Assessment and Treatment of PTSD in People with Intellectual Disabilities

17

Liesbeth Mevissen, Robert Didden, and Ad de Jongh

Contents

Introduction 282
Assessment of PTSD in People with ID 284
Anxiety Disorders Interview Schedule-Children Intellectual Disabilities, PTSD Section (ADIS-C-IDs PTSD Section) 284
Lancaster and Northgate Trauma Scales (LANTS) 285
Impact of Event Scale-Intellectual Disabilities (IES-IDs) 285
Treatment of PTSD in People with ID 286
Cognitive Behavioral Therapy 286
EMDR Therapy 289
Conclusion 296
Summary Points 297
References 297

Abstract

People with intellectual disabilities (ID) are more often exposed to potentially traumatic events than people without ID. Due to impairments in their cognitive and adaptive skills, processing adverse life events is supposed to be more

L. Mevissen (✉)
Mental Health Organization (MHO) GGZ Friesland, Department De Swaai Youth, Center for Intellectual Disability and Psychiatry, Drachten, The Netherlands
e-mail: lmevissen@gmail.com; liesbeth.mevissen@ggzfriesland.nl

R. Didden
Behavioural Science Institute, Radboud University Nijmegen, Nijmegen, The Netherlands
e-mail: r.didden@pwo.ru.nl

A. de Jongh
Department of Behavioral Sciences, Academic Centre for Dentistry Amsterdam (ACTA), University of Amsterdam and VU University Amsterdam, Amsterdam, The Netherlands

School of Health Sciences, Salford University, Manchester, UK
e-mail: a.de.jongh@acta.nl

C.R. Martin et al. (eds.), *Comprehensive Guide to Post-Traumatic Stress Disorders*,
DOI 10.1007/978-3-319-08359-9_95

difficult. This chapter contains an overview of the literature on the (1) manifestations and assessment of post-traumatic stress disorder (PTSD) in people with ID and (2) treatment (i.e., trauma-focused cognitive behavioral therapy [TF-CBT] and eye movement desensitization and reprocessing [EMDR] therapy) of PTSD symptoms in people with ID. There is evidence to suggest that manifestations of PTSD in children with ID correspond with those in children without ID. To assess the effects of psychological trauma in children and to establish the diagnosis of PTSD, the Adapted ADIS-C PTSD Section appears to be a valid and reliable clinical interview. To determine the severity of PTSD symptoms in adults, two questionnaires with good psychometric properties are available (i.e., LANTS; IES-IDs). TF-CBT and EMDR therapy are the only psychotherapies recommended by the World Health Organization (WHO) for the treatment of PTSD. However, the literature on the treatment of manifestations of PTSD in people with ID is limited to case reports showing positive outcomes. For persons with ID suffering from PTSD, EMDR therapy seems most suited, particularly considering its nonverbal character and the lack of need to do homework and practice outside the sessions. Controlled studies are needed to establish empirical support for PTSD treatments in this population at risk for the development of PTSD.

List of Abbreviations

AAIDD	American Association on Intellectual and Developmental Disability
ADIS-C	Anxiety disorder interview scale- children
ASD	Autism spectrum disorder
CBT	Cognitive behavioral therapy (CBT)
DM-ID	Diagnostic Manual-Intellectual Disability
DSM	Diagnostic and Statistical Manual of Mental Disorders
EMDR	Eye movement desensitization and reprocessing
ID	Intellectual disability (ID)
IES	Impact of Event Scale
IES-IDs	Impact of Event Scale-Intellectual Disabilities
LANTS	Lancaster and Northgate Trauma Scales
MBID	Mild to borderline intellectual disability
PTSD	Post-traumatic stress disorder
SUDs	Subjective Units of Disturbance scale
VoC	Validity of Cognition Scale
WHO	World Health Organization

Introduction

Intellectual disability (ID) is defined by significant impairments in both intellectual (IQ) and adaptive functioning (see AAIDD; Schalock et al. 2010; DSM-5; APA 2013). ID is considered to be approximately two standard deviations or more below

the population average, which equals an IQ score of about 70 or below. Adaptive skills are impaired in the conceptual, social, and practical domain whereby individuals with ID show deficits in language, memory, reasoning, social judgment, communication skills, and self-management in areas such as personal care, money management, and school and work tasks (AAIDD; Schalock et al. 2010). Symptoms of ID begin during the individual's developmental period, and the impairments are chronic. Deficits in intellectual and adaptive functioning determine how well an individual copes with everyday tasks. The ID may be mild or more severe (IQ < 50), and the following four levels of ID are distinguished: profound, severe, moderate, and mild. Individuals with mild ID have an IQ score between 50 and 70 and show relatively mild deficits in adaptive behavior. In the literature, individuals have borderline ID if they have an IQ test score between 70 and 85 and mild deficits in adaptive skills.

Individuals with ID are susceptible to the full range of mental health problems. However, research shows that the prevalence of a psychiatric disorder in individuals with ID is approximately two to four times higher than in individuals with average intelligence, with the most common conditions being ADHD, mood disorders, anxiety disorders, conduct disorder, schizophrenia and other psychotic disorders, autism spectrum disorder, and post-traumatic stress disorder (PTSD) (Cooper et al. 2007; Fletcher et al. 2007; Einfeld et al. 2011). A range of biological, psychological, and social factors elevate the risk for psychiatric disorders in individuals with ID (Fletcher et al. 2007). Without adequate assessment and treatment, these disorders tend to persist over time. It should be noted that the symptoms of a psychiatric condition may express atypically in persons with ID relative to those without ID.

