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**Assessment and treatment of
posttraumatic stress disorder
in individuals with intellectual disabilities**



E.H.M. Mevissen-Renckens

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E.H.M. Mevissen-Renckens

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General introduction

INTRODUCTION

About 80% of the population experiences at least one potentially traumatic event at some time in their lives such as a serious accident, a natural disaster, the sudden loss of a loved one, and sexual or physical abuse (De Vries & Olff, 2009). Most people recover in a natural way from the psychological consequences of being confronted with a potentially traumatic event. About 5% to 10% (Kessler et al., 2005) develops PTSD with a mean estimated prevalence rate for children of about 16% (Alisic, 2014). Research 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). If PTSD in children remains untreated, severe and long-term impairments resulting from this condition might occur in that their well-being and emotional, social, academic and physical development are negatively affected (Alisic, 2011). For PTSD treatment, trauma-focused cognitive behavioural therapy (CBT) and Eye Movement Desensitisation and Reprocessing (EMDR) therapy are the evidence-based first-line treatments, recommended by the World Health Organization (WHO, 2013).

Individuals with intellectual disability (ID) are more frequently exposed to potentially traumatic events, such as sexual and physical abuse, bereavement, and life-threatening illness or injury, than those without ID (Focht-New et al., 2008; Hatton & Emerson, 2004). Although prevalence rates of PTSD are supposed to be higher in people with ID, PTSD has been found to be a largely under-diagnosed and under-treated mental health disorder in this population (Fletcher et al., 2007; Wigham et al., 2011; Wigham & Emerson, 2015). As a consequence, a considerable number of individuals with ID will - undiagnosed and untreated - suffer from the disruptive effects of trauma.

The main purpose of the present research project was to contribute to a valid and reliable PTSD diagnosis, and to explore the effectiveness of EMDR therapy on symptoms of PTSD in individuals with ID. To this end, (1) a review of the literature on PTSD in individuals with ID was conducted, (2) clinical experiences with EMDR therapy in individuals with various levels of ID who reported a history of exposure to potentially traumatic events were systematically described, (3) the Dutch version of the *ADIS-C PTSD section* (Anxiety Disorders Interview Schedule of DSM-IV – Child version, Siebelink & Treffers, 2001) was adapted and validated for the assessment of PTSD according to DSM-IV-TR and DSM-5 in children and adolescents with mild to borderline ID, and (4) a multiple baseline study across persons was conducted to explore the effectiveness of Eye Movement Desensitisation and Reprocessing (EMDR) therapy on the course of PTSD symptoms in children and adolescents with mild to borderline ID.

This chapter starts with a description of the background of the thesis. The definitions of PTSD and ID will be presented as well as factors that may put people with ID at greater risk for the development of PTSD. Subsequently, the core features of EMDR therapy as a potentially effective psychotherapeutic treatment for PTSD in persons with ID will be described. The chapter concludes with an overview of the research questions and the outline of this thesis.

Background of the thesis

As a clinical psychologist working with people with ID for three decades, I discovered that many of my clients who had serious emotional and behavioural problems also reported a history with overwhelming negative events. About ten years ago, I got to know about EMDR, a psychotherapeutic treatment method (Shapiro, 2001), recommended by the World Health Organization (WHO, 2013) as an evidence-based first-line treatment for Posttraumatic Stress Disorder. I started EMDR training, gained experience in EMDR treatment, and practiced EMDR in persons with mild, moderate and severe ID. Obvious improvements in daily life functioning like in the cases of Mitchell, Maria and Peter (see framework) were the result.

Mitchell was a 11-year old boy with mild ID (Total IQ 66) who lived in a group home. He had been diagnosed with autism spectrum disorder. For over four years he suffered from fears, compulsive behaviours, obsessive thoughts and voices in his head. When visiting his parental home he acted out aggressively. History taking revealed that he had witnessed domestic violence and a car-fire in front of his home. Mitchell had been outplaced from the home because his parents were not able to control his behaviours. After EMDR treatment his problematic behaviours disappeared, visits at his parental home went smoothly, and he even was able to sleep at home without any difficulties. The diagnosis of autism spectrum disorder was no longer applied. Antipsychotic medication which he had used for over four years was discontinued. Hearing voices was misinterpreted as a psychotic feature. The voices turned out to be a PTSD re-experiencing symptom which disappeared as a result of trauma treatment.

Maria was a young woman with moderate ID (Total IQ 44) and symptoms of autism. She was restless, had sleep problems, was often tearful and displayed aggressive outbursts and obsessive behaviour. Her personal hygiene deteriorated, and she proved to be quite demanding of her mother. These problems started after she had been sexually abused by peers. Play therapy as well as pharmacological treatment were not effective. Maria was placed in a crisis unit since her parents could no longer manage her behaviours. After EMDR therapy Maria's problematic behaviours disappeared. She moved into a sheltered home close to her parents and her independence continued to increase.

Peter was a 10-year old boy with severe ID ($20 < IQ < 35$) and Down syndrome. Peter refused eating solid food and experienced aggressive outbursts. Due to severe heart problems he had a history of intrusive medical treatments starting at the age of three months. He typically refused to drink any liquids during this time, which was required for his cardiac treatment. Consequently, at 4 months of age, he underwent heart surgery and had to be fed liquids intravenously. Upon his return home, the drip-feed was discontinued and from that time on any form of eating turned into a fight. These food related problems resulted into placement in a specialized clinic for the treatment of his food refusal. Treatment turned out to be unsuccessful. Since Peter returned home he refused to join the family at dinner table, he only ate when eating was combined with various forms of distraction and he avoided solid food. Additionally, he experienced aggressive outbursts. After EMDR therapy (including EMDR therapy of his parents) his aggressive outbursts faded, and he became able to eat solid food in normal circumstances.

In several ways the rapid, impressive positive effects on clients well-being, like in the cases of *Michell*, *Maria* and *Peter*, appeared to be strong incentives for my research project. These experiences supported my idea that people with ID are at high risk of exposure to potentially traumatic events and negative life events. Further, I discovered that EMDR was appropriate and feasible for individuals with various levels of ID. Only a few of them had been offered psychotherapeutic trauma-focussed treatment. Instead, many were offered ineffective treatments or no treatment because their symptoms of posttraumatic stress had been falsely attributed to (1) other mental health conditions like autism spectrum disorder, attention deficit and hyperactivity disorder, psychotic disorder, mood and anxiety disorders, (2) contextual factors, and/or (3) the intellectual disability itself, so called “diagnostic overshadowing” (Fletcher et al., 2007). As in the case of *Mitchell*, *Maria* and *Peter*, treatments such as pharmacological interventions, interventions focussing on changing the person’s environment, play therapy, or psychomotor therapy, often proved unsuccessful. To reduce mental health costs, timely detection and subsequent effective treatment of posttraumatic stress symptoms in individuals with ID can be considered of great importance.

A review of the literature on PTSD and its assessment and treatment in persons with ID until 2008 (see Chapter 2), which became the start of the present research project, revealed that there was a (a) research gap with regard to knowledge of manifestations of PTSD in people with ID, (b) lack of valid and reliable instruments for the assessment of PTSD, (c) very small number of (uncontrolled) case descriptions regarding PTSD treat-

ment and (d) lack of studies on therapies that showed effectiveness for PTSD treatment in individuals with ID.

DSM-5 classification of Posttraumatic Stress Disorder

Whereas in the DSM-IV-TR PTSD was classified as an anxiety disorder (APA, 2000), in the DSM-5 (APA, 2013) PTSD is categorized as one of the “Trauma- and stressor related disorders”, a clustering of disorders in which, unlike other mental health disorders, the aetiology is part of the definition (Thakur, Creedon, & Zeanah, 2016). PTSD criteria are met when a person was exposed to death, threatened death, actual or threatened serious injury, or to actual or threatened sexual violence as follows: (1) direct exposure, (2) witnessing in person, (3) indirectly by learning that a close relative or close friend was exposed to trauma (if actual or threatened death occurred it must have been violent or accidental) or (4) repeated or extreme indirect exposure to aversive details of the event(s), usually in the course of professional duties. In addition, exposure to the traumatic stressor should also involve (1) symptoms of re-experiencing, (2) avoidance of distressing trauma-related stimuli, (3) negative alterations in cognitions and mood and (4) alterations in arousal and reactivity. These symptoms need to be present for at least one month and should cause impairment in functioning and significant distress.

Compared to DSM-IV-TR, several changes have been achieved for the DSM-5 PTSD criteria, including a sharpened definition of criterion A1 (traumatic event), elimination of criterion A2 (the individual’s response), addition of a symptom cluster pertaining to negative alterations in mood and cognitions associated with the traumatic event(s), and the extension of symptoms of alterations in arousal and reactivity with self-destructive or reckless behaviour and aggressive behaviour. Another change in the DSM-5 PTSD criteria is the introduction of the developmental subtype “PTSD for Children 6 Years and Younger”, based upon findings that developmental differences affect the presentation of PTSD in children. Meeting the A criterion for trauma according to the “PTSD for Children 6 Years and Younger” means that in case of having witnessed the traumatic event, or having learned that the traumatic event occurred, the event has to have been experienced by a parent or caregiver figure. This PTSD subtype does not include symptoms that require skills which young children have not yet developed, such as verbal expression, memory or abstract thought, thereby improving the identification of PTSD for this age category (Gigengack, van Meijel, Alisic, & Lindauer, 2015).

