2003, p. 82). The concept of IDD has evolved from a focus on IQ scores and the related inference of limitations in global function to a conceptualization that recognizes that individuals with IDD have a wide range of abilities that are not adequately or appropriately represented by typical assessment scales. Traditional markers such as verbal skills and academic skills are not necessarily indicative of the psychosocial or overall intellectual capacities of the person.

In the absence of this expanded conceptualization of IDD, challenging behaviors and emotional displays generated by mental illness, grief, or trauma were often written off as part of the intellectual/developmental disability, in what has been referred to as diagnostic overshadowing (Lowry, 1998). Emerging evidence, experience, and increasing compassion are changing this explanation for challenging behavior. Counseling and psychotherapy have been shown to be “feasible and successful” (Fletcher, 1993, p. 328; Seubert, 1999) with this population. Particularly effective are approaches that utilize and integrate concrete, experiential, and behavioral aspects of treatment (Mevisen & de Jongh, 2010).

In the authors’ experience most individuals with IDD and challenging behaviors had received many years of behavior management and psychiatric medications as sole forms of therapy. Sedation has usually been the medication treatment of choice, even when it does not have an impact on the challenging behaviors (Mikkelsen, 2007, p. 122). Results improved when medications matched an accurate syndrome-based diagnosis (Mikkelsen, 2007). Yet challenging behaviors are not resolved and many people continue to evince highly challenging behaviors, including self-abuse, aggression, rageful outbursts, and property destruction. Further assessment using biographical timelines indicated prolonged disturbing life events and severe traumatic experiences. These traumatic experiences were assessed to be the root cause of the challenging behaviors (Cope, Markovitz, & Phillips, 2001).

Protocols for trauma-informed support were developed and implemented as a result. Good results were achieved over time for many people using the six-point protocol recommended by Ruth Ryan and her colleagues (Ryan, 1994). This treatment protocol involves;

1. Treating any accompanying mental health issues
2. Addressing medical problems
3. Minimizing harm due to treatment interventions, such as restrictive procedures
4. Transforming the person’s support system
5. Educating everyone in the person’s environment to understand the nature of the person’s condition and to reduce triggers
6. Use of counseling or psychotherapy.

While the teams mobilized on the behalf of the person being supported were able to quickly address the first five points in the protocol, it was very difficult finding therapists who would address the sixth point, using a trauma-informed therapy with this population. Even after the need for and validity of

psychotherapy for this population had been established, the issue of trauma treatment was still being neglected (Focht-New, 2004; Tomasulo & Razza, 2007).

Part of the reason for this seems to be a bias in favor of behavior management and solution-focused therapy. Of course, if a simple solution to a person’s dysfunctional challenging behavior can be successful, then why make treatment any more difficult or drawn out? This behavior/solution focus, while often effective, is at times insufficient in the case of trauma resolution, particularly when the trauma history is a complex one (Focht-New, Barol, Clements, Faulkner, M., & Service, 2008; Focht-New, Clements, Barol, Service, & Faulkner, 2008). There are other reasons for the neglect of implementing trauma treatment approaches. Both the staff and the person with IDD may share the common attitude of “Why bring up old issues? Why rock the boat?” This way of thinking assumes a lack of connection between past events (“It’s over and done with”) and present challenging behaviors, thoughts, and feelings. Even when a person with IDD recognizes the influence of past events on present behavior, s/he might lack the confidence that s/he would be able to handle the pain of revisiting the trauma.

Therapists have also played a role in overlooking the need for trauma treatment, particularly with clients with IDD. In general, there is a lack of training among therapists in trauma treatment. More specifically, therapists working with people with IDD are even less inclined to approach trauma, not only because of a lack of therapeutic familiarity with trauma treatment paradigms, but even more so due to a lack of confidence in the feasibility of trauma treatment with people in this population.

Consequently, in order to better meet the therapeutic needs of clients with IDD and a trauma history, the authors have expanded the last point of Ryan’s approach by introducing a trauma-informed perspective and EMDR as the treatment protocol.

EMDR

Faced by the resistance as well as the dearth of evidence in effective trauma treatment for people with IDD (Mevisen & de Jongh, 2010) we decided to explore the use of EMDR as a trauma treatment for people with IDD (Seubert, 2005). We thought that this might be a particularly important treatment choice since many people with IDD do not have the awareness or the communication skills to identify the source of their posttraumatic reactions, making it difficult to participate in routine psychotherapy

(Bedard, Burke, & Ludwig, 1998). Being able to articulate the source of the trauma is not a prerequisite of EMDR therapy.

EMDR is a physiologically based phase model of trauma treatment that integrates aspects of cognitive, Gestalt, client-centered, body-oriented, psychodynamic, and behavioral therapies. It employs bilateral stimulation (BLS) and encourages free association during the processing phase of treatment. EMDR uses standardized protocols and procedures to desensitize or neutralize the effects of painful experience so that clients can learn new lessons from those events.

Numerous research articles have established EMDR's efficacy (e.g., Mevissen & de Jongh, 2010; Seidler & Wagner, 2006). The American Psychological Association, the American Psychiatric Association, the Department of Veteran Affairs, the International Society for the Study of Traumatic Stress, and the International Society for the Study of Dissociation have also recognized EMDR as an effective treatment modality for trauma and posttraumatic stress disorder (PTSD).