Experiencing negative life events is an important risk factor, especially for the development of PTSD (Edwards et al. 2003). Several studies in individuals with ID have shown a causal relationship between exposure to life events and anxiety, mood, and behavioral problems (see, e.g., Esbensen and Benson 2006; Wigham et al. 2014). It has been found that individuals with ID are more likely than individuals without ID to experience potentially traumatic events such as sexual and physical abuse, bereavement, and life-threatening illness or injury (Hatton and Emerson 2004; Focht-New et al. 2008). Also, the range of potentially traumatic experiences may be greater in individuals with ID compared to those without ID (Martorell and Tsakanikos 2008), and a higher level of trauma exposure is supposed to be associated with more serious mental health problems (Esbensen and Benson 2006). The ID itself may contribute to the risk of developing PTSD, and it could be argued that people with ID are more vulnerable than those without ID to the disruptive effects of life events and trauma. Early separation from parents through early institutionalization or hospital admissions, fewer previous experiences in managing negative life events successfully, and a limited availability as well as capacity for gathering social support and supportive social network may make individuals with ID particularly vulnerable for the development of PTSD (Tomasulo and Razza 2007). Moreover, starting to understand oneself as intellectually disabled may be traumatic in itself (Hollins and Sinason 2000; Levitas and Gilson 2001).

Although there is evidence to suggest that, for the aforementioned reasons, people with ID have an elevated risk of developing PTSD, very few studies have been conducted on the manifestations of PTSD and the assessment of PTSD in this population. Reliable estimates of the prevalence of PTSD are lacking for people with ID (Mevissen and de Jongh 2010). The same holds true for (the effectiveness of) treatments meant to alleviate PTSD symptoms in people with ID (Mevissen and de Jongh 2010; Wigham et al. 2011a, b). In the following sections, an overview of the literature on the assessment and treatment of PTSD in people with ID will be presented.

Assessment of PTSD in People with ID

In the Diagnostic Manual-Intellectual Disability (DM-ID; Fletcher et al. 2007), developed in association with the American Psychiatric Association, recommendations have been made for adapted PTSD symptoms concerning people with ID. These recommendations, based on clinical and anecdotic information, suggest that their PTSD symptoms are similar to those seen in children (Tomasulo and Raza 2007). However, it has been reported that in individuals with the more severe ID levels, PTSD symptoms are manifested atypically in that, for example, symptoms of reexperiencing can give the impression of the presence of a psychotic disorder (Tomasulo and Raza 2007). During the past few years, several studies have been performed to empirically investigate the effects of trauma and adverse life events in people with ID, resulting in the development of one clinical interview and two self-report instruments (also, see Table 1).

Anxiety Disorders Interview Schedule-Children Intellectual Disabilities, PTSD Section (ADIS-C-IDs PTSD Section)

Mevissen et al. (2014) developed the ADIS-C-IDs PTSD Section for the assessment of PTSD in children and adolescents (aged 6–18 years) with mild to borderline ID (MBID) and explored manifestations of PTSD in this target group. The clinical interview uses simplified language and visual cues and consists of an event section, including type A trauma events as well as life events. Events the child had been exposed to are visualized on a timeline to help the child keep in mind the events when symptoms are asked for. The symptom section consists of symptoms originating from PTSD measures that are used for children without ID, which have been extended with atypical symptoms. The child is asked to rate his or her subjective level of daily life impairment. To this end, a thermometer card is used. The ADIS-C-IDs PTSD Section is applicable and child-friendly (Mevissen et al. 2014). The results suggest that the consequences of trauma in children with MBID are similar to those in children without ID. No support was found for broadening criterion A1 for children with MBID (Mevissen et al. 2014). In another study, using both a child and caregiver version in a

Table 1 Trauma in people with ID: assessment instruments

Instrument	Aim	Target group	Psychometric properties
LANTS (Wigham et al. 2011) Self-report and informant measure	Measuring effects of stressful traumatic life events	Adults with moderate to mild ID	Good internal consistency, test-retest reliability and validity
Adapted ADIS-C PTSD Section (Mevissen et al. 2014, 2016) Semi-structured clinical interview, child and caregiver version	Diagnosing PTSD according to DSM-IV and DSM-5	Children aged 6–18 years, with mild to borderline ID (IQ 50–85)	Excellent inter-rater reliability, good content and convergent validity
IES-IDs (Hall et al. 2014) Semi-structured interview	Screening subjective stress caused by traumatic events	Adults with mild ID	Good to excellent internal consistency and test-retest reliability and good validity

larger sample of children and adolescents with ID, the ADIS-C-IDs PTSD Section was validated according to DSM-IV and DSM-5 criteria, including DSM-5 for 6 years and younger. The results yielded excellent inter-rater reliability and good content and convergent validity (Mevissen et al. 2016).

Lancaster and Northgate Trauma Scales (LANTS)

Wigham et al. (2011b) developed the LANTS which comprise a 29-item self-report and a 43-item informant measure of the effects of stressful traumatic life events on individuals with ID. In an effort to validate the LANTS, this measure was completed by 99 adults who had moderate to mild ID and 88 staff members. The results showed that the LANTS had good internal consistency and test-retest reliability and validity. Scores on the self-report version correlated significantly with those on the IES (see below) and measures of behavioral and emotional problems. Low convergence was found between the two versions of the LANTS.