Intellectual Disability

Intellectual disability (ID) is defined by significant impairments in both intellectual (IQ) and adaptive functioning (American Association of Intellectual and Developmental Disabilities/AAIDD; Shalock et al., 2010; DSM-5; APA, 2013). Although the former DSM-IV-TR

criterion of an IQ test score of 70 or below (i.e. two standard deviations below average) is still applicable, in the DSM-5 the (severity of the) disability is based on impairments in adaptive functioning, rather than on IQ tests alone (American Psychiatric Association, 2000, 2013). Adaptive skills are impaired in the conceptual, social and practical domain whereby individuals with ID show deficits in language, memory, reasoning, social judgement, communication skills and self-management in areas such as personal care, money management and school and work tasks (AAIDD; Shalock et al., 2010). Deficits in intellectual and adaptive functioning determine how well an individual copes with everyday tasks. Four levels of ID are distinguished: profound, severe, moderate and mild. Symptoms of ID begin during the individual's developmental period and the impairments are chronic. Although the limitations in adaptive functioning are leading, in daily practice as well as scientific publications the IQ criteria to define ID (APA, 2000) are still in use as a comprehensive standardized assessment of adaptive behaviour is not yet available and assessment often will take too much time and costs (AAIDD). The IQ equivalents are 0-20 (profound ID), 21-35 (severe ID), 36-50 (moderate ID), and 51-70 (mild ID). According to the normal IQ distribution ($mean = 100$, $SD = 15$), the majority of people with ID have mild ID. They represent about 2.1% of the general population.

Individuals have borderline ID if they have an IQ test score between 70 and 85 and mild deficits in adaptive skills. In DSM-5 (APA, 2013) Borderline Intellectual Functioning (BIF) is a V-code and is viewed as a circumstance of personal history that may be focus of clinical attention, influencing treatment or prognoses. Thus, in contrast to the DSM-IV-TR, BIF is no longer considered to be a disorder *per se*. About 13.6% of the general population falls into this category (Wieland & Zitman, 2015). Individuals with BIF often present in mental health care with a combination of problems in cognitive, social-emotional and adaptive functions, multiple complex psychiatric disorders and a mix of psycho-social problems (Wieland et al., 2014). In the Netherlands, people with BIF and co-morbid psychiatric disorders are eligible for specialized psychiatric outpatient services for patients with ID. Assessment and treatment procedures in general health care are heavily cognitively based and require a level of abstraction that is too difficult for individuals with BIF. They profit from programs that are adapted to a lower level of cognitive and social-emotional functioning (Wieland, 2016). Therefore, individuals with BIF are included in this dissertation. Individuals with mild ID and borderline intellectual functioning are referred to as individuals with mild to borderline intellectual disability (MBID).

Individuals with intellectual disability (ID) are susceptible to the full range of mental health problems. Research shows that the prevalence of mental disorders in individuals with ID is approximately 2 to 4 times higher than in individuals with average intelligence (Cooper, 2007; Einfeld et al., 2011). Symptoms of a mental disorder may be expressed atypically in people with ID - especially in people with severe ID - relative to those without

ID (Fletcher et al., 2007). A range of biological, psychological and social factors elevate the risk for mental disorders, including PTSD, in individuals with ID (Hatton et al., 2015; Smiley et al., 2007).

Individuals with ID at high risk for PTSD

A number of factors that are present before, during or after trauma exposure have been identified in explaining why some individuals go on to develop PTSD while others recover naturally (Bomyea et al., 2012). Pre-trauma risk factors include social and developmental history, a history of prior exposure to trauma, as well as the individual's biological and cognitive functioning including people's stress response systems, intelligence, neuropsychological functioning (especially executive functioning) and forms of cognitive biases such as negative attributions, ruminations, negative appraisals and fear of emotion (Bomyea et al., 2012). Examples of risk factors during trauma are characteristics of the event such as degree of life threat, and presence of panic or dissociation. Examples of post trauma risk factors are environmental stress and lack of social support.

Considering the aforementioned risk factors, prevalence rates of PTSD in individuals with ID are supposed to be relatively high. Having a lower intelligence is in itself a risk factor. In addition, the ID often goes along with other of the above pre trauma biological PTSD risk factors such as deficiencies in stress response systems and neuropsychological functioning. Moreover, people with ID are more likely than individuals without ID to be confronted with potentially traumatic events (Hatton & Emerson, 2004; Focht-New et al., 2008) thereby enhancing the risk of having a history of prior trauma. Regarding post trauma risk factors, people with ID have a limited availability as well as capacity for gathering social support and a supportive social network (Tomasulo & Razza, 2007). In conclusion, PTSD risk factors occur more often in individuals with ID compared to individuals without ID.

Purpose and aims of this dissertation

The introduction underlines the importance of determining how PTSD manifests in people with ID, for example what kind of negative events elicit post traumatic stress, what kind of symptoms are related to overwhelming events, and whether these aspects differ dependent of the level of ID. Further, professionals need to get opportunities to learn how to diagnose PTSD, and how PTSD can be effectively treated in people with various levels of ID.

Therefore, the main purpose of the present research project, was to contribute to a valid and reliable PTSD assessment, and to explore the effects of EMDR therapy on symptoms of PTSD in individuals with ID. The first step was an effort to extend the literature regarding manifestations of posttraumatic stress and the applicability of EMDR treatment

in people with ID. Accordingly, ten systematic case reports were conducted. Children as well as adults with mild, moderate and severe ID who showed behavioural and emotional problems, and also had been exposed to various types of negative events, were offered EMDR therapy (see Figure 1).

As indicated before, to fill the PTSD assessment gap the first aim was to develop and validate a clinical interview, the *adapted ADIS-C PTSD section*. Dictated by clinical practice constraints, subsequent research focussed on children and adolescents with MBID.

A pilot study was conducted, aimed at investigating the feasibility of the *adapted ADIS-C PTSD section* and to explore to what extent the manifestations of PTSD in children with MBID correspond to the manifestation of PTSD in children without ID. With regard to trauma-exposure two hypotheses were tested: (1) events not specifically meeting PTSD stressor criterion (A1) would be associated with the development of PTSD symptoms and (2) a greater level of exposure to potentially traumatic events would be associated with more PTSD symptoms.

This pilot study was replicated and extended to validate the *adapted ADIS-C PTSD section* using a larger sample of children with MBID including their caregivers and tested the following hypotheses: (1) PTSD symptoms in children with MBID would correspond with those included in the DSM-IV-TR (APA 2000) and DSM-5 (APA, 2013) PTSD algorithms, (2) fulfilling the A criterion for trauma would be associated with the presence of PTSD, (3) children meeting PTSD symptom criteria would report higher subjective levels of daily life impairments than children not meeting criteria for PTSD, (4) children meeting PTSD symptom criteria would report a higher level of exposure to potentially traumatic events than those not meeting PTSD symptom criteria and, finally, given that children exposed to trauma have high rates of psychiatric disorders (Copeland, Keeler, Angold, & Costello, 2007), (5) positive correlations would be found between rates of PTSD symptoms and Child Behavior Checklist (CBCL; Achenbach, 1991; Verhulst, Van der Ende, & Koot, 1996); internalizing, externalizing and total scale scores.

Finally, a study was conducted to explore the effectiveness of EMDR on symptoms of PTSD and the PTSD diagnosis in two individuals with MBID. Limitations of the existing case studies were taken into account by (1) using a multiple baseline across subjects design which controlled for natural recovery in the course of time, (2) using the *Adapted ADIS-C-PTSD section* as a valid and reliable PTSD instrument (3) conducting video-analyses to assess reliability of recording, and (4) assessing maintenance of outcomes at 6 weeks follow-up.

Eye Movement Desensitisation and Reprocessing (EMDR) therapy

EMDR therapy is a protocolized, 8-phase psychotherapeutic approach, developed by Shapiro (2001) aimed to resolve symptoms resulting from disturbing and unprocessed life experiences. EMDR Phase I consists of history taking and case formulation, resulting in a treatment plan. In Phase II the participant is prepared for the trauma work. Skill building and resource development might be necessary. Phase III to VII pertain to the reprocessing of the traumatic memory. Phase III begins with a focus on the traumatic memory itself by asking the participant to bring up the memory and to concentrate on various aspects of it, specifically the most distressing image and the dysfunctional negative cognition (NC) 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 a working memory demanding task, typically, the therapist moving his fingers back and forth in front of the client, asking him or her to track the movements, 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 or her fingers, while encouraging to 'go with' whatever freely arises in the client's awareness. Repeatedly the client is asked to report about emotional, cognitive, somatic and/or imagistic experiences that arise, until intern disturbances reach a SUDs (Subjective Unit of Disturbances scale) of zero and an adaptive and positive statement about oneself (PC, Positive Cognition) is rated as fully believable 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 re-evaluation 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 the limited working memory capacity. If another task is executed during recall, less capacity will be available for recalling a distressing event. This makes allows for the memory to be experienced as less vivid and emotional. Eye movements are held to serve as such a 'secondary' task that taxes working memory. As in children, 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, 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. 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 in clients with a developmental level of about three years and below, the Story Telling Method (Lovett, 1999, 2015) 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).