EMDR posits that dysfunctionally stored, that is, unprocessed, past experiences when activated or "triggered" cause us to react (think, feel, behave) in the present as we would have at the time of the trauma (Shapiro, 2001). In a word, the painful events are buried, but "buried alive," and continue to influence our lives until they are desensitized and until we learn the necessary lessons from them. In EMDR, this desensitization is accomplished by means of a BLS of the brain either through horizontal eye movements (as in rapid eye movement sleep) or alternating bilateral auditory or tactile stimulation. Bergmann (2008) has posited that the bilateral influence jump-starts the brain's natural ability to access, move, and resolve material typically stored in a "mute" part of the brain that does not deal with words or concepts. This would explain not only the inadequacy of purely verbal approaches to trauma treatment, but also suggests an advantage in using EMDR with clients with IDD who often struggle with verbal and cognitive deficits.

In this process of desensitization, the painful memory is not erased, but is linked to adaptive information and skills that the client has developed over the years (or has learned as part of therapy), but is not yet integrated with the dysfunctionally stored memory. This is why someone can *know* something was not his/her fault, but *feels* guilty. When the linkage occurs via BLS, the natural healing process takes over as the painful and negative experiences are integrated with and transformed by the adaptive resources stored in other memory networks.

Memory processing begins with the client identifying various aspects of the distressing memory (i.e., image, negative cognition about self, emotions, body disturbance) and then focusing on that while attending to BLS for a "set" of about 30 seconds. Then the client is asked to report what s/he experienced in order to keep track of her/his internal experience and to redirect the focus if needed. The client's internal experience can be emotional, cognitive, somatic, imagistic, or any combination of these four dimensions of experience. It can, at times, associate to other memories.

This process is continued until internal disturbances reach a score of 0 on the subjective units of disturbance (SUD) scale (where 0 = no disturbance and 10 = worst possible disturbance) and until adaptive and positive beliefs are rated as valid on the validity of cognition (VOC) scale, (where 1 = completely false and 7 = completely true). These two ratings reflect two of the tasks of the brain regarding painful experience: neutralizing the negative effects (desensitization) and learning new lessons (reprocessing). During processing, the therapist makes very few suggestions, intervening only when the client does not seem to be progressing, with a light redirection, a brief supportive suggestion, so that the client's own healing system can once again take over.

Current Study

The Purpose of This Study

Research findings regarding trauma treatment with clients with IDD have been limited (Mevissen & de Jongh, 2010). The purpose of this study was, first, to support the already existing studies that demonstrate/indicate the need for trauma treatment for individuals with PTSD and IDD (Focht-New et al., 2008). Secondly, this study attempted to test whether EMDR is an effective model in eliminating or reducing symptoms associated with traumatic experience and, hence, with the diagnosis of PTSD in clients with an IDD diagnosis. Finally, it is the intent of this article to suggest variations in a phase model of trauma treatment and in the EMDR protocol that would support a clinician's ability to use EMDR effectively with this population. One of the researchers in this study spent 10 years as a full-time consultant to the Pennsylvania State office responsible for services to individuals with IDD. Her role included training, technical assistance, and mentoring for staff who were struggling to support individuals with challenging behaviors in public, private, and personal home environments.

Method

This is an exploratory research study that used a multiple single case study design (Tellis, 1997). The researchers' observations were triangulated (Rubin & Babbie, 2008) by client self-reporting, caregiver observations, pre- and postevaluations, and ongoing in-session response scaling.

Participants

Participants in this study were recruited in two ways using purposive and snowball sampling. First, one of the clinicians/researchers was affiliated with a residential facility that had three individuals struggling with symptoms of PTSD. Two of these individuals were not able to articulate their trauma stories. However, the caregivers became aware of the individuals' traumatic experiences when a biographical timeline was employed to delve more deeply into their ongoing challenging behaviors. The third client from this agency requested support after an incident of abuse by a support staff person left her with an exacerbation of previous challenging behaviors.

Three additional participants were referred to the clinicians through outside sources when the availability of this study was made public by word of mouth. Each of the participants consented to be part of the study and to have their sessions videotaped, although their names and other identifying details have been changed to protect confidentiality.

Assessment Tools

In the pretreatment assessment, a biographical timeline was developed for each participant. It was used to identify areas that needed special focus, such as painful past events, issues, and missed opportunities (Barol, 2001; Focht-New et al., 2008).

Prior and following intervention, authors compiled an assessment tool to determine PTSD symptoms and/or behavioral equivalents for each of the participants. This tool was an integration of the list of 19 PTSD symptoms according to the *DSM IV* (American Psychiatric Association, 1994), 59 items from the Psychiatric Questionnaire, an adaptive checklist of psychiatric symptoms (Sovner, 1993), and a generic list of 32 possible indicators of PTSD in this population. The same checklists were administered after treatment to four of the six participants, coupled with feedback from the participants' direct support workers when possible. The study also collected data related to client self-reporting, caregiver

observations, and ongoing in-session response scores using the SUD and VOC scales.

EMDR Treatment Provision

True to a trauma-informed phase approach, each participant received psychoeducation, skills training, and resource development in preparation for trauma processing. When trauma processing was not possible, the preparation work became a goal unto itself. Sessions with several of the participants were routinely videotaped. Additionally, the researcher/clinicians kept process notes on each session.

EMDR was used with the participants by the clinicians for 6–12 sessions. Although the standard EMDR protocols and procedures were used as far as possible, modifications were made according to clients' needs and are described here.

Data Analysis

Case Descriptions

Teresa. Teresa was a 31-year-old female, living on a residential campus for people with developmental disability. Her father was 61 years old and saw Teresa from time to time. Teresa's mother died when she was 16. Teresa was very energetic, very verbal, and expressed a fear of not being heard, not being taken seriously. She was a spokesperson for an advocacy group for people with disabilities and functioned in the mild range of mental disability.