Impact of Event Scale-Intellectual Disabilities (IES-IDs)

The IES (Horowitz et al. 1979) and IES-revised (Weiss and Marmar 1997) have been designed as screening self-report questionnaires indexing subjective stress caused by traumatic events. The IES corresponds with the three DSM-IV-TR PTSD symptom categories (avoidance, intrusion, and hyperarousal) and contains 22 items that are scored on a 5-point Likert-type scale. Hall et al. (2014) adapted the IES-R in terms of

wording, format, and item organization for use with individuals with mild ID which was called the IES-IDs. Each of the 22 items is scored on a 3-point Likert-type scale. Participants in Hall et al.'s study were 40 adults with mild ID who had experienced at least one traumatic event. They completed the IES-IDs and the LANTS on two occasions, separated by 2 weeks. (The instrument was used as a semi-structured interview.) Results indicated that both the IES-IDs and the LANTS had good to excellent internal consistency and test-retest reliability. Both instruments had good validity as scores on both instruments correlated with those of measures of depression and anxiety.

Treatment of PTSD in People with ID

In their review of the literature on PTSD treatment in people with ID, Mevissen and De Jongh (2010) distinguished three treatment approaches: (1) pharmacological, (2) changes in environment and personal contacts intended to eliminate frightening cues of PTSD, and (3) psychotherapy. The authors concluded that for none of these approaches empirical evidence was available in this population. Now, 6 years later, this conclusion still stands although more clinical evidence from case studies has become available.

In this section, we will provide an overview of the international literature on the two PTSD treatment methods that have been shown to be evidence-based first-line treatments for PTSD and which are recommended by the World Health Organization (World Health Organization 2013): trauma-focused cognitive behavioral therapy (CBT) and eye movement desensitization and reprocessing (EMDR) therapy.

Cognitive Behavioral Therapy

Cognitive behavioral therapy (CBT) is a psychological therapy for a wide range of psychiatric and behavioral problems, directed toward solving current problems and modifying dysfunctional thoughts and behavior (see, e.g., Taylor et al. 2013). CBT is based upon a combination of behavioral and cognitive principles and focuses on examining the relationships between thoughts, emotions, and behaviors. The core assumption of CBT is that improvements in psychological well-being can result from changes in cognitions. Individuals with mental health problems are taught to modify their patterns of thinking to improve coping. CBT is goal-directed and problem-focused, and individuals receiving CBT are expected to do homework and practice outside the sessions.

CBT has been adapted for use in individuals with mild ID and has been shown to be effective in the treatment of mood disorders, anxiety disorders, and aggression in individuals with mild ID (see Taylor et al. 2013). It should be noted, however, that findings across studies are mixed and many studies show methodological problems

(see Sturmey and Didden 2014). As far as we know, no controlled studies have been conducted on the efficacy of CBT for the treatment of symptoms of PTSD. Several case reports have appeared in which CBT techniques were used in the treatment of PTSD symptoms. For example, Lemmon and Mizes (2002) used exposure therapy (a CBT technique) in a woman with mild ID who had been a victim of sexual assault. Imaginal and in vivo exposures were combined. The authors describe her behavior in terms of DSM-IV PTSD criteria, thereby paying special attention to the specific way in which the traditional reexperiencing symptoms are presented. After 25 sessions combined with homework, she was no longer distressed when exposed to trauma-related stimuli, she no longer avoided talking about the events, and anger outbursts and hypervigilance decreased.

Stenfert Kroese and Thomas (2006) used Imagery Rehearsal Therapy (another CBT approach) in the treatment of chronic post-traumatic nightmares in two women with mild ID, both victims of sexual assault. The first case presents a woman who had been abused over a period of 10 years, and the second case involves a woman with Down's syndrome with a single sexual abuse experience. The treatment procedure, during which a "new dream" was created, is described in detail, including the modifications due to the ID. According to the authors, three sessions combined with daily homework were needed to stop the nightmares, an outcome that was maintained at 3, 4, and 6 months follow-up. In both cases, Imagery Rehearsal Therapy was part of a broader treatment program offered to the clients. In the first case, initial supportive counseling, practical problem-solving, and basic coping strategies had been used in order to treat symptoms of anxiety and depression. After treating the nightmares, psychological treatment was continued. In the case of the woman with the single trauma, the authors report a decrease of PTSD symptom severity and a sense of increased self-control after treatment of the nightmares.

Jones and Banks (2007) presented a case report of a 30-year-old man with moderate ID who was referred for the assessment and treatment of possible PTSD following a road traffic accident 5 years previously. He showed aggressive responses and was reported to awaken four to five times a night shouting and talking about the accident. The client was seen, together with his father, on five occasions (four sessions plus follow-up) in a room in a hospital clinic. Sessions lasted approximately an hour during which the client was encouraged to recall the details of the car crash from his perspective. Next to this, the sequence of events was audiotaped, and the client was encouraged to listen to the tape recording as much as possible and to tell his father about any extra memories of the accidents that were triggered by listening to the recording. Finally, in vivo exposure was used whereby the client and his father visited the crash site. The treatment package was successful, and at a 14-week follow-up, the client remained largely symptom free. For an overview of the CBT case studies, see Table 2.

At present, no conclusions can be drawn regarding the effectiveness of CBT for the treatment of symptoms of PTSD in individuals with ID. Though a small number of case reports show promising results, controlled studies are lacking.