Figure 1

General outline of this dissertation

Chapter 2 presents a review of the international literature on PTSD in people with ID from 1992 to 2008 regarding publications on the manifestations of PTSD, the assessment of PTSD and the treatment of PTSD in this population.

Chapter 3 displays ten case descriptions in which the applicability and efficacy of EMDR therapy is explored respectively in two children and two adults with mild ID (**Chapter 3.1**), an adult and an adolescent with moderate ID (**Chapter 3.2**), and two children and two adults with severe ID (**Chapter 3.3**). All of the subjects showed behavioural and emotional problems and also had been exposed to various types of negative events.

Chapter 4 consists of two studies that were conducted in view of the development of a PTSD clinical interview for the assessment of PTSD in children and adolescents with MBID. **Chapter 4.1** presents the pilot study in a sample of 15 children visiting a special school, investigating the feasibility of the *adapted ADIS-C PTSD section*, to assess PTSD in children with MBID, and exploring to what extent the manifestation of PTSD in children with MBID corresponds to the manifestation of PTSD in children without ID. **Chapter 4.2** presents the replication and extension of the pilot study to validate the *adapted ADIS-C PTSD sec-*

tion for the diagnoses of PTSD according to DSM-IV-TR and DSM-5 in a larger sample of 80 children and adolescents with mild ID and their caregivers, who were referred to an outpatient treatment for child and adolescent psychiatry.

A multiple baseline across subjects study is described in **Chapter 5**. This study was conducted in a child and an adolescent with MBID, who had a DSM-IV-TR as well as DSM-5 PTSD diagnosis according to the *adapted ADIS-C PTSD section*. The effectiveness of EMDR for symptoms of PTSD and the PTSD diagnosis was explored.

The main results of this dissertation on PTSD and its treatment in individuals with (MB)ID are summarized and discussed in **Chapter 6** (in English) and **Chapter 7** (in Dutch), including suggestions for future research.

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2

PTSD and its treatment in people with intellectual disabilities: A review of the literature

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ABSTRACT

Although there is evidence to suggest that people with intellectual disabilities (ID) are likely to suffer from Post-Traumatic Stress Disorder (PTSD), reviews of the evidence base, and the potential consequences of this contention are absent. The purpose of this article is to present a comprehensive account of the literature on the prevalence, assessment, and treatment of PTSD in people with ID. Some support was found for the notion that people with ID have a predisposition to the development of PTSD. Differences in comparison with the general population may consist of the expression of symptoms, and the interpretation of distressing experiences, as the manifestation of possible PTSD seems to vary with the level of ID. Since valid and reliable instruments for assessing PTSD in this population are completely lacking, there are no prevalence data on PTSD among people with ID. Nine articles concern the treatment of PTSD in people with ID. Interventions reported involve those aimed to establish environmental change, the use of medication and psychological treatments (i.e., cognitive behavioral therapy, EMDR and psycho-dynamic based treatments). Case reports suggest positive treatment effects for various treatment methods. Development of diagnostic instruments for the assessment of PTSD symptomatology in this population is required, as it could facilitate further research on its prevalence and treatment.

INTRODUCTION

Intellectual disability (ID), historically referred to as mental retardation (MR), is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills (Schalock, Luckasson, & Shogren, 2007). According to the definition of the American Association on Intellectual and Developmental Disabilities (Luckasson et al., 2002) ID originates before the age of 18.

During the past few decades there have been important developments in research aimed at assessing mental health problems in people with ID. It is now a well-known fact that psychiatric problems are not only common in this population, but their frequency seems to be approximately 2 to 4 times higher compared to the general population (Cooper, Smiley, Morrison, Williamson & Allan, 2007; Dekker, Koot, van der Ende & Verhulst, 2002; Eaton & Menolescino, 1982; Einfeld, Piccinin, Mackinnon, Hofer, Taffe, Gray, Bontempo, Hoffman, Parmenter & Tonge, 2006; Emerson, 2003; Linna, Moilanen, Ebeling, Piha, Kumpulainen, Tamminen & Almqvist, 1999; Rutter, Graham & Yule, 1970; Reiss, Levitan & Szyszko, 1982).

Although there is evidence to suggest that individuals with ID are susceptible to the full range of psychiatric disorders (Deb, Matthews, Holt & Boura, 2001; Došen, 2007) psychiatric assessment is considered to be problematic. Impairments in receptive and expressive language make it difficult for individuals with ID to understand, and respond to, clinicians who typically rely on the person's identification and description of his or her experiences and emotional states, especially as the level of intellectual functioning declines (Fletcher, Beasley & Jacobsen, 1999; Fletcher, Loschen, Stavrakaki & First, 2007; Rush & Francis, 2000). Moreover, the symptoms of diverse psychiatric disorders are often expressed differently in persons with ID relative to those without ID (Fletcher et. al, 2007). In addition, practitioners often overlook psychopathology by attributing severe behavioral disturbances as part of the intellectual disability itself, a phenomenon termed 'diagnostic overshadowing'. To this end, release of the Diagnostic Manual-Intellectual Disability in 2007 (Fletcher et. al, 2007), developed in association with the American Psychiatric Association, can be considered a milestone. It is both an effort to enhance the reliability of psychiatric diagnoses in people with ID, and a recognition of the need for evidence based treatment methods for those who have an intellectual disability along with a mental disorder (Ninivaggi, 2008).

There is growing interest in understanding the psychological consequences of traumatic events and life events in people with ID (Martorell & Tsakanikos, 2008). Individuals with ID have been found to be more likely to experience traumatic events, especially sexual and physical abuse (Focht-New, Clements, Barol, Faulkner, & Pekala, 2008; Mansell,

Sobsey, & Moskal 1998; Rayn 1994). Children with ID also report more negative life events (e.g. bereavement, move of house or residence, life-threatening illness or injury and serious problems with significant others) than children without ID (Hatton & Emerson, 2004). Although distinguishing traumatic events from life events proves to be difficult, it is suggested that the range of potentially traumatic experiences is greater in people with ID compared to those with a relatively high level of intellectual functioning (Martorell et al., 2008). Another finding is that children and adults with ID who have been exposed to sexual abuse are likely to experience a range of symptoms, psychopathology and behavioral difficulties (Beail & Warden, 1995; Mansell et.al, 1998; Sequeira & Hollins, 2003; Turk & Brown, 1993). Previous exposure to life events has generally been found to be associated with mental ill-health (Cooper et. al 2007), and in particular the occurrence of affective disorders and aggressive or destructive behaviors (Hamilton, Sutherland, & Laconc, 2005; Hastings, Hatton, Taylor & Maddison, 2004; Levitas & Gilson 2001; McGilivray & McCabe, 2007; Tsanikos, Bouras, Costello & Holt, 2007; Owen et al., 2004;). More importantly, in a prospective study by Esbenson & Benson (2006) a causal relationship between psychopathological symptoms and previous exposure to negative life events has been found. These authors also state that the effect of exposure to past negative or traumatic events may be cumulative.

In the present article the focus is on the presence of Post-Traumatic Stress Disorder (PTSD) among people with ID. PTSD is a trauma-related chronic anxiety disorder based on clear operationalized criteria (American Psychiatric Association, 2000), is often cyclic and progressive which can compromise the biological, as well as the psychological, social and spiritual functioning of a person (Brady, 1997; van der Kolk & McFarlane, 1996). Based on estimates of comprehensive studies in the United States, in the general population prevalence rates vary between 5% and 10% (Kessler, Chiu, Demler & Waters, 2005). PTSD proves to be associated with not only the presence of other psychiatric disorders, especially major depressive disorder, agoraphobia, social phobia, but also with high rates of medical visits (Brady, 1997). Features of PTSD vary among adults, adolescents and children. In children, feelings of intense fear, helplessness or horror that go along with exposure to the traumatic event, can take the form of disorganised or agitated behavior. Re-experiencing could take the form of repetitive play, frightening dreams without recognizable content or trauma-specific re-enactment (American Psychiatric Association, 2000). Thus, in children who have been exposed to a traumatic event, behavioral problems are a common feature.

In the development of PTSD individual characteristics such as developmental level may be of significant importance (Bowman, 1999). Developmental level has been found to have a major impact on individuals' capacity to cope with traumatic events (van der Kolk & McFarlane, 1996). In the general population high levels of intelligence seem to be associated with a greater ability to successfully avoid exposure to potentially traumatic events

and their PTSD effects (Breslau, Lucia & Alvaro, 2006). Likewise, in combat veterans, a lower level of intelligence appears associated with a greater likelihood of developing PTSD symptoms (Macklin, Metzger, Litz, McNally, Lasko, Orr & Pitman, 1998). In addition, there are indications that severity of PTSD symptoms is negatively associated with level of intelligence (McNally & Shin, 1995). Accordingly, it could be argued that people with ID are more vulnerable than the general population to the disruptive effects of trauma. In addition, there are indications that early separation from parents through early institutionalisation or hospital admissions, fewer previous experiences in managing negative life events, and a limited capacity for gathering social support may make people with ID more vulnerable for the development of PTSD (Tomasulo & Razza, 2007). Moreover, it has been suggested that starting to understand oneself as disabled is potentially traumatizing in itself, thereby being another factor that might contribute to an elevated risk of developing PTSD (Hollins & Sinason, 2000; Levitas, 2001).