Teresa's goal was to react with more appropriate control when being criticized or corrected. Her reactivity to such experiences seemed to be rooted in past experiences of being ridiculed and made fun of by siblings and peers throughout her years of schooling, as well as being raised by a domineering mother and an anxious father.

The assessments used in Teresa's case included SUD and VOC scores, case notes from the sessions, and the three pre- and postinventories described earlier.

Teresa met with the therapist for 10 sessions of approximately 1 hour each over a period of 8 months. Infrequency of the sessions was due to the distance the therapist had to travel to be with the client, as well as holiday interruptions. Due to difficulty tracking bilaterally with eye movements, Teresa elected to use an electronic tactile-auditory system.

Teresa chose three memories to work on. These were more recent and involved staff at her facility. Since they were more pressing and preoccupied her, the decision was made to treat them first, even though there was the strong possibility that events

from childhood and adolescence laid the groundwork for her present reactions and were exacerbating current experience.

Each of the memories took two or three sessions to complete. Interesting to note, however, was the fact that even when the SUD score was at zero and the VOC for the positive, desired self-belief was at a 7, when we returned to the next session, some disturbance had returned.

This is a very unusual occurrence in EMDR treatment. Typically, once the disturbance is cleared, the positive cognition strengthened, and a body scan performed to check for disturbance, there is no return of the discomfort. For the first memory, Teresa's SUDs in the second session returned to a 2, which then cleared with more processing. The third session began with a 4 disturbance, which then resolved to zero for good.

This same pattern repeated with the next two memories, eventually, however, resolving to no disturbance permanently. One can only conjecture why this occurred. One possible reason might be the client's need to please the therapist, reporting less disturbance than she experienced. A second reason might have to do with the difficulty that clients with IDD have in generalizing learning and sustaining new learning when faced with life triggers and challenges. A final reason may be the fact that earlier, unprocessed traumatic memories might have been bleeding through to and associating with the memories being treated.

In addition to addressing this pattern of disturbance return, it was necessary to do more verbal focusing during processing (usually there is no talking during the BLS), as Teresa would easily lose focus. Additionally, an electronic audio-tactile device was used for the BLS, since following the therapist's hand visually from side to side proved too difficult. Finally, it was necessary (compared to clients without a diagnosis of IDD) to use resources that had been developed during the preparation phase more frequently. This served effectively as a means of titrating the intensity of the processing.

The following are summary notes from the last session:

"Teresa reports that she is more able now to remember that she is 'worthy' even when [staff] says something to her that seems critical. We reviewed the last processed event, and disturbance was still at 'absolute zero'. We practiced the use of mind/body skills to remain in the present moment in anxiety provoking situations (skill rehearsal). Teresa demonstrated an outstanding comprehension of where her sense of worthiness must originate."

James. At the time of his referral, James was a 28-year-old Caucasian male with mental disability (mild range) who had been sexually abused a year prior by a female staff person. Although the staff person was reported and disciplined, no further prosecution occurred. James would occasionally see her in public, an event that became a powerful trigger for him subsequent to the abuse. The abuse involved threats with scissors and a knife, culminating in intercourse. The experience was both frightening, as well as arousing for James, as he had had no previous sexual experience and no sexual education, having been raised in a conservative Christian family in which his mother was a critical and dominant presence.

James was also diagnosed with Tourette's syndrome and bipolar disorder. He presented with some anxiety, and wanted to rid himself of the PTSD symptoms that had plagued him for the past year. These symptoms included, but were not limited to, flashbacks, nightmares, anger outbursts, avoidant behaviors, frequent startle responses, sexual obsession, and self-hitting. James also experienced periods of acute fearfulness, lack of focus, loss of ability to enjoy activities, sadness, and bouts of crying.

James was verbal, able to read, and was involved in several forms of part-time and volunteer work. He also brought with him a history of being personable, kind, and easy to get along with. Much of that had deteriorated since the abuse. Prior to the abuse events that brought him into therapy, James had experienced a number of painful events. These included head injuries, frightening medical treatment, being laughed at by teachers, and teased by peers.

To provide the therapist with any necessary updates, as well as to provide James with a sense of safety, either James's father or primary therapist was present for all sessions. Sessions continued for about 8 months. There were 12 sessions in all, averaging approximately 2 hours each. Several sessions were devoted to strengthening awareness, self-soothing, and affect management skills. Internal, as well as external, resources and supports were developed to enable James to navigate his way successfully through the various memories we chose to process.

In order for James to use the SUDs scale to rate disturbance and the VoC scale to determine the truthfulness of positive cognitions, the therapist needed to write them out and point to the relevant numbers. It was also important for the therapist to be more verbally involved during processing in order to keep James focused and on task.

The trauma processing phase began with childhood memories that disempowered and shamed

him. These were chosen since the evaluation phase revealed issues of safety/loss of power and unwarranted responsibility/shame. They then proceeded to the memory of being intimidated into sexual contact and intercourse with a female staff person. The idea of dealing with the entire memory, as well as associated events, immediately proved to be overwhelming. The primary abuse experience was, therefore, mapped out or titrated into ten sub-events. These were drawn out on paper in the form of a puzzle with 10 pieces.

The standard EMDR protocol was employed to desensitize each segment of the memory. Minor adaptations were made to compensate for James's short attention span and his inability to multitask. More verbal encouragement on the therapist's part was required during processing, as well as the continual repetition of directives when James was asked to hold both the memory and positive cognition in his awareness, while checking for the VoC of the cognition and, finally, scanning for body disturbance while focusing on VoC and cognition.