Table 2 Cognitive behavioral treatment (CBT) of PTSD in people with ID: case reports

Authors/year	N	CBT treatment method	Age	M/F	Level of ID/comorbidity	Trauma's/life events	Results
Lemmon and Mizes (2002)	1	Exposure	32 years	F	Mild	Sexual abuse and recent frightening incidents	No longer distressed when exposed to trauma-related stimuli, no avoidance in speaking about the traumatic events, anger outbursts and hypervigilance significantly decreased
Stenfert Kroese and Thomas (2006)	2	Imagery Rehearsal Therapy	18 years	F	Mild/basic verbal capacities	Sexual, physical, and emotional abuse	Nightmares ceased, improved self-confidence
			24 years	F	Mild/basic verbal capacities Down's syndrome	Rape	Nightmares ceased
Fernando and Medlicott (2009)	1	(Education) Relaxation training Problem-solving Cognitive restructuring Exposure	24 years	F	Mild	Abusive romantic relationship and repeatedly hit with weapon and kicked	Intrusions ceased, better mood, self-care improved
Jones and Banks (2007)	1	Exposure	30 years	M	Moderate to severe	Road traffic accident	Largely symptom free (symptoms: aggressive responses, awakening four to five times a night shouting and talking about traumatic event)

EMDR Therapy

Eye movement desensitization and reprocessing (EMDR) therapy is a protocolized, eight-phase psychotherapeutic approach, developed by Shapiro (2001) and aimed to resolve symptoms resulting from disturbing and unprocessed life experiences. In Mevissen et al. (2012), the protocol has been outlined as follows, including a brief description of the eight phases, a summary of the underlying adaptive information processing theory, and a description of the necessary adjustments for applying EMDR in children without ID and in individuals with ID whereby the person's developmental age is leading:

EMDR Phase I consists of history taking and case formulation, resulting in a treatment plan. In Phase II, the client is prepared for the trauma work. Skill building and resource development might be necessary. Phase III to VII consist of the reprocessing of the traumatic memory. It begins with a focus on the traumatic memory itself by asking the client to bring up the memory and to concentrate on various aspects of it, specifically the most distressing image and the dysfunctional negative cognition of oneself in relation to the image as well as the accompanying emotions and the body disturbance that go along with it. A core feature of the procedure is the performance of eye movements (typically, the therapist moving his fingers back and forth in front of the client, asking him or her to track the movements while keeping his or her head still) while concentrating on the trauma memory. Following the image and negative cognition, access to the emotional and somatic aspects of the memory takes place. The therapist then asks the client to follow his fingers, while encouraging to "go with" whatever freely arises in his awareness. Repeatedly, the client is asked to report emotional, cognitive, somatic, and/or imagistic experiences until intern disturbances reach a SUDs (Subjective Unit of Disturbances scale) of zero and adaptive and positive beliefs are rated strong on a VoC (Validity of Cognition) scale. Phase VII is dedicated to closing down the session and preparing the client for the interim between sessions. Phase VIII consists of reevaluation and integration.

The underlying adaptive information processing theory asserts that the application of the EMDR procedure induces a physiological condition in which unprocessed memories of traumatic events become linked up with networks that already include adaptive information and skills (Shapiro 2007). Various experimental studies support this theory by showing that eye movements during recall of aversive memories reduce their vividness and emotionality (Engelhart et al. 2011). During recall, emotional memories become "labile," and their reconsolidation is affected by experiences during recall (Baddeley 1998). Recalling a traumatic memory is assumed to tax working memory capacity which is limited. If another task is executed during recall, less capacity will be available for recalling a distressing event. This makes that the memory is experienced as less vivid and emotional. Eye movements are held to serve as such a "secondary" task that taxes working memory. As in children with typical development, in persons with ID, task variations might be necessary, for instance, the therapist putting stickers on his fingers to facilitate tracking, using buzzers to vibrate alternately between the person's right and left hand, administering

alternating tones via a headphone or audio speakers placed on either side of the person, or tapping on the person's hands or knees (Adler-Tapia and Settle 2008).

Instructions as to how to activate the trauma memory, and how to support the client during the desensitization and reprocessing phase, are age-related and are adjusted to the person's developmental age, taking into account any comorbid disorders such as autism (Mevissen et al. 2011a, b). In Phase III, for example, children between a developmental age of 4 and 8 years are asked to draw the target image instead of describing it verbally. The negative and positive cognition are omitted with clients younger than five, and in Phase IV the level of distress is measured in a concrete, visual way, for example, with the use of facial images or spreading hands.

When applying EMDR to the youngest children (<3 years), the Story Telling Method (Lovett 1999) is of great use. Typically, parents or caregivers tell the story of the traumatic event which has a positive beginning, but gradually includes more distressing details as to what was seen, heard, felt (emotionally and physically), thought, or smelled. Photos, drawings, physical objects, and physical touch might be employed to engage the senses and to activate the trauma memory. The story further involves the way the person responded. The ending is always positive. The story is repeated until it evokes no stress at all according to the trusted observations (Subjective Unit of Disturbance = 0). The example of Jane, described by Mevissen et al. (2012), illustrates how EMDR therapy is applied in clinical practice (see Box 1).

Box 1. Example: EMDR Therapy

Jane is a 49-year-old woman with severe ID and Down's syndrome. She lives in a group home and visits a day care center. Jane suffers from severe sleeping problems. She screams every night around midnight. As her adaptive skills decline, she is less engaged with other people, and her physical complaints have increased. For a period of time, these complaints were thought to be due to Alzheimer's disease. Caregivers and family members eventually realized that these problems started 2 years earlier after the night Jane had been trapped with her head in between the bars of her bed and had to be rescued by a fireman.