Although there is evidence to suggest that people with ID are likely to suffer from PTSD, reviews of the evidence base, and the possible consequences of this contention are absent. Therefore, the purpose of this paper is to present an overview of the available literature on the assessment, prevalence and treatment of PTSD in people with ID.

METHODS

A literature search of the literature published from 1992 to 2008 was conducted using Picarta and Pubmed Journal citations, the NADD (National Association for the Dually Diagnosed) bulletins and book chapters as well as article and book reference lists. Keywords included Post-Traumatic Stress Disorder, trauma, life events, Anxiety Disorders, psychiatric disorders, mental health problems, Intellectual Disability, Mental Retardation, Learning Disability, assessment, diagnostic instruments, prevalence, treatment, and psychotherapy. The search keywords were used in combinations of descriptive labels. A search was conducted from the references of every article. No specific exclusion criteria were used.

RESULTS

A total of 18 studies were identified and reviewed in terms of i) the assessment of PTSD in people with ID, ii) prevalence of PTSD in people with ID, and iii) treatment of PTSD in people with ID.

Assessment of PTSD in people with ID

Because of both its importance and it being a frequently under diagnosed anxiety disorder, posttraumatic stress disorder is assigned its own chapter in the DM-ID (Fletcher et al., 2007, p.6). In spite of its importance, studies on PTSD in people with ID are extremely rare and their strength of evidence is generally considered to be low (Esralew, 2006; Tomasulo et al., 2007). The literature suggests that at the lower developmental levels PTSD symptoms are more like those seen in children, even if it concerns an adult (Tomasulo et al., 2007). For example, as in children, behavioral equivalents are supposed to be a common symptom of PTSD in individuals with ID. Self injurious behavior, for example, can be a symptom of PTSD in people with a lower level of ID (Tomasulo & Razza, 2007). However, the empirical evidence for behavioral equivalents for PTSD as well as for others psychiatric disorders in ID is still clinical and anecdotal at best. Based on the available literature and clinical expertise until 2003, in the DM-ID, recommendations have been made for adapted PTSD symptoms concerning people with mild to moderate ID on one hand, and severe to profound ID on the other (Tomasulo et al., 2007). Table 1 presents PTSD symptoms in general, the recommended adaptations for children and those recommended for people with ID by Tomasulo and his colleagues (2007).

Recently a few measures with good psychometric qualities have been developed to assess symptoms of anxiety in people with ID (Davis, Saeed, & Antonacci, 2008). However, besides the DM-ID, no diagnostic instrument is available specifically aimed at assessing PTSD in this population. Regarding the traumatic event itself other assessment problems arise. Caregivers often don't possess information concerning the person's trauma history or do not even recognize events typically associated with PTSD (Ryan, 1994; Esralew, 2006). Moreover, certain events, for example a move arranged by others is in general not considered as potentially traumatic. Nevertheless, such events may have a negative or traumatizing effect on individuals with ID (Levitas, 2001; Martorell et al., 2008; Tomasulo et al., 2007).

Prevalence of PTSD in people with ID

As displayed in Table 2, four articles were found reporting on incidence rates of PTSD in samples (with a total number of 359 persons) with ID who were referred for treatment, and had a history of one or more traumatic experiences (Balogh, Bretherton, Whibley, Berney, Graham, Richold, Worsley & Firth, 2001; Firth, Balogh, Berney, Bretherton, Graham & Whibley, 2001; Mitchell, Clegg & Furniss, 2006; Ryan, 1994). The studies of Firth et al. (2001) and Balogh et al. (2001) are related to the same sample. Prevalence rates of PTSD varied substantially, from 2.5 to 60 %. However, prevalence studies usually address the incidence of a feature in large heterogeneous populations. Unfortunately, such studies are completely lacking.

Table 1. Posttraumatic Stress Disorder

DSM-IV-TR Criteria	Adapted Criteria in children	Adapted Criteria for individuals with ID (DM-ID)
A (1+2)		
<p>1. Experienced, witnessed, or was confronted with event(s) that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others</p> <p>2. Response involved intense fear, helplessness, or horror</p>	<p>1. No adaptation</p> <p>2. Response might have involved disorganized or agitated behavior</p>	<p>1. No adaptation Note: the range of potentially traumatizing events is greater for individuals with ID</p> <p>2. Increased likelihood of disorganized or agitated behavior when developmental age is lower (quite common with severe to profound ID)</p>
B (one or more)		
<p>1. Recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions</p> <p>2. Recurrent distressing dreams of event</p> <p>3. Acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated)</p> <p>4. Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event</p> <p>5. Physiological reactivity on exposure to internal cues that symbolize or resemble an aspect of the traumatic event</p>	<p>1. In young children repetitive play may occur in which themes or aspects of the trauma are expressed</p> <p>2. Frightening dreams without recognizable content may occur</p> <p>3. In young children trauma-specific re-enactment may occur</p> <p>4. No adaptation</p> <p>5. No adaptation</p>	<p>1. In individuals with lower developmental age behavioral acting out of traumatic experiences or self-injurious behavior (quite common with severe to profound ID)</p> <p>2. Frightening dreams without recognizable content appear to be more common when developmental age is lower</p> <p>3. Trauma-specific enactments have been observed in adults with moderate to severe ID; they can appear to be symptoms of psychosis in adults</p> <p>4. No adaptation</p> <p>5. No adaptation</p>

Table 1. Posttraumatic Stress Disorder (continued)

DSM-IV-TR Criteria	Adapted Criteria in children	Adapted Criteria for individuals with ID (DM-ID)
C (three or more)		
1. Efforts to avoid thoughts, feelings, or conversation associated with the trauma	1. No adaptation	1. No adaptation Note: assessment may be difficult in individuals with severe verbal limitations
2. Efforts to avoid activities, places, or people that arouse recollections of the trauma	2. No adaptation	2. No adaptation Note: avoidance behavior can be reported by caregivers as “non-compliance” especially when individuals cannot adequately verbalize their posttraumatic desire to avoid activities, places or people that arouse recollections of the trauma
3. Inability to recall an important aspect of the trauma	3. No adaptation	3. No adaptation Note: problems with recall may appear to be solely a function of the individual’s developmental age. Assessment may be difficult
4. Markedly diminished interest or participation in significant activities	4. No adaptation	4. No adaptation Note: caregivers may report the symptom as “non-compliance” especially for individuals with lower developmental age who cannot verbalize their feelings
5. Feeling of detachment or estrangement from others	5. No adaptation	5. For individuals with severe to profound ID caregivers may report that the individual isolates him or herself
6. Restricted range of affect (e.g., unable to have loving feelings)	6. No adaptation	6. No adaptation
7. Sense of a foreshortened future (e.g. does not expect to have a career, marriage, children, or a normal life span).	7. No adaptation	7. There may be a risk of false positives on this criterion: people with a lower developmental age are not able to think abstractly; the ones with less impairment often realise that they are different from peers and siblings and therefore don’t expect a normative future

Table 1. Posttraumatic Stress Disorder (continued)

DSM-IV-TR Criteria	Adapted Criteria in children	Adapted Criteria for individuals with ID (DM-ID)
D (two or more, not present before the trauma)		
1. Difficulty falling or staying asleep	1. No adaptation	1. No adaptation
2. Irritability or outbursts of anger	2. No adaptation	2. No adaptation
3. Difficulty concentrating	3. No adaptation	3. No adaptation
4. Hypervigilance	4. No adaptation	4. No adaptation
5. Exaggerated startle response	5. No adaptation	5. No adaptation
E		
Duration of the disturbance (symptoms B, C and D) is more than 1 month	No adaptation	No adaptation Note: with severe and profound ID clinically significant impairment in functioning may appear to be solely a function of the cognitive limitations so careful assessment is necessary
F		
The disturbance causes clinically significant distress or impairment in social, occupational or other important area's of functioning	No adaptation	No adaptation Note: clinically significant impairment in functioning may appear to be solely a function of the cognitive limitations so careful assessment is necessary
Specify if	Acute: if duration of symptoms is less than 3 months	
	Chronic: if duration of symptoms is 3 months or more	
Specify if:	With Delayed Onset: if onset of symptoms is at least 6 months after the stressor	

Table 2. Prevalence of PTSD in people with ID

Authors/Year	N	Sample characteristics	Method	Findings
Ryan, 1994	310	Adults Average age: 36 years 66% women, 33% men Average level of functioning: moderate ID Referred to community based psychiatric, behavioral and medical consultation for violent or disruptive behavior History of trauma	Retrospective analysis of routine initial psychiatric interview and record review Assessment: DSM-III-R	51 patients (16,%) met criteria for PTSD 35 patients also suffered from other psychiatric disorders, mostly major depression Traumatic events: -mostly childhood sexual en physical abuse -each patient reported at least 2 events, most of them reported more than 5 events -in about half of the cases the traumatic events were known to someone In none of the cases, PTSD had been previously considered
Firth et al., 2001	43	Children and adolescents 46% women, 53% men 44% mild ID, 37% moderate ID, 7% severe ID	Retrospective analyses of case notes made by clinicians, Assessment instrument: DSM-IV criteria for PTSD. (defined some more detailed)	1 patient (2,5%) met the criteria for PTSD
Balogh et al., 2001		Victims and/or perpetrators of sexual abuse Inpatients of a psychiatric service		
Mitchell et al., 2006	6	Adults, Range: 23-57 years 33% women, 66% men Mild ID History with multiple traumatic events; a key life event changed their life Receiving professional support	Interpretative phenomenological analysis to explore the personal experience of traumatic life events Assessment instruments: -adapted Post-traumatic Diagnostic Scale, based on DSM-IV -semi-structured interview scale	3 of 5 patients (60%) met PTSD criteria on the PDS (one drop out for PDS measurement) Key traumatic events: -sexual abuse (3x) -death of mother -father's involvement in a pit strike

Treatment of PTSD in people with ID

Three articles were found recommending an interdisciplinary treatment approach for PTSD in people with ID (Focht-New et al., 2008; McCarthy, 2001; Ryan, 2000; see Table 3). From the biological point of view pharmacological interventions are described targeting the deregulation that occurs in various neurotransmitter systems (Focht-New et al., 2008; McCarthy, 2001; Ryan, 2000). Comprehensive medical evaluation is recommended because of the frequency of existing other medical conditions in this population that possibly influence the individual's mental health. Indeed specific medication can have a negative side effect, thereby interfering with recovery (Ryan 2000). Empirical studies of the pharmacological treatment of PTSD in people with ID are lacking.