At the beginning of treatment, James and his parents jointly reported in the affirmative to 14 items of the 19 items on the PTSD checklist, 30 items on the 59-item Psychiatric Questionnaire, and 8 out of 32 items on the Behavioral Symptoms Cross Reference List. At the end of treatment, they reported affirmatively to only 2 items from the PTSD checklist, 9 from the Psychiatric Questionnaire, and 0 from the Behavioral Cross Reference List. The posttreatment items that were still troublesome had to do with one of two things. He had ongoing conflict with his conservative mother, who could not control the fact that her son's sexuality and sexual interests had been awakened. He was sometimes triggered by current situations that reminded him of the abuse. These needed to be treated as well as the precipitating abuse memory; treatment of current triggers is a part of the EMDR standard protocol.

Despite the presence of parental conflict and triggers, James reported no disturbance regarding the abuse itself after a 3- and 6-month telephone review. Specifically, he no longer experienced nightmares, flashbacks, or intrusive feelings and thoughts related to the abuse. Hypervigilance and startle reflex behaviors disappeared, and he ceased avoiding women and places/objects that reminded him of the trauma. Sleep patterns and his ability to concentrate returned to normal, and his tendency to emotionally overeat and to self-injure ceased as well. Prior to EMDR, James cried easily and experienced frequent periods of excessive fear and sadness during the year

following the abuse. After EMDR, these reactions were eliminated, as well as his preoccupation with death and suicide.

Tom. Tom was 20 years old when referred to the treatment program. He was diagnosed with autism and displayed artistic and musical capacities, but had limitations with interpersonal exchange and struggled with angry outbursts, particularly when his routine was disrupted or when disappointed. Managing and reducing his angry behaviors was a primary goal of the treatment.

It became evident that Tom would not be capable of processing past events, since his focus was exclusively in the present and on immediate concerns. The therapist's attention was, therefore, limited to whatever was alive in Tom's awareness during any particular session.

Tom's trauma history included the death of his mother at age 12, his father's remarriage and subsequent divorce from a woman whom he came to regard as "mom," and his father's third marriage. During this last marriage, Tom attached again to his father's wife and experienced difficulties whenever she traveled away to visit her family.

Although convinced of the improbability of being able to process past losses, much less connecting them to present triggers, the therapists continued to hypothesize about the role of loss in Tom's development, in what they called "compassionate guesswork."

Tom was always accompanied by a male staff person who used a tapping form of BLS to help Tom calm down when agitated. Either tapping on Tom's knees or shoulders consistently reduced Tom's level of agitation, both in and outside of sessions. Although it was not possible to determine the reason for this effect, it was surmised that it may have been the rhythmic, single stimulus of the tapping that quieted his arousal response, allowing at times for release of deeper emotion (guilt and sadness) and grounding in the present. Early sessions continued to focus on developing skills (diaphragmatic breathing, progressive relaxation, use of music) and resources (images of supportive family and friends) to enable Tom to cope more appropriately with upsetting everyday occurrences.

Procedures in session typically involved dealing with any momentary disturbance that Tom might be experiencing, then applying BLS, almost always successfully. Halfway through the course of our treatment (approximately nine sessions in all), Tom's primary caregiver documented five incidents of anger outside session time in which BLS (tapping) and breathing were employed. Tom relaxed quickly in all situations.

Session notes from a pivotal session:

Tom entered very upset about a video game not having arrived from Amazon. When he realized that a package in the mailroom was not for him, he began to wail, then cried with great intensity. Taps were administered, Tom continued to sob, stating, "It will take forever!"

Despite focusing on the present event, I wondered if anything else, present or past, aside from autistic symptomatology, might be feeding his reactions. Logical explanations of the postal delay were of no avail. Thanks to his caregiver's knowledge of Tom's family connections, however, it was discovered that not only was Tom's father's second wife moving to Florida to battle cancer, but that his father's present wife had left on a trip to Ireland. We hypothesized that it all had to do with the frustration and the sadness of waiting, with no power to change the process.

When this was suggested to Tom, more tears followed, but quieter tears of loss and from the difficulty of waiting, rather than of anger and rage.

We suggested that some people felt lucky to have two mothers, bringing up the idea of Susan (father's present wife). He then mentioned that Susan had been away during the spring break.

Therapist asked: "Is Susan back?"

"Yes."

"Have books always come in the past?"

"Yes."

"Can you visit Florida to visit your mom?"

"Yes."

I then strengthened the three statements above by repeating them while the caregiver applied BLS.

"I'm fine," were his parting words.

Tom could finally take in simple, cognitive reality statements once the affect storm had been tapped into, managed, and allowed to pass. During the entire session, BLS was employed both to reduce affective responses (desensitization) and to reinforce the new realizations (reprocessing).

Most noteworthy was the fact that Tom previously would typically have to leave a room to reduce his reactivity. The after effects of his outbursts would often for last hours, sometimes for days. In the EMDR session described here, his reactivity and calming down period took place within half an hour. He did not need to leave the room to reduce reactivity, and there was no return of disturbance afterwards.

Kate. At the time of our sessions, Kate was 28 years old and diagnosed with autism. Her mother, Brenda, was her primary caregiver and worked closely with

the therapist. Kate received treatment over a 4-month period.

Kate's trauma history included three eye operations and multiple ear infections during the first two years of her life. There were also two difficult experiences in high school. One high school incident involved a peer, who acted out aggressively in class, triggering a "code red" alarm. This resulted in Kate's fear of going to school and a state of hyper-vigilance, which seemed to continue into the present. The other event was centered around the impact of two rigid educators (according to Kate's mother) in her senior year.

Kate's present behaviors included ongoing episodes of severe perseverative self-talk, during which she was not able to maintain any contact with a task or with other people. She also reverted to kicking other people, not only when upset emotionally (anger, jealousy, guilt, sadness), but also when excited. The kicking behavior appeared to be a release of various kinds of emotional charge.