Hypothesizing a connection between this overwhelming event and her sleep problems, Lovett's Story Telling Method was employed. A trusted caregiver and her elder sister narrated the story of being trapped in her bed, which included her subsequent hospitalization and loss of adaptive skills. EMDR was administered, using buzzers that vibrated alternately between her left and right hand as a task used to tax working memory. Because of her muscle weakness, the caregiver assisted her in holding the apparatus. During the desensitization phase, strong physical sensations in her stomach arose. Given her history of constipation, it was noted that Jane had been writhing with stomach pain the night of the mishap, a possible reason why her head became trapped in the bars of her bed.

After four sessions of EMDR, the caregiver reported that the screaming had completely stopped, and her sleeping problems disappeared. Physical complaints decreased. Her pain medication was discontinued, her muscles felt more relaxed, and

she enjoyed a more frequent cheerful mood. The caregivers also noted that Jane was now cooperative when asked to go to bed, whereas before treatment, she was typically resistant. However, a weekly episode of sadness persisted. Family and caregivers were so excited about the positive treatment results that they rejected the offer to treat the residual mood problem. At a follow-up of 7 months, the improvements maintained, and the episodes of sadness were still present. Seven months after that, Jane was again referred for treatment because she had become very tearful, was inconsolable, and could not stop talking about her mother.

Eight years earlier, her father had died, and 5 years ago her mother, with whom she had had a close relationship, died as well. Additionally, within a rather short period, two other people had died: one a family member and another the mother of one of her peers. Disturbing memories regarding the death of both parents were reprocessed. EMDR's Story Telling Method was used once again with her sister narrating the stories. Each parent's story included activities she had shared with the parent while they were still healthy, changes during the time of the parent's illness, the actual death and subsequent sense of loss, and new, positive, routines which replaced the old ones. After three EMDR sessions, the complaints disappeared as well as the remaining weekly episodes of sadness. After this processing, whenever the sadness returned, she was able to (simply) talk about her feelings and improve her mood. These results were maintained at a 6-week follow-up. Regarding her sleep disturbance, positive effects remained stable at a 15.5-month follow-up.

The first case reports on the application of eye movement desensitization and reprocessing (EMDR) in PTSD treatment in individuals with ID described two women with mild ID and visual impairments (Giltaij 2004). One was the victim of a single sexual abuse. PTSD symptoms disappeared after four sessions of EMDR treatment with results maintained at 3-months follow-up. The other woman witnessed her sister threatening their mother with two knives. Twelve EMDR sessions were used to decrease problem severity from 9 to 1, as indexed on a self-report 0–10 scale with several problem areas, including clinging to mother, initiating social contact, going out, initiating activities, having defense against parents, and sleeping problems.

Since then, the number of published EMDR case studies in the international literature has been extended by 19, of which 14 concerned adults and 5 pertained to children (Barocliff and Evans 2015; Barol and Seubert 2010; Dilly 2014; Mevissen et al. 2011a, b, 2012; Rodenburg et al. 2009), reporting positive treatment outcomes not only for individuals with mild ID but also for those with moderate ID (Barol and Seubert 2010; Mevissen et al. 2011b) and severe ID (Mevissen et al. 2012). Clients were known with various comorbidities (e.g., epilepsy, Down's syndrome, Marshall-Smith syndrome) and psychiatric disorders such as ASD, anxiety disorder, bipolar disorder, Tourette's syndrome, obsessive-compulsive disorder, and psychotic disorders. In three adults with mild to severe ID and comorbid ASD (Barol and Seubert 2010), traumatic memories could not be activated. In all other clients, markedly positive outcomes were reported such as disappearance of flashbacks and sleep disturbances; reduction of different kinds of aggressive, obsessive, and avoidance

Table 3 EMDR treatment of PTSD in people with ID: case reports

Authors/year	Age	M/F	Level of ID/comorbidity	Trauma's/life events	Results
Giltaij (2004)	Young woman	F	Mild/blind	Single sexual abuse	Complaints resolved (complaints: fears/avoidance, being dependent on caregivers, often crying, uncertain)
	16 years	F	Mild/nearly blind; epilepsy; brain damage	Witnessed mother being threatened with knives	Significant decrease of self-reported problem score (9 → 1) (complaints: fears/avoidance, sleep problems, demanding behavior)
Rodenburg et al. (2009)	18 years	M	Mild/epilepsy	Repeated physical abuse, being threatened with knife by his father, and parents divorced	Significant decrease of Impact of Event Scale score (complaints: flash backs, sleep problems, frequent nightmares, suicidal thoughts)
Barol and Seubert (2010)	31 years	F	Mild/autism, anxiety disorder	Mother died, ridiculed and made fun of by peers and siblings, and raised by a dominating mother and an anxious father	"Some generalization to daily events" (complaints: out of control when being criticized or corrected)
	28 years	M	Mild/Tourette's syndrome	Sexual abuse	Absence of pretreatment symptoms (flashbacks, nightmares, anger outbursts, avoidant behaviors, frequent startle response, sexual obsession, self hitting, and periods of acute tearfulness, lack of focus, loss of ability to enjoy activities, sadness and bouts of crying)
	40 years	M	Moderate/cerebral palsy; mild bipolar illness	Outplacement, nine foster homes before he was 4 years old, then institutionalized, death of relatives, abusive and unfair treatments by staff, and adoptive parent illness	Absence of pretreatment symptoms (episodes of property destruction, yelling and crying, and periods of depression). At follow-up, he was able to live in a less restrictive living arrangement and held a job in the community for several years