The second treatment approach focuses on changes in environment and personal contacts with a view to eliminate frightening cues (Ryan, 2000). It has been suggested that the lower the level of intellectual functioning, the higher the dependency on others, resulting in a lack of opportunities to avoid traumatic stressors on their own (McCarthy, 2001). Training and support of caregivers is recommended to increase understanding of the symptoms and teach appropriate responses (Ryan, 2000). A series of practical guidelines for carers are offered to help the traumatized person with ID (Focht-New et al., 2008; Ryan, 2000). One article has been found recommending similar guidelines with special attention to the lives of institutionalized clients (Pitonyak, 2005; see Table 3). As far as this treatment approach is concerned, again, no empirical evidence appears to be available.

Finally, psychotherapy is recommended in the treatment of PTSD in people with ID (see Table 4). Clinical evidence suggests that this patient category responds well to a broad range of therapeutic modalities, and that there are no reasons for not using psychotherapeutic methods that have been established for other disorders (Focht-New et al., 2008; McCarthy, 2001; Ryan, 2000). The same holds true for methods that have proved to be successful in the psychotherapeutic treatment of PTSD in the general population (Focht-New et al., 2008; McCarthy, 2001; Ryan, 2000). Five articles were found on psychotherapeutic treatment of PTSD in people with ID (see Table 4). Two of these reports pertain to the use of Cognitive Behavioral Therapy (CBT) in a total of three adults with mild ID (Lemmon & Mizes, 2002; Stenfert Kroese & Thomas, 2006). The core assumption of CBT is that improvements in psychological wellbeing can result from changes in cognitions (thoughts, beliefs, attitudes, strategies; see Willner, 2006). Lemmon and Mizes (2002) used Exposure Therapy (a CBT technique) in the treatment of PTSD symptoms in one woman with mild ID. This woman had been a victim of several incidents of sexual assault. The authors emphasize the difficulties of diagnosing PTSD in persons with ID and describe this woman's behavior in terms of DSM IV PTSD criteria, paying special attention to the specific way in which the traditional re-experiencing symptoms are presented. The treatment procedure is reported in great detail, including specific modifications due to the cognitive limitations of the client. Symp-

Table 3. Multidisciplinary treatment of PTSD in people with ID

Authors/ Year	Type	Interventions
Focht- New et al. (2008)	Descriptive study, based on the literature of PTSD in the general population with clinical and anecdotal reports of PTSD in people with ID	Interventions that should be carried out by support persons (carers, family members , friends) are described Psychotherapeutic methods are listed Pharmacological treatment possibilities are described
McCarthy (2001)	Descriptive study, based on the literature of PTSD in the general population and clinical and anecdotal reports of PTSD in people with ID Some limited attention for psychological treatment approaches and psychopharmacology	Psychotherapeutic methods used in the general population are recommended Inclusion of support persons is recommended Some pharmacological interventions with proven efficacy in the general population are recommended
Pitonyak (2005)	Descriptive study, based on the literature of PTSD in the general population as well as clinical and anecdotal reports of PTSD in people with ID Interventions with the focus on support persons of institutional clients	Comprehensive guidelines/tips for caregivers and illustrated with examples from the lives of institutionalised clients
Ryan (2000)	Descriptive study, based on the literature of PTSD in the general population as well as clinical and anecdotal reports of PTSD in people with ID Interdisciplinary treatment guidelines	Pharmacological interventions based on an accurate description of PTSD symptoms, the person's history and co-morbid psychiatric and medical conditions and any side effects of other medications An eclectic approach of psychotherapy is recommended in collaboration with the person's caregivers, using a variety of treatment methods that are well established in the general population Various interventions focussed on the person's environment are illustrated as well as staff-training and support

Table 4. Psychotherapeutic treatment of PTSD in people with ID

Authors/ Year	N	Treatment method	age	M/F	Level of ID & comorbidity	Complaints	Trauma's/ life events	Number of sessions	Results	Follow- up
Giltaij (2004)	2	EMDR	?	F	Mild Blind	Fears/avoidance Being dependant on caregivers Often crying Uncertain	Single sexual abuse	4	Complaints resolved	3 months
			16 years	F	Mild Nearly blind Epilepsy Brain damage	Fears/avoidance Sleep problems Demanding behavior	Witnessed mother being threatened with knives	12	Significant decrease problem score on self-report scale (9a1)	None
Lemmon et al. (2002)	1	CBT (exposure)	32 years	F	Mild	Crying and fearful when questioned about perpetrator and when driving to where the event took place	Sexual abuse by former work supervisor	25	No longer distressed when exposed to trauma-related stimuli	None
						Refusing to discuss traumatic experiences and not looking at the place where the traumatic event happened	Suspected sexual abuse by former foster father		No avoidance in speaking about the traumatic events	
						Outbursts of anger, and hypervigilance	Recent frightening incidents		Anger outbursts and hypervigilance significantly decreased	

Table 4. Psychotherapeutic treatment of PTSD in people with ID (continued)

Authors/ Year	N	Treatment method	age	M/F	Level of ID & comorbidity	Complaints	Trauma's/ life events	Number of sessions	Results	Follow- up
Razza (1997)	1	Psychody- namic	27 years	F	Mild	Insomnia Tearfulness Lack of self-care skills Suicidal ideation Agitation Hostility	Chronic childhood sexual abuse	?	Reduction of symptoms after 5 years of individual and group treatment	None
Stenfert, Kroese et al. (2006)	2	CBT/ Imagery Rehearsal Therapy	18 years	F	Mild	Frequent nightmares	Sexual, physical and emotional abuse from the ages of 5years.-15 years.	3, and daily homework	Nightmares ceased	4 & 6 months
			24 years	F	Mild	Frequent nightmares Sleep disturbance Flashbacks General anxiety Fear of the dark and being left on own	Rape	3, and daily homework	Improved self- confidence Nightmares ceased	3 & 6 months
Thamer (2006)	19	EMDR	Children M and & F adults		Mild	Not specified	Not specified	?	16 successful treatments i.e.: patient thinks of trauma without much distress and with positive selfcognition	None

tom description is not only used to diagnose PTSD but also to measure treatment progress. After 25 sessions combined with homework, the woman was no longer distressed when exposed to trauma-related stimuli, she no longer avoided talking about the events and anger outbursts and hypervigilance significantly decreased. Unfortunately, information about the assessment procedure is lacking and a follow-up is not reported.

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 ten years, the second case involves a woman with Down's syndrome with a single sexual abuse experience. Unfortunately, information about the assessment procedures is limited. In the first case there is only a statement that a PTSD diagnosis has been established. In the second case PTSD symptoms are described. The treatment procedure, during which a 'new dream' is created, is described in detail, including the modifications due to the mild intellectual disability (the use of drawings and a therapist who illustrated the dream sequences). According to the authors three sessions combined with daily homework were needed to stop the nightmares, an outcome that was maintained at three/four and six months follow-up. In both cases Imagery Rehearsal Therapy was part of a broader treatment programme offered to the clients. In the first case initial supportive counselling, 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 but no information was provided about the length and content of all these treatment phases. In the case of the woman with single trauma the authors report a decrease of PTSD symptom severity, and a sense of increased self control in waking life after treatment of the nightmares. No information was presented on how this success had been rated and how many sessions the total treatment had taken.