The perseveration and kicking became the targeted goals. Given Kate's minimal communication skills, it was not possible to make any connections between Kate's history and her current behaviors, not even with her mother's input. This fact, as well as the limited time available for meetings, led us to focus on developing self-management and interpersonal skills.

BLS in the form of alternate tapping either on shoulders or knees was employed when Kate drifted into her perseverative world instead of remaining in contact. In most cases, this rhythmic and steady tactile input brought Kate back to the present moment. It also, at times, helped her de-escalate during times of emotional disturbance.

From session notes:

"Andrew (therapist) asked ...(mother) Brenda to bilaterally tap on Kate's shoulders. Kate started to respond more directly to Andrew once Brenda did the tapping for a while. It seemed to interrupt the way Kate was fixated....Other types of touch, used previously by Brenda that were meant to soothe or calm her down, but were not bilateral in nature, had not changed Kate's behavior."

The use of bilaterally recorded music often proved to have positive effects, similar to the outcomes when using tactile BLS.

In addressing the kicking behaviors, the use of storytelling in the third person was employed. A story was created that mimicked Kate's typical response when upset or excited. It concluded with a negative, hopefully aversive, ending. A second story was

then developed, using more appropriate behavioral responses and concluding positively. Both stories were developed, then told while administering BLS, the hypothesis being to neurologically link negative behavior with negative ending, positive behavior with positive ending (Greenwald, 2007). Kate was able to follow the negative story and, when asked, chose to hear a more positive version. Unfortunately, she was not able to follow the second story. Instead, she became upset, but was able to quiet down with the assistance of the bilateral music. This form of storytelling was to have continued at home with Kate's mother, but the time limitation brought EMDR work to a close.

Mark. Mark was a 22-year-old man diagnosed with autism. He was very capable intellectually; however, his anxiety, irritability, thought perseverations, and rageful outbursts kept him from reaching his goals of holding down a part-time job while in school, rock climbing, and maintaining a relationship with a girlfriend.

Mark had ongoing behavioral incidents, including screaming at peers that he found annoying, at meals, in classes and in community gatherings. He would be triggered by voice tones, invasion of his private space, or by teasing, good-natured or otherwise. He would turn red in the face, and finally force himself to leave the room. He often avoided social situations for fear of being triggered by others.

According to Mark's mother, his birthday was associated with a tragic event. Many years earlier, his father had killed himself and Mark's brother a few days before Mark's birthday. Over the course of several years, Mark was hospitalized annually for depression and suicidal ideation. These hospitalizations came at the end of winter as his birthday approached.

Mark refused to discuss, or even name this incident. He would not mention his father or his sibling and would become enraged when the topic was broached. When asked as part of the protocol for his most difficult experiences, he spoke of his sense of loss at not having had a chance to graduate from his high school and not having had the opportunity to ask a specific girl out on a date. He said that he had been building up to it for over a year, and right before he could ask her, he was transferred to another program. He had been mourning the missed opportunity for two years and said that he could not move on.

Mark agreed to start by working on being able to tolerate the presence of a particular peer. At first, Mark was resistant to any interventions. He did not make eye contact with the clinicians. He spoke with

his head down in short gruff statements. Several sessions were spent building rapport and establishing the capacity to visualize and quickly conjure up a safe space and to work on deep breathing and other self-calming techniques. He became proficient in this and seemed to warm up to the sessions. When the focus moved to working on his responses to his peer, Mark became irritable and resistant.

The therapist asked if Mark knew about the Harry Potter series. He had indeed read each of the books. She then reminded Mark of one scene where Harry the young hero had to work very hard to control his mind in order to take power away from a scary creature. He had to train himself to think of funny thoughts instead of scary thoughts in the presence of the creature. Mark could remember that, and made the association that this therapy work was like wizard training to help him develop control over his own mind. As with other resources and skills throughout the preparation phase, BLS was used to reinforce this particular image.

From that point on, Mark became a willing partner in his own healing work. He worked to overcome his resistance to the therapy and to concentrate on positive images. Mark soon reported that he no longer exploded at the dinner table or in classes. He could force himself to breathe deeply when provoked and to think of funny thoughts. He said that the peers who plagued him no longer bothered him. Upon interview, his staff confirmed these changes.

After four sessions, Mark's birthday was approaching, and Mark's annual symptoms of depression, anxiety, and suicidality reappeared. The staff and Mark's mother were concerned that he would end up in the hospital again, saying that he was behaving as he always did at the start of his cycle. The staff called one of the clinicians to the house who applied EMDR to Mark's current "concerns" only. These included a pinching feeling in his arm, fear of a mouse potentially biting him in his room, and a fear of the side effects of his medications. The connection between these presenting complaints and the underlying cause of his annual cycle was unclear, but the current symptoms were all they had to work with.

After exploring the complaints verbally and cognitively, Mark said that he still felt tense in his body and gave this tension a high SUDS score. This body tension was targeted with auditory BLS. His body then relaxed, and his SUDS score dropped to a 1. Mark had no more episodes that year, was not hospitalized, and has not been hospitalized in subsequent years. The cessation of his annual decompensation took place with no change in his treatment other than the

addition of EMDR. Mark has continued to be hospitalization-free for over 5 years.

After 8 months of semimonthly sessions with Mark, he reported that he had a girlfriend and was holding two part-time jobs. He was very proud of himself and made eye contact as he thanked the clinicians for their support.