Mevissen et al. (2011a)	32 years	M	Mild	Severe scooter accident, girlfriend broke off relationship, parents divorced, accused of and treated for sexual abuse	Able to think of traumatic memories without getting upset, avoiding behavior disappeared, taking up activities, outbursts of anger decreased, physical complaints decreased. At follow-up, he had build up a stable relationship
	11 years	M	Mild	Witnessing car fire, being threatened, witnessing domestic violence, patents divorced, and outplacements	Absence of pretreatment symptoms (fears, compulsive behavior, obsessions, hearing voices, difficulties distinguishing reality and fantasy, avoiding to sleep at parental home). At follow-up, medication was successfully faded out
	53	F	Moderate-mild	Troubles at school, repeatedly witnessing domestic violence, witnessing father's death, divorced twice, mother died, emergency admission in hospital, and various surgeries	Absence of pretreatment symptoms (panic attacks, often followed by hospitalization, physical complaints when distressed, easily upset, persistent anger, nightmares, obsessive thoughts, hearing voices, avoiding places). At follow-up growing independency
	7	F	Mild/autistic disorder	Two dear family members died, suicide attempt of fathers' best friend, and serious illness of school friend	Disturbing thoughts disappeared, more often cheerful, significant decrease of anger outbursts, more relaxed
Mevissen et al. (2011b)	Young woman	F	Moderate/symptoms of autism	Sexual abuse by two perpetrators	Absence of pretreatment symptoms (restless, sleep problems, often tearful, aggressive outbursts, obsessive behavior, deteriorated personal hygiene, demanding of her mother)
	Middle-aged man	M	Moderate	Death of mother, sudden death of father, and outplacement	Absence of pretreatment symptoms (threatening people, ongoing physical shaking, overeating, possessive of friend and caregivers) and continuing growth in independence

(*continued*)

Table 3 (continued)

Authors/year	Age	M/F	Level of ID/comorbidity	Trauma's/life events	Results
Mevissen et al. (2012)	49	F	Severe/Down's syndrome	Trapped with head in bars of bed and rescued by a fireman, death of father, death of mother, and death of four people in personal environment	Sleep problems disappeared, physical complaints↓, muscles more relaxed, mood problems disappeared. She was more able to "talk" about feelings and was cooperative when going to bed
	10	F	Severe/Marshall-Smith syndrome	Life-threatening medical problems; repeatedly hospitalized with painful examinations and operations	Absence of pretreatment symptoms (panic attacks with medical procedures, anxiety in daily life situations, avoiding places and people, poor ability to focus, volatile, easily upset, always physically tense), and she learned new skills
	10	M	Severe/Down's syndrome	Heart surgery and forced to eat when back home, outplacement into an eating clinic	Aggressive outburst disappeared. Eating problems (refusing to eat solid food, has to be fed, unable to eat together with family members, unable to eat without distracting stimuli) significantly decreased. He learned new skills and finally, with additional professional educational support, he was able to eat fast food independently
	32	F	Severe/symptoms of autism	Frequent physical and sexual abuse by a group member for a period of half a year, repeatedly outplacements as a result of serious problem behaviors, and serious illness, and death of father	Better tolerating being touched in support of personal hygiene, more cheerful, energy level increased, tolerating crowded environments, decrease of aggressive outbursts; however at follow-up, aggressive outbursts increased

Dilly (2014)	25	M	Mild	Childhood physical and sexual abuse over a prolonged period, carried out by a number of perpetrators, and deliberate exposure to an event involving fire	Reduction in re-experiencing, avoidance and arousal symptoms with most evidence in the avoidance domain (measure: PDS with some minor adaptations for people with ID)
Barrocliff and Evans (2015)	Between 40 and 50 years	F	Moderate-severe/ Mucopolysaccharidosis Hunter's syndrome	Became blind in adulthood, childhood specialized foster care with a number of unsuccessful placements, a house fire (carried from the smoke-filled house and forcibly placed in an ambulance)	Trauma-related complaints disappeared (significant decrease of Impact of Event Scale score). Complaints were rocking, distress noises, repetitive phrases, hypervigilance and self harm when reminded of the event, constantly checking the risk of fire, also at night

behaviors; and improved mood and social functioning. For an overview of the EMDR case studies, see Table 3.

As with CBT, controlled studies on the effectiveness of EMDR for the treatment of symptoms of PTSD in individuals with ID are lacking. However, the growing number of case descriptions with clinically positive outcomes is a reason for optimism considering that EMDR appears to be applicable in clients with mild, moderate, as well as severe ID. Moreover, homework and practice outside the sessions are not needed.

Conclusion

People with ID have relatively high rates of exposure to trauma and adverse life events. A lack of coping resources is likely to impede the natural process of recovery in people with ID making people with ID particularly vulnerable for the development of PTSD. Accordingly, PTSD is expected to be a common psychiatric disorder in this population. However, PTSD is largely underdiagnosed and undertreated in people with ID. Misinterpretation of symptoms might be the best explanation for this. First, in clinical practice, PTSD symptoms could falsely be interpreted as belonging to the ID, the so-called diagnostic overshadowing (Fletcher et al. 2007). Secondly, symptoms of PTSD might be misinterpreted as features of other psychiatric disorders such as anxiety and mood disorders, ASD, ADHD, conduct disorder, or psychotic disorders. As a consequence, no treatment or inappropriate treatments are offered. It is known from studies in the general population that if PTSD remains untreated, severe and long-term impairments resulting from this condition might occur and that well-being and emotional, social, academic, and physical development are negatively affected (Alisic et al. 2011). Research in adults showed that many years after trauma exposure, patients were still having PTSD going along with high costs of care and low levels of subjective quality of life (Priebe et al. 2009).