Two articles, including two case reports, were found on the application of Eye Movement Desensitisation and Reprocessing (EMDR) in PTSD treatment in individuals with mild ID (Giltaij, 2004; Tharner, 2006). EMDR is a protocolized, highly non-verbal, psychotherapeutic approach aimed to resolve symptoms resulting from disturbing and unresolved life experiences by modification (reprocessing) of the maladaptive information upon which psychopathology (e.g. PTSD) is assumed to be based (Shapiro, 2002). Giltaij (2004) describes the EMDR treatment of a blind woman with mild ID, victim of a single sexual abuse, and a sixteen year old girl with visual impairments who witnessed her sister threatening their mother with two knives. The treatment protocol is presented in detail, including modifications with regard to the level of cognitive functioning and the visual problems. In the first case, PTSD symptoms disappeared after 4 sessions of EMDR treatment with results maintaining at 3 months follow-up. No information was presented on how PTSD was diagnosed and how the results were measured. In the second case 12

EMDR sessions were used to decrease problem severity from 9 to 1, as indexed on a self-report 0 to 10 scale with several problem areas, including clinging to mother, initiating social contact, going out, initiating activities, having defense against parents and sleeping problems. Again in this case no information is given on how PTSD was diagnosed. Unfortunately, follow-up data were lacking. In both EMDR treatments no homework was given as it is not part of the standard procedure. In his article on the application of EMDR in people with mild ID Tharner (2006) reports about the treatment of 20 clients of whom 10 were diagnosed with PTSD and 9 with complex PTSD; that is, a chronic trauma, often caused by childhood maltreatment, neglect and abuse and mostly characterized by the loss of a coherent sense of self (Herman, 1992a, b). Eighty percent of this sample was successfully treated; that is, at the end of the treatment the client was able to think of the traumatic event without any disturbance and the validity of the newly formulated positive cognition felt to be highly true. Unfortunately, no further details of these cases were described.

In addition to CBT (Willner, 2004) and EMDR (Benjamin, 2007; Greenwald, 1994; Seubert, 2005) psychodynamic psychotherapy is a rather frequently used approach for trauma treatment including all levels of ID. Case reports suggest positive treatment effects (Beail, 1998; Carlsson, 2000; Cottis, 2008; De Belie, Ivens, Lesseliers & Van Hove, 2000; Peeters-Thijssen; Hoekman, Mous, Arends & Broesterhuizen-Janssen, 1998; Sinason, 1992). In psychodynamic psychotherapy the use of nonverbal media is quite common. Psychodynamic oriented therapists are generally concerned with patients' mental representation of themselves within the world and seek to identify the origin, meaning and resolution of difficult feelings and inappropriate behaviors, making links with early life experiences (Beail, Warden, Morsley, & Newman, 2005). The treatment procedure is not protocolized. Razza (1997) discusses PTSD treatment in one woman with mild ID and a history of childhood sexual trauma. The treatment consisted of individual and group therapy, based on Herman's (1992a, b) stages of recovery, which is a treatment approach based on psychodynamic principles. It took a total of five years of treatment before a reduction of problems had been achieved. No further data were presented.

DISCUSSION

It has been argued that people with ID are at greater risk of suffering from the disruptive effects of trauma. The present study found support for the notion that in the general population a lower developmental level goes along with a higher PTSD risk and more serious PTSD symptoms (Macklin et al., 1998; McNally et al., 1995). There are indications that besides the cognitive impairments there are other factors making people with ID more vulnerable, including early institutionalisation and hospital admissions due to

comorbid medical impairments (Tomasulo & Razza, 2007). Further, it has been argued that understanding oneself as disabled can be traumatizing in itself (Hollins & Sinason, 2000; Levitas & Gilson, 2001). Thus, the findings of this study support the importance of the potential predisposition of people with ID to the development of trauma-related symptoms, due to previous trauma exposure or other vulnerabilities. Meanwhile, it would seem that in the field of people with ID there is little awareness of PTSD and its disturbing effects on daily life functioning. There are several possible explanations for this. Firstly, although it is conceivable that with regards to the MH-ID criteria, the range of potentially traumatising events is greater in people with ID, professionals often do not seem to realize that prolonged small traumas, for example ongoing experiences of failure or cumulative negative life events, might increase their vulnerability of developing PTSD-like symptoms. Therefore, medical and mental health professionals, parents and caretakers of people with ID should pay more attention to behavioral changes following potentially negative life events as this may enable them to take appropriate preventive or therapeutic measures, and to reduce further risk of psychological harm. To this end, the high staff turnover in institutional care is an obstacle, therefore those who were placed in institutions might be even more at risk of developing PTSD. Second, in people with ID, PTSD can be manifested differently compared to the general population. That is, different kinds of problem behaviors can be considered as symptoms of PTSD, such as aggression and anger outbursts, self-injurious behavior, non-compliance, social isolation, sleeping problems and restlessness. Overshadowing, i.e. attributing problem behavior as part of ID itself, is a well known feature in mental health care for people with ID. Third, the lack of PTSD diagnostic instruments prevents professionals from taking this disorder into consideration. That is, no validated diagnostic instruments aimed at assessing PTSD among people with ID are available. Following on from this, it is an obvious consequence that prevalence rates for PTSD for this population are lacking.

There are no empirically based treatment methods for PTSD for people with ID. Only nine articles could be found that concerned the treatment of PTSD in people with ID. However, poor or no information was offered on how PTSD had been diagnosed. The interventions reported involved those aimed to establish environmental changes (e.g., staff-training), the use of medication and psychological treatments (i.e. cognitive behavioral therapy, EMDR, and a psycho-dynamic based treatment). Although these case reports suggest positive treatment effects for various treatment methods applied to clients with mild ID, PTSD treatment in people with ID has proven to be relatively complicated and is still in its infancy. This is in accordance with the findings of Prout & Nowak-Drabic (2003), who conducted a review on the general outcome of psychotherapeutic interventions in people with ID over a period of thirty years. A moderate effect was pointed out, taking into account several cautions and limitations. In only nine of the 92 studies a treatment versus

untreated control group was utilized, and appropriate data for calculation of effect sizes were provided; case studies and single subject designs seem to dominate. These authors suggest including accurate description of the intervention along with the use of treatment protocols or guidelines for the therapists, treatment integrity procedures to assess adherence, accurate description of outcome data, a relationship between outcome measures and intervention and an accurate description of demographics and client characteristics. It may be necessary to profit from findings on PTSD treatment in the general population. To this end, strong evidence has been found for trauma-focused CBT, and EMDR to provide significant and efficient relief of PTSD symptoms (Bisson, Ehlers, Matthews, Pilling, Richards & Turner, 2007; Cloitre, 2009; National Collaborating Centre for Mental Health, 2005). There is no evidence to allow a determination of any particular advantage of one versus the other in terms of PTSD outcome in adults (Cloitre, 2009). However, in a recent meta-analysis on treatments of PTSD in children an incremental efficacy of EMDR has been found when compared to other forms of PTSD treatments (Rodenburg, Benjamin, de Roos, Meijer & Stams, 2009). In contrast, although widely used, there is as yet no empirical evidence for a clinically important effect of psychodynamic therapy on PTSD (National Collaborating Centre for Mental Health, 2005; Schottenbauer, Glass, Arnkoff, & Gray, 2008).

In his article on the efficacy of CBT in people with ID Sturmeijer (2006) argues that claims on the efficacy of CBT in this population often are not well-founded. Techniques, labelled as cognitive, are more likely to be based on the principles of applied behaviour analyses (ABA), an already evidence based treatment method for people with ID. However, in this review no studies have been found on the use of ABA in the treatment of PTSD in people with ID.

In conclusion, development of diagnostic instruments for the assessment of PTSD and its symptomatology among people with ID is warranted, as it could facilitate further research on its prevalence. To be able to determine whether or not people with ID are at greater risk for developing PTSD symptoms, it is necessary to develop standardized protocols to properly establish a PTSD diagnosis in people with ID. Meanwhile, evidence based methods have to be developed to treat people with various levels of ID who suffer from PTSD. A first step might be to systematically evaluate the use of already established methods such as trauma-focused CBT and EMDR.

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3

**EMDR treatment in individuals with mild, moderate or
severe ID: 10 cases**

3.1

EMDR treatment in individuals with mild ID

EMDR treatment in people with mild ID and PTSD: 4 cases

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ABSTRACT

Although there is evidence to suggest that people with intellectual disabilities (ID) are likely to be more susceptible to the development of posttraumatic stress disorder (PTSD) than persons in the general population, until now only eight case reports on the treatment of people with ID suffering from PTSD symptoms have been published. In an effort to enrich the literature on this subject, the aim was to investigate the applicability of an evidence-based treatment for PTSD (i.e., EMDR) in four people with mild ID, suffering from PTSD following various kinds of trauma. In all cases PTSD symptoms decreased and the gains were maintained at 3 months to 2.5 year follow-up. In addition, depressive symptoms and physical complaints subsided, and social and adaptive skills improved. It is concluded that clients' improvements converge to suggest the applicability of EMDR in people with mild ID. Difficulties involved in arriving at an accurate PTSD diagnosis in ID clients are discussed.

INTRODUCTION

Certain events are so overwhelming that they clearly leave behind deep impressions. People who have experienced, witnessed, or been confronted with such an event may develop a pathological stress response syndrome, such as posttraumatic stress disorder (PTSD) (American Psychiatric Association, 2000). To meet criteria for PTSD, an individual must have been exposed to a traumatic stressor, followed by a subjective response of fear, helplessness or horror. The principal clinical feature of PTSD is the painful re-experiencing of the traumatic incident in the form of recurrent and distressing recollections of the event, including intrusive images, nightmares and flashbacks (American Psychiatric Association, 2000). Other hallmark symptoms of PTSD are avoidant reactions and symptoms of arousal (American Psychiatric Association, 2000). In the general population PTSD prevalence rates vary between 5 and 10 % (Kessler, Chiu, Demler, & Waters, 2005), while a lower developmental level appears to coincide with a higher PTSD risk and more serious PTSD symptoms (Macklin, Litz, McNally, Lasko, Orr, & Pitman, 1998; McNally & Shin, 1995).