Anthony. Anthony, age 40, was referred because of his episodes of property destruction, yelling and crying, and periods of depression. Diagnosed with bipolar disorder as well as a moderate intellectual disability, Anthony was seen as emotionally fragile and impulsive. His bipolar illness was being managed with effective medications, yet his emotional struggles continued. Anthony had received behavioral therapy and sexuality counseling for many years, and while he thought positively of his therapists, he and his caregivers did not see any improvement in his emotional state.

Anthony had endured many traumatic events during his life. He was in nine foster homes before he was 4 years old, and then institutionalized. Anthony would stand at the entrance of the facility and beg everyone who came in the door to take him home with them. When Anthony was nine years old, two support staff developed a relationship with him, took him home to live with them, and eventually adopted him.

Ever since that time Anthony feared being institutionalized. When anyone mentioned an institution in any context, he would blanch, grow wide-eyed, and panic. He would repeat, "Don't send me there; I am not going back."

Additionally, he had many subsequent traumatic incidents involving the death of relatives, abusive and unfair treatment by staff, as well as recent adoptive parent illnesses that threatened his stability. At the onset of treatment, Anthony was living in a two-person group home and was very unhappy there, but was feeling stuck. Staff was frustrated with him because, despite his intellectual ability to differentiate between appropriate and inappropriate behaviors, Anthony was not able to contain his challenging behaviors.

Anthony created a list of his worst experiences. Weekly sessions started with the lesser traumas first. Anthony identified intense anger with staff who bossed him around and intruded on his privacy in his room. Using auditory and tactile BLS, he was able to completely release his feelings of anger when he thought of the incident. In subsequent sessions, he reported a continued absence of any anger when asked to think of the incident.

Anthony responded very quickly to EMDR with minimal protocol variations with the exception of

the need for more suggestive and active interventions by the practitioner. Although possessing a very good receptive vocabulary, Anthony would occasionally search for words to identify feelings. The practitioner would suggest possible feeling words, and Anthony would agree or disagree, repeating the words that he felt described his feelings.

At the therapist's suggestion, Anthony agreed to work on the more severe trauma of discovering that his biological mother had been found dead under a bridge. He had not been told until after the funeral. Staff had tried to help him mourn his loss, but for 10 years he remained fixated on his mother's death and angry with his sister for not notifying him sooner. During the session, it became apparent that Anthony believed that he could have saved his mother if he had known earlier. Consequently, he held the negative belief that he was a bad son. These issues were dealt with using the EMDR protocol, and Anthony was able to resolve any negative disturbance about the incident. He replaced the negative belief with a more positive belief that he had been a good son and had done his best. Upon further assessment, over the course of the last 5 years, Anthony reported that his symptom relief maintained. Subsequent sessions focused on reducing and eventually eliminating his fear of being institutionalized. After several sessions, these fears disappeared.

As part of the weekly check-in, Anthony was asked to describe how he felt, how his week had been, and to describe any changes he had experienced. He was very excited about his progress and able to articulate his relief of symptoms. When asked what he thought was the most helpful aspect of the treatment, he said, while moving his hands, "Right, Left, Right, Left," indicating the use of the BLS.

His previously identified challenging behaviors have disappeared. He has been living very successfully in a less restrictive alternative living arrangement, and has been holding a job in the community for several years. He has been cited as a model employee both by his employer and by his job coach. When asked how he is doing, Anthony replies, "Very, very, very good!"

Results

A summary of the types of client abilities, interventions, and results can be found in Table 1.

James no longer qualified for the diagnosis of PTSD after treatment. The emotional and behavioral symptoms assumed to be related to his abuse ceased with few exceptions. He was then able to return to former

TABLE 1. Table of the Types of Intervention/Abilities/Results

Name	Verbal Communication Abilities	Diagnoses	Direct Work on Primary Traumatic Event?		Tools Employed	Results
			Yes	No		
Teresa	Very articulate, mild perseveration. Able to communicate thoughts and feelings.	IDD mild range, autism, anxiety disorder	Yes		BLS, EMDR, visualization	Client able to desensitize several memories to completion. Required more revisiting of memories to ensure maintenance of results. Client and caregivers reported some generalization to daily events.
James	Very articulate, able to communicate thoughts and feelings.	IDD mild range, Tourette syndrome, bipolar disorder	Yes		BLS, EMDR, visualization, drawing to render treatment plan and concepts more concrete	Client and parents reported absence of pretreatment symptoms related to sexual abuse at end of treatment, as well as at 3- and 6-month follow-up.
Tom	Minimally articulate when focused, not a reliable respondent. Great deal of perseveration.	IDD moderate range, autism	No		Drawing, breathing, BLS “as needed” in session and at home, imagery/mental movies	Useful in self-calming. Occasionally would facilitate a more focused verbal response. Caregiver reported success in between sessions when using BLS to calm the client. Client could only work on what was active during the session (memory work was not possible). Client successfully resolved an explosive situation in less than a half hour with no postsession reactivity with the use of BLS “as needed.”
Kate	Not articulate. Not able to reflect feelings verbally or appear to focus directly on conversation. Constant muttering to self.	IDD severe range, autism, bipolar disorder	No		Breathing exercises, BLS “as needed” in session and at home	While there was no way to measure change in the impact of trauma, caregivers reported that when they used BLS they were able to lessen episodes of screaming and agitation, help her to go to sleep or return to sleep, and that she typically seemed more focused during the use of BLS.
Michael	Very articulate, able to reflect feelings verbally.	IDD mild range, autism, bipolar disorder	No, worked on lesser issues		Visualization, auditory EMDR, BLS Metaphor	Client able to desensitize several memories to completion. Client and caregivers reported good generalization to daily events. Mental illness symptoms largely diminished.
Anthony	Very articulate, able to reflect feelings verbally.	IDD moderate–mild, cerebral palsy—mild, bipolar illness	Yes, addressed each of his issues directly		Visualization, EMDR, BLS Metaphor	Client able to desensitize several memories to completion. Client and caregivers reported considerable generalization to daily events. Symptoms of anxiety and depression largely diminished.