Therefore, the clinical interview for children with MBID (ADIS-C-IDs PTSD Section) is of great value. The ability to index PTSD symptoms in children (and adults) with MBID also offers opportunities to contribute to the establishment of an evidence base for PTSD treatment for this target group. Compared to trauma-focused CBT, EMDR therapy seems particularly suited for persons with ID because (1) the adapted EMDR protocol for youth without ID appears applicable in persons with severe to mild/borderline ID; (2) in EMDR, there is no need to do homework and to practice with difficult cues and situations related to the traumatic event outside the therapy sessions; and (3) a growing number of case descriptions report positive treatment outcomes of EMDR in people with ID (Gilderthorp 2015).

Clearly, future research is needed to improve assessment of PTSD in children with more severe levels of ID and in adults with ID. With regard to adults with ID, it should be noted that the LANTS have been developed as a trauma measure and not as an assessment instrument aimed to diagnose PTSD in terms of DSM-IV or DSM-5 features. Currently we are adapting the ADIS-C-IDs PTSD Section for use in adults

with MBID to investigate the manifestation and clinical assessment of PTSD in adults with MBID.

Such attempts will facilitate the strongly needed rigorous research to determine the presence of PTSD in this target population and to establish the effectiveness and efficacy of PTSD treatment methods for people with ID regardless of their age and developmental level. Finally, mental health services should adjust their policies to meet the needs of people with ID and PTSD in terms of facilitating professionals to timely detect and effectively treat clients with ID and PTSD.

Summary Points

PTSD risk

- Individuals with ID are at risk for developing PTSD.
- Individuals with ID have high rates of exposure to trauma and life events.

PTSD assessment

- Professionals tend to misinterpret PTSD symptoms by attributing them to the developmental delay or to another psychiatric condition.
- Recently, a clinical interview and self-report instruments to measure manifestations and severity of PTSD symptoms, as well as other effects of trauma in individuals with MBID, have become available.
- Research on trauma measures for individuals with severe ID is lacking.

PTSD treatment

- PTSD mistreatment and PTSD remaining untreated have serious and long-lasting consequences.
- EMDR is a feasible and possibly effective therapy for PTSD in individuals with ID.
- Empirical studies on prevalence and treatment of PTSD in people with ID are lacking.

References

Adler-Tapia R, Settle C. EMDR and the art of psychotherapy with children. New York: Springer; 2008.

Alisic E, Jongmans M, van Wesel F, Kleber R. Building child trauma theory from longitudinal studies: a meta-analysis. Clin Psychol Rev. 2011;31:736–47.

American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. - Washington, DC: American Psychiatric Association; 2013.

Baddeley A. Human memory: theory and practice. Needham Heights: Allyn and Bacon; 1998.

Barol B, Seubert A. Stepping stones: EMDR treatment of individuals with intellectual and developmental disabilities and challenging behavior. J EMDR Pract Res. 2010;4:156–169.

Barrowcliff A, Evans G. EMDR treatment for PTSD and intellectual disability: a case study. Adv Ment Health Intellect Disabil. 2015;9(2):90–8.

Cooper S, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. Br J Psychiatry. 2007;190:27–35.

Dilly R. Eye movement desensitisation and reprocessing in the treatment of trauma with mild intellectual disabilities: a case study. Adv Ment Health Intellect Disabil. 2014;8(1):63–71.
Edwards V, Holden G, Felitti V, Anda R. Relationship between multiple forms of childhood maltreatment and adult mental health in community respondents: results from the adverse childhood experiences study. Am J Psychiatry. 2003;160:1453–60.
Einfeld S, Ellis L, Emerson E. Co morbidity of intellectual disability and mental disorder in children and adolescents: a systematic review. J Intellect Dev Disabil. 2011;36:137–43.
Engelhart I, van den Hout M, Smeets M. Taxing working memory reduces vividness and emotionality of images about the Queen's Day tragedy. J Behav Ther Exp Psychiatry. 2011;42:32–7.
Esbensen A, Benson B. A prospective analysis of life events, problem behaviors and depression in adults with intellectual disability. J Intellect Disabil Res. 2006;4:248–58.
Fernando K, Medlicott L. My shield will protect me against the ANTS: Treatment of PTSD in a client with an intellectual disability. J Intellect Dev Disabil. 2009;34:187–192.
Fletcher R, Loschen E, Stavrakaki C, First M, editors. Diagnostic Manual-Intellectual Disability (DM-ID): a textbook of diagnosis of mental disorders in persons with intellectual disability. Kingston: NADD Press; 2007.
Focht-New G, Clements P, Barol B, Faulkner M, Pekala K. Persons with developmental disabilities exposed to interpersonal violence and crime: strategies and guidance for assessment. Perspect Psychiatr Care. 2008;44(1):3–13.
Gilderthorp C. Is EMDR an effective treatment for people diagnosed with both intellectual disability and post traumatic stress disorder? J Intell Dis. 2015;19:58–68.
Giltaij H. Alsof er een stofzuiger door mijn hoofd is gegaan. EMDR bij mensen met een visuele en verstandelijke beperking. [As if a vacuum cleaner went through my head. EMDR in people with visual and intellectual disabilities]. Tijdschrift voor Kinder- & Jeugdpsychotherapie [J Child Adol Psychother]. 2004; 3:81–97.
Hall J, Jobson L, Langdon P. Measuring symptoms of post-traumatic stress disorder in people with intellectual disabilities: the development and psychometric properties of the Impact of Event Scale-Intellectual Diabilities (IES-IDs). Br J Clin Psychol. 2014;53:315–32.
Hatton C, Emerson E. The relationship between life events and psychopathology amongst children with intellectual disabilities. J Appl Res Intellect Disabil. 2004;17:109–17.
Hollins S, Sinason V. Psychotherapy, learning disabilities and trauma: new perspectives. Br J Psychiatry. 2000;76:32–6.
Horowitz M, Wilner N, Alvarez W. Impact of event scale: a measure of subjective stress. Psychosom Med. 1979;41:209–18.
Jones R, Banks R. Behavioural treatment of PTSD in a person with intellectual disability. Eur J Behav Anal. 2007;8:251–6.
Lemmon V, Mizes J. Effectiveness of exposure therapy: a study of posttraumatic stress disorder and mental retardation. Cogn Behav Pract. 2002;4:317–23.
Levitas A, Gilson, S. Predictable crisis in the life of people with mental retardation. Ment Hlth Asp Dev Dis. 2001;3:89–100.
Lovett J. Small wonders. Healing childhood trauma with EMDR. New York: The Free Press; 1999.
Martorell A, Tsakanikos E. Traumatic experiences and life events in people with intellectual disability. Curr Opin Psychiatry. 2008;5:445–8.
Mevissen L, De Jongh A. PTSD and its treatment in people with intellectual disabilities. Clin Psychol Rev. 2010;30:308–16.
Mevissen L, Lievegoed R, De Jongh A. EMDR treatment in people with mild ID and PTSD: 4 cases. Psychiatry Q. 2011a;82:43–57.
Mevissen L, Lievegoed R, Seubert A, De Jongh A. Do persons with intellectual disability and limited verbal capacities respond to trauma treatment? J Intellect Dev Disabil. 2011b;36:278–83.
Mevissen L, Lievegoed R, Seubert A, De Jongh A. PTSD treatment in people with severe intellectual disabilities: a case series. Dev Neurorehabil. 2012;15:223–32.