Although their cognitive impairments may make individuals with ID more susceptible to the development of PTSD, those who work with this population often lack this awareness (Mevisen & De Jongh, 2010). Furthermore, it is unclear to what extent individuals with ID suffer from the same PTSD symptoms as people without ID. To this end, recommendations for adapted PTSD symptom description in people with ID have been proposed (Fletcher, Loschen, Stavrakaki, & First, 2007). Moreover, reliable and valid instruments for assessing PTSD in this population are lacking, there are no PTSD prevalence data, and there are no evidence-based treatment methods available for people with ID who suffer from PTSD (Mevisen & De Jongh, 2010).

Regarding PTSD treatment with ID clients, several evidence-based treatment methods have been utilized. Among them, trauma-focused cognitive behavioral therapy (CBT) and Eye Movement Desensitization and Reprocessing (EMDR) have the strongest empirical support (Bisson, Ehlers, Matthews, Pilling, Richards, & Turner, 2007; Cloitre, 2009; National Collaborating Centre for Mental Health, 2005; Rodenburg, Benjamin, Roos de, Meijer, & Stams, 2009). However, to date only eight case reports of PTSD treatment in individuals with ID have been found in the literature (Fernando & Medlicott, 2009; Mevisen & De Jongh, 2010; Rodenburg, Benjamin, Meijer, & Jongeneel, 2009). In seven of these case reports CBT (Table 1) or EMDR (Table 2) was employed. In most studies however, valuable information, including follow-up data, was lacking.

In an effort to enrich the literature regarding PTSD treatment in people with ID, this study explores the applicability and efficacy of EMDR in a sample of four people with mild ID, children as well as adults, who experienced various types of negative life events.

Table 1. Cognitive behavioral treatment (CBT) of PTSD in people with ID

Authors/ Year	N	CBT treatment method	age	M/F	Level of ID and comorbidity	Complaints	Trauma's/ life events	Number of sessions	Results	Follow- up
Lemmon & Mizes (2002)	1	Exposure	32 years	F	Mild	Crying and fearful when questioned about perpetrator and when driving to the place where the event took place	Sexual abuse by former work supervisor Suspected sexual abuse by former foster father	25	No longer distressed when exposed to trauma-related stimuli No avoidance in speaking about the traumatic events	None
Stenfert Kroese & Thomas (2006)	2	Imagery rehearsal therapy	18 years	F	Mild	Refusing to discuss traumatic experiences and not looking at the place where the traumatic event happened	Recent frightening incidents	3, and daily homework	Anger outbursts and hypervigilance significantly decreased	4 & 6 months
						Outbursts of anger, and hypervigilance	Sexual, physical and emotional abuse from the ages of 5yrs.to15 yrs.		Improved self- confidence	
	24 years	F	Mild	Frequent nightmares	Rape	3, and daily homework	Nightmares ceased 3 & 6 months			
				Sleep disturbance	Flashbacks					
				Basic verbal capacities	General anxiety					
	Down syndrome	Fear of the dark and being left on her own								

Table 1. Cognitive behavioral treatment (CBT) of PTSD in people with ID (continued)

Authors/ Year	N	CBT treatment method	age	M/F	Level of ID and comorbidity	Complaints	Trauma's/ life events	Number of sessions	Results	Follow- up
Fernando & Medlicott (2009)	1	(education) Relaxation training Problem solving Cognitive restructuring Exposure	24 years	F	Mild	Flashbacks Nightmares Avoiding thinking of event Avoiding places Less interest in activities Restricted affect Difficulties staying asleep Increased startle response More irritable Feeling angry Stress-related headache and black outs	Abusive romantic relationship: repeatedly hit with weapon and kicked	9, and home- work	Intrusions ceased Better mood Self care improved	None

Table 2. EMDR treatment of PTSD in people with ID

Authors/ Year	N	Treatment method	age	M/F	Level of ID & comorbidity	Complaints	Trauma's/ life events	Number of sessions	Results	Follow- up
Giltaij, (2004)	2	EMDR	?	F	Mild	Fears/avoidance	Single sexual	4	Complaints resolved	3
					Blind	Being dependant on caregivers	abuse			
			16	F	Mild	Fears/avoidance	Witnessed	12	Significant decrease of self-reported problem score (9→1)	None
					Nearly blind	Sleep problems	mother being			
			years		Epilepsy	Demanding behavior	threatened with			
					Brain damage	knives				
Rodenburg et al. (2009)	1	EMDR	18	M	Mild	Flash backs	Repeated	5	Significant decrease of Impact of Event Scale score	None
					Epilepsy	Sleep problems	physical abuse			
			years		Frequent nightmares	Most disturbing:	Being threatened			
					Suicidal thoughts	with knife by his father	Parents divorced			

The findings are discussed with consideration for the difficulties in establishing a PTSD diagnosis in people with ID (Mevisen & De Jongh, 2010).

METHOD

Participants

Subjects were four clients with mild ID in the Netherlands who were referred for outpatient treatment by a mental health professional, a physician or a psychiatrist. All clients suffered from PTSD-like symptoms, according to DSM-IV TR (American Psychiatric Association, 2000) and DM-ID (Fletcher, Loschen, Stavrakaki, & First, 2007) criteria. Symptoms and/or behaviors of the clients were supposed to be related to one or more overwhelming negative life events. Except for long-standing medication (clients #2 and #3), EMDR was the sole treatment administered during the course of the study.

Procedure

The first author determined appropriateness of each participant for treatment based on client's records and by means of a clinical interview with the client and caregiver. Information about the treatment and related procedures were explained in detail to the caregivers, who were also given written information about the treatment to be read at home.

All treatments were administered by the first author, who is a clinical psychologist and a registered EMDR practitioner with more than 30 years experience with ID clients. Treatment was provided in weekly sessions of 60 minutes each of which the exact number of sessions was based on their clients' individual needs. All sessions were videotaped with written consent of the client or caretaker. During treatment all clients, except one (client #3), were accompanied by a parent or professional caregiver in order to provide a sense of safety, to overcome communication disabilities, to facilitate an integration of the therapeutic process and daily life, and/ or to function as a co-therapist. In each session clients, parents or caregivers were asked to report observed changes in daily life functioning, with specific attention to complaint-related behaviors.

Treatment

Eye Movement Desensitisation and Reprocessing (EMDR) is a psychotherapeutic approach, developed to resolve symptoms resulting from disturbing and unresolved life experiences (Shapiro, 2002). Eleven randomized controlled trials have evaluated the effects of the eye movements in relation to memory and demonstrated a variety of effects including emotional dearousal, decrease in imagery vividness and episodic retrieval (Bisson et al., 2007). EMDR is based on a theoretical, information processing model, which

posits that the symptoms are likely to disappear when the memories are fully processed and integrated (Maxfield, 2007; Shapiro, 2002). It requires the client to attend a bilateral “dual attention” stimulus (typically the therapist’s fingers moving back and forth in front of client’s face; sometimes audio tones or hand taps are used) while concentrating on the trauma memory (Shapiro, 2001).

Briefly, EMDR treatment consists of (1) Taking history and planning treatment, (2) an explanation of and preparation for memory processing, (3) preparation of the target memory, in which the client is asked to focus on the worst moment of the memory in a multi-modal manner, including image, thought, emotion and physical sensation, with concomitant measurements and (4) active reprocessing of the memory. In the desensitization phase, the therapist asks the client to hold the target image in mind while concentrating on the bilateral stimulation (BLS) for about 30 s. The client reports briefly what comes up, and is guided by the therapist to refocus attention along with the stimulus according to standardized procedures. During subsequent ‘sets’ associations that arise may become the focus of attention. Processing continues until the client reports no remaining distress related to the memory. The client is then (5) guided to embrace a relevant positive belief regarding the event and to (6) identify and process any residual disturbing body sensations. The therapist then facilitates (7) a positive closure to the session, which is followed by (8) a re-evaluation during the subsequent session, in which the client comments on previously processed targets as a basis for guiding further intervention.

The EMDR procedure in the present study is the Dutch translation (De Jongh & Ten Broeke, 2009) of Shapiro’s (Shapiro, 2001) protocol, and has been adapted to the level of clients’ cognitive and emotional functioning as suggested by Tinker and Wilson (1999), Lovett (1999), Greenwald (1999), De Roos & Beer (2008) and Seubert (2005). In general a short explanation of the treatment in terms of “exercises to get rid of bad feelings about events” or “to help you fix the problem that brought you here” has been found to be sufficient. Parents or caregivers play a significant role in motivating the client, either as an information source for the therapist, as a co-therapist if the developmental level is significantly impaired, and/or as a support in reinforcing positive behaviors. In general, in contrast to the usual utilization, the therapist’s attitude is more directive without taking over, and language is simplified. Visual cues are used instead of abstract language, for example using facial images to represent feelings, or a drawing might represent the target memory if the person is not able to mentally visualize it. Physical gestures help communication. By spreading hands or arms apart or bringing them closer, the client can indicate the amount of disturbance related to the target image. Parts of the protocol that appear to be too difficult are eliminated.