Note. BLS = bilateral stimulation to reinforce positive experience and resources; EMDR = BLS applied to traumatic memory. BLS “as needed” = bilateral stimulation applied to reduce presently experienced affective disturbance without utilizing the full EMDR protocol.

activities and public places that he had enjoyed prior to the abuse.

Theresa's results were not as clear-cut, partially due to inconsistent data reporting from staff and the lack of time to process past, significant events. The data that was gathered (see appendix), however, did show a reduction in intrusive recollections and nightmares, as well as in avoidant behaviors involving persons, places, and activities. Sleep improved, although Theresa still experienced some sleep disturbance and occasionally pulled her hair when she became anxious.

It is important to note that in selecting target memories to process, the authors focused on recent and current events and relationships, since these had most relevance for Theresa. Unfortunately, there was not time enough to also attend to earlier life experiences that were assumed to be reinforcing her current reactivity.

Observable and reportable results with both Kate and Tom were limited to present moment experiences. Given the severity of their autism, they were not able to focus on or make connections to past events. Consequently, BLS was applied whenever Kate or Tom became distraught, anxious, or angry. Interestingly, whether in session or in their daily environment, the BLS had a significant calming effect, whether the disturbance was due to an immediate frustration, as with Tom not receiving his package in the mail, or with Kate when she became inexplicably upset.

In Tom's case, the authors also employed the assistance of Tom's primary caregiver, who was able to provide current information about his client's family relationships. Verbal interactions and directives were interspersed with the BLS, resulting in a resolution of Tom's frustration and anger in a fraction of the time it would typically have taken. Importantly, there was no recurrence of his outburst after the session.

Michael responded to the EMDR protocol once a metaphor was found to give him frame of reference that helped him engage in the effort it took to work with the therapists. Considering his struggle during the session as comparable to wizard training in "Harry Potter" helped him to tolerate the processing despite his discomfort. Although Michael did not directly work on what the therapists presumed to be his primary trauma, namely the murder/suicide by his father, he took on several other traumas and challenges that he identified. Post treatment he continued to be PTSD symptom free.

Anthony moved very quickly in his recovery. He was able to work on issues in his distant past as well

as current stressors during sessions. BLS was highly calming for him, and he looked forward to that aspect of the therapy. At the end of treatment he said that he thought he would come back for more "right-left-right-left" if he was ever upset again. After 5 years he continues to do well, and has not requested follow-up therapy.

Discussion

Effects When EMDR Used for Processing

Continuous in-session assessment, conversations with caregivers, and, when available, pre- and postchecklists indicated a reduction in or elimination of pretreatment symptoms. This is particularly clear in James's case, in which pretreatment experiences (flashbacks, nightmares, triggers) and behaviors (sleep disturbance, irritability, anger outbursts, hypervigilance) were either completely eradicated or minimized to near extinction.

Although Theresa was not able to generalize the effects of the targeted memories to other memories and situations, she and her caregivers reported the cessation of disturbance with regard to the specific memories and the staff persons involved in those memories. With both clients, given the fact that no other treatment was delivered during the time of this project, there is a strong indication that EMDR was a significant factor in restoring affective and cognitive equilibrium, as well as improving the clients' sense of self. This latter, positive shift in self-experience, as reported by both clients and staff, point to the potential for change on a core level in clients with ID.

James had originally presented with reticence, poor self-image, depression, and explosive behaviors. At the end of his last session, knowing that the author/therapist would be using project material to teach other therapists, he looked directly at his therapist and said, "If you ever need help in your trainings, just ask me. I can help; I can talk..." James' self-image had come a long way.

Both Anthony and Mark were able to clear disturbances from their past. They reported changes in their self-experience. They were able to verbalize their pride in their accomplishments in being able to handle formerly stressful and provocative situations without responding inappropriately. Each had doubted their ability to assume and maintain employment prior to treatment, and had gained and maintained employment subsequent to EMDR therapy. Each had also proceeded during the subsequent year to move into less restrictive living arrangements with

maintained improvement in their lives at the time of this writing.

Discussion of Effects When EMDR Used for Dearousal

In some cases, the greater the intellectual disability and the more severe the coexisting diagnoses, particularly in the autism spectrum, the less the positive effects in session seemed to generalize to daily living and to other areas of experience. This is possibly due to the impaired ability to generalize learning, common to some clients with IDD. However, when caregivers applied BLS during times of irritability or heightened arousal in between sessions, there was significant calming and deepening of focus reported.

Typically, the EMDR approach includes processing of past, present, and future events. With Tom and Kate, for example, the authors were limited to a present focus. As mentioned earlier, the application of BLS in an “as needed” fashion almost without fail led to a reduction in affective disturbance and physiological distress. Additionally, there was often an increase in the ability to focus on present tasks, rather than being lost in a fantasy world (particularly with Tom) or in perseverative thought/speech (as with Kate).

Consistent success with the “as needed” use of BLS was reported outside of sessions by caregivers. Reasons for this can only be hypothesized at this point, but it may well involve an impact on brain functioning by the rhythmic and single sensory input that BLS, delivered in the form of tapping, provides. It should also be noted that the person doing the tapping was always a close and trusted caregiver, and that the physical tapping seemed to provide a soothing element, as well as a connection to present reality.

It was also noted that clients were able to tolerate various session lengths ranging from 20 minutes to an hour and a half. Again, the greater the disability, the more compromised the attention span and ability to focus.