Mevissen L, Barnhoorn E, Didden R, Korzilius H, De Jongh A. Clinical assessment of PTSD in children with mild to borderline intellectual disabilities: a pilot study. Dev Neurorehabil. 2014;17:16–23.

Mevissen L, Didden R, Korzilius H, De Jongh A. Assessment of PTSD in children with mild to borderline intellectual disabilities. Eur J Psychotraumatol. 2016;7:29786. doi: 10.3402/ejpt.v7.29786.

Priebe S, Mtanov A, Gavrilović J, Crone P, Ljubotina D, Knežević G, Kučukalić A, Frančišković T, Schützwohl M. Consequences of untreated posttraumatic stress disorder following war in former Yugoslavia: morbidity, subjective quality of life and care costs. Croat Med J. 2009;50:465–75.

Rodenburg R, Benjamin A, De Roos C, Meijer A, Stams G. Efficacy of EMDR in children: A meta-analysis. Clin Psych Rev. 2009;29:599–606.

Schalock R, Borthwick-Duffy S, Bradley V, Buntinx W, Coulter D, Craig E, et al. Intellectual disability: definition, classification, and systems of supports. 11th ed. Washington, DC: AAIDD; 2010.

Shapiro F. Eye movement desensitization and reprocessing: basic principles, protocols and procedures. 2nd ed. New York: Guilford Press; 2001.

Shapiro F. EMDR and case conceptualization from an adaptive information processing perspective. In: Shapiro F, Kaslow L, Maxfield A, editors. Handbook of EMDR and family therapy processes. Hoboken/New York: Wiley; 2007. p. 3–34.

Stenfert Kroese B, Thomas G. Treating chronic nightmares of sexual assault survivors with an intellectual disability-two descriptive case studies. J Appl Res Intellect Disabil. 2006;19:75–80.

Sturmey P, Didden R, editors. Evidence-based practice and intellectual disabilities. Oxford: Wiley-Blackwell; 2014.

Taylor J, Lindsay W, Hastings R, Hatton C, editors. Psychological therapies for adults with intellectual disabilities. Oxford: Wiley-Blackwell; 2013.

Tomasulo D, Razza N. Posttraumatic stress disorder. In: Fletcher R, Loschen E, Stavrakaki C, First M, editors. Diagnostic Manual-Intellectual Disability (DM-ID): a textbook of diagnosis of mental disorders in persons with intellectual disability. Kingston: NADD Press; 2007. p. 365–78.

Weiss D, Marmar C. The impact of event scale–revised. In: Wilson J, Keane T, editors. Assessing psychological trauma and PTSD: a handbook for practitioners. New York: Guilford Press; 1997. p. 399–411.

Wigham S, Hatton C, Taylor J. The effects of traumatizing life events on people with intellectual disabilities: a systematic review. J Ment Health Res Intellect Disabil. 2011a;4:19–39.

Wigham S, Hatton C, Taylor J. The Lancaster and Northgate trauma scales (LANTS): the development and psychometric properties of a measure of trauma for people with mild to moderate intellectual disabilities. Res Dev Disabil. 2011b;32:2651–9.

Wigham S, Taylor J, Hatton C. A prospective study of the relationship between adverse life events and trauma in adults with mild to moderate intellectual disabilities. J Intellect Dev Disabil. 2014;58:1091–184.

World Health Organization. Guidelines for the management of conditions specifically related to stress. Geneva: World Health Organization; 2013.