Modifications to the Protocol

Whenever possible, particularly with James and Theresa, the full EMDR protocol was employed. The first two phases of (1) client history and treatment planning and (2) preparation required expansion. With regard to James, for example, target selection in Phase I appeared to be straight forward, given the fact that there was a single traumatic event that James wanted to heal. Yet, the trauma-informed perspective of EMDR led the authors to take into account

and treat previous experiences, particularly those involving his disabilities, which made James more vulnerable to the negative belief that “I’m powerless” and “There’s something wrong with me.” The single abusive event needed to be approached as existing within a larger context of trauma.

Additionally, with all clients, a greater amount of time than is usual was invested in the preparation phase. Resources and skills developed during this phase enabled James, in particular, to stabilize, re-group, and continue processing whenever his emotional storms seemed overwhelming to him. Again, this seems to highlight the need for a trauma-informed phase model, as contained within the EMDR protocol.

More specifically, a review of the case studies identified a number of tasks specific to the ID population, as well as adaptations to the EMDR protocol.

As mentioned earlier, a greater amount of time was required to develop therapeutic rapport and to gather sufficient history from the client, his/her family, and support network (Phase I). The biographical timeline as described by Barol (2001) was utilized to ensure thorough history taking. More preparation time was needed for development of self- and other- awareness, affect awareness and management, self-soothing skills, focusing skills to interrupt perseverative thinking, psychosocial skills, and the development of internal as well as external resources. More attention was also given to the education and support of the client’s family and direct care staff, this due to the interdependency with caregiver systems found in ID clients.

During processing of painful events, standard EMDR procedures call for the therapist to “stay out of the way” of the client’s innate healing system. With this population, more directive intervention during the course of processing was required in a number of areas, including:

- a. More frequent checking on the internal status of the client’s level of disturbance (SUDs level)
- b. More frequently directing client from dysfunctional material to positive resources (a form of titrating intense material described as “pendulating” by Peter Levine, 1997)
- c. Titrating of the painful event by breaking the memory into smaller, more manageable parts, and the use of intentional distancing
- d. Greater verbal involvement of the therapist during trauma processing to help client maintain focus and provide encouragement

Other adaptations were employed to compensate for cognitive deficits. The SUDs and VoC scales, for

example, often needed to be written out or communicated by means of physical gestures in order to make them more concrete and, hence, understandable. At other times, the scale itself had to be modified to achieve comprehension. Furthermore, the language of the negative and positive cognitions often needed to be adapted to achieve congruency with the developmental age of the client. Occasionally, the use of even simplified abstract words and concepts was unsuccessful. In these situations, an image was used to represent and express a cognition.

Given the general difficulty among clients with IDD in generalizing learning from one part of a memory to another and from one event to another, it became necessary to devise a way of checking the outcome of the memory processing. To this end, the authors employed the “recent events protocol” (Shapiro, 2001, pp. 224–227) by asking the client to imagine a sequential “movie” of the traumatic event, to check for any overlooked disturbance.

In the case of greater disability and the presence of autism, as with Tom and Kate, focusing on the immediate present and what the client brought to the session was necessary. In other words, target selection was limited to here-and-now experience, given their inability to relate to the past as past. Finally, it was found that processing emotional and somatic material, even when the client was unable to relate cognitive/narrative content, proved to be very useful. This was clearly the case during Tom’s session, in which he was greatly upset about a number of relational events that he was unaware of. It was the processing of the intense affect that cleared the way for eventual, more conscious understanding. Even in the overall absence of any cognitive content, as was often the case with Kate, processing and soothing the emotional disturbance itself consistently provided relief.

Keeping in mind the first rule of any treatment modality, which is to do no harm, it should be noted that in all of the cases there was not a single report of adverse effects, either during or after treatment. Even when a pause in the processing was required due to affective intensity, clients were able to manage their reactions with the skills and resources learned during the preparation phase.

Limitations and Recommendations for Future Research

This study is limited by the fact that it was an exploratory study relying on case studies of six clients. We were not able to control other variables in the environment that might have contributed to the clients’

improvement. As a result, we cannot conclude definitively that the use of EMDR and BLS was the cause of the change in their affect and behavior. However, the change in each person with the application of EMDR and BLS after many other approaches have been tried with poor results, plus the ability of several of the clients to attribute their symptom relief to their experience of EMDR, suggests a causal relationship that merits future study.

Future research should be designed to address the following research questions: (1) Does EMDR without adaptation work with people with IDD? (2) Is there an advantage to using adaptations to the EMDR protocol with this population? (3) Does BLS alone provide short-term symptom relief? (4) Does BLS alone provide long-term symptom relief? (5) What additional effects do EMDR and BLS have on people with IDD (i.e., does BLS help some people with Autism focus and communicate better as we saw with two clients in the study)?

Research using an experimental or quasi-experimental design to test the use of the EMDR protocol using the adaptations authors suggest would be very appropriate.

Timely and thorough data collection proved to be an ongoing problem when relying on caregivers. The researchers/therapists had to rely more on in-session notes and client reports than a steady informed data set from caregivers. We would therefore recommend training the caregivers to be better informants and to keep charts more rigorously. Data collection could be improved by offering an incentive. Random sampling, control groups, and having researchers unaffiliated with the delivery of the therapy would be strengths associated with the more rigorous research design.

Conclusion

In conclusion, the experiences of this project provide preliminary evidence that EMDR can be an effective method of trauma treatment for clients with intellectual disabilities. Depending on the level of disability, the entire EMDR protocol or an adapted form of it can provide relief for clients who are so vulnerable to harm and abuse.

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