When the person is unable to perform eye movements, other forms of bilateral stimulation are used, primarily bilateral sound and tactile stimulation. From a developmental

level of ± 3 years downward the Story Telling Method (Lovett, 1999) is employed, with parents or caregivers narrating the story. The story will have a positive start, recognizable by the client. The next part of the story concentrates on the traumatic events, including distressing details the person might have seen, heard, felt, thought or smelled. The way in which the client had responded to the symptoms that emerged after the event was included. Finally, a recognizable positive ending is formulated as well as positive client self-beliefs. During the entire story, bilateral stimulation is applied. The story is repeated until the disturbance related to the target image has disappeared (SUD=0). Between the story narrations, an enjoyable game can be suggested to relax the client and to emphasize safety and empowerment in present time, in contrast to the temporary disturbance from the traumatic past. In the beginning of each session a positive self-belief may be installed, gleaned from some recent positive experience.

The primary treatment goal for all clients was to eliminate PTSD-like symptoms.

In the following case descriptions client's level of functioning is represented as noted in the client's records.

RESULTS (SEE ALSO TABLE 3)

Client 1

John is a 32-year old man with mild ID (WISC-R: Dutch version of the Wechsler intelligence scale for children-revised [Haassen, 1986; Wechsler, 1974]; Total IQ 69, Verbal IQ 70, Performance IQ 69). He lives in a supervised apartment in a large city and works in a sheltered workshop. 5 years ago he had a severe scooter accident. Since then John has been extremely frightened whenever he sees a motor vehicle or scooter accident on television. Each year he feels badly on the anniversary of the accident. John's stress impacts greatly on his intestines, requiring approximately 20 daily visits to the bathroom. At work he is not able to tolerate criticism and his pace is slow. Riding had always been his favourite hobby, but since the accident he has avoided horses. John does not remember anything about the accident itself, since he lapsed into a coma. He becomes agitated at the thought of the man who, after he woke up from coma, accused him of jumping the traffic lights, something he said never happened before. In his files other negative life events were discovered. His parents had divorced when he was at the age of 12 and when 22 years old he was accused of sexual abuse and was treated for that.

The scooter accident was treated in the first session. He described the target image, which he could mentally visualize, as "the car en me lying on the ground". He was thinking "I am in danger", he felt anxiety and rated the distress as 10 on a 0-10 scale, located in his stomach. Bilateral stimulation was applied by using an electronic auditory device. After fully

reprocessing this traumatic memory, a future template was installed: "I am riding again and feel relaxed". During the second session John revealed that he was suffering from outbursts of anger and he reported that there was another overwhelming event that bothered him much of the time. His girlfriend broke off their engagement after having been together for 4 years. Enraged, he hit her and now considered himself a criminal as a result. In the target image he saw himself hitting his girlfriend, and judged himself an "abuser". By way of contrast, he wanted to perceive himself as "being good with girls". The latter preferred belief did not feel very true (he rated this a 4 on a 1-7 scale with one feeling not true at all and seven feeling completely true). He felt angry, with a distress of seven on a 0-10 scale located in the upper part of his body. The event was reprocessed during that second session.

At a 4 month follow-up, John was no longer upset when experiencing scooter accidents. He was able to take the same route to work as he had before the accident (John had not mentioned earlier that he had been avoiding this route since the accident). The anniversary of the accident passed without his being triggered. He was very proud that he had started riding again; a bit stressful at first, but manageable. Outbursts of anger as well as physical complaints had decreased. He was doing well at work and he noticed he was working more efficiently. The only problem remaining was the fact that he was still single. He asked his care giver to help him learn how to create new relationships.

Recently, 28 months later, John's now former caregiver visited him on his birthday. John was doing very well. The positive effects of therapy had lasted, and John had succeeded in building a new, stable relationship, which he was still enjoying after 2 years.

Client 2

Mitchell is an 11-year old boy with mild ID (Total IQ 61, Verbal IQ 72, Performance IQ 55). He has been diagnosed with autism spectrum disorder, specified as multiple complex developmental disorder (MCDD; [de Bruin et al., 2007]). Prominent are fears, compulsive behavior, obsessions (e.g. fires), hearing voices and difficulties distinguishing reality from fantasy. Pipamperon, a mild antipsychotic, had been prescribed for a period of 4 years. Play therapy had ended a few months before an EMDR referral. At age 7 Mitchell had been removed from the home because his parents were not able to control his behaviors. After two temporary placements he was eventually put in a group home and a special needs school at the age of 8 and is functioning quite well in both. Due to considerable fear, he avoids sleeping at home where his mother lives together with her third partner, Mitchell's brother and little sister. Because he hears voices urging him to act out aggressively, Mitchell's visits to his mother's home are accompanied by outbursts of anger and fights with his brother. The visits are consequently limited and require the presence of a caregiver.

Mitchell was able to draw and successfully process the following overwhelming events that still bothered him: 1) as a little boy, voices forced him to throw things. He threw a

Table 3. EMDR treatment in four patients with mild ID

Case number	age	M/F	Level of ID and comorbidity	Complaints	Trauma's/ life events	Number of sessions	Results	Follow-up
1	32	M	Mild	Frightened when confronted with accident-related stimuli; feeling bad every year at accident date Easily upset, accompanied with intestinal problems Unable to take criticism Slow pace Avoiding activities	Severe scooter accident 5 years ago 4 years ago girlfriend broke off relationship, then he hit her Parents divorced at age of 12 Accused of and treated for sexual abuse at the age of 22	2	Able to think of traumatic memories without getting upset	4 months: Avoiding behavior disappeared Taking up activities Outbursts of anger decreased Physical complaints decreased 32 months: Results maintained Client had build up a stable relationship

Table 3. EMDR treatment in four patients with mild ID (continued)

Case number	age	M/F	Level of ID and comorbidity	Complaints	Trauma's/ life events	Number of sessions	Results	Follow-up
2	11	M	Mild	Fears Compulsive behavior Obsessions Hearing voices Difficulties distinguishing reality and fantasy Avoiding to sleep at parental home Visiting parental home goes along with outbursts of aggression	Witnessing car fire As a little child throwing things when hearing voices Being threatened by an abusive man; police were called but did not come Witnessing domestic violence Parents divorced Outplacements	5	Able to visit parental home without problems Relaxed Obsessive and compulsive behaviours decreased	6 weeks: Results maintained and able to sleep at parental home without problems 3 months: Results maintained Behavioral problems completely disappeared Medication was successfully faded out 18 weeks: Results maintained

Table 3. EMDR treatment in four patients with mild ID (continued)

Case number	age	M/F	Level of ID and comorbidity	Complaints	Trauma's/ life events	Number of sessions	Results	Follow-up
3	53	F	Moderate / Mild	Panic attacks, often followed by hospitalization Physical complains when distressed Easily upset Persistent anger Nightmares Obsessive thoughts Hearing voices Avoiding places	During childhood troubles at school Repeatedly witnessing domestic violence Witnessing father's death Divorced twice Mother died Emergency admission in hospital Various surgeries	13	Panic attacks disappeared Sleep problems disappeared Mentally relaxed Initiating activities Feeling cheerful Social relationships improved Keeping calm when physical complaints and medical treatments	6 months: Results maintained 13 months: Results maintained with still growing independency

Table 3. EMDR treatment in four patients with mild ID (continued)

Case number	age	M/F	Level of ID and comorbidity	Complaints	Trauma's/ life events	Number of sessions	Results	Follow-up
4 Eve	7 years	F	Mild Autistic disorder	Fears Compulsive behaviors Outbursts of anger Frequent mood changes Disturbing thoughts about illness/knives/death	2 dear family members died Suicide attempt of fathers' best friend Serious illness of school friend	3	Disturbing thoughts disappeared	7 weeks: Results maintained and more often cheerful significant decrease of anger outbursts more relaxed
								3 months: results maintained

vase and his little brother started crying: 2) a car fire in front of his family home: 3) a quarrel between his mother and her friend; 4) a “nasty man” was at the house ordering him to speak to his mother; the police were called, but never arrived. Mitchell preferred the combination of both auditory (headphones) and tactile (buzzers) stimulation. The choice of the sequence of target memories was left to Mitchell. He decided to begin with the target image of “the nasty man”. In this memory, the target image of seeing the nasty man standing in the door, was accompanied by the negative belief “I am in danger”, a feeling of anger with distress rated 9 on a 0-10 scale, and a ticklish feeling in his belly. His second choice centered around the image of seeing his mother coming back from a first aid station, with his negative thought “I can’t do anything”. He felt angry, sad and anxious simultaneously, and again reported a distress of nine with the same ticklish feeling in his belly. In the third memory he targeted the image of “the car, completely black with broken windows”. His corresponding, presently held, negative belief was “I can’t do anything” and he pointed to his right forearm as the location of an anxious feeling which he rated at a maximum level of ten. The fourth session targeted an intense fight between his mother and his first stepfather, which resulted in his stepfather packing his bags, and leaving the house for good. He brought up this event in light of a recent nightmare. Mitchell described the corresponding target image as follows: “My stepfather is standing in front of my mother and shaking his hands at her. I see my self close to them, and I’m afraid of my stepfather’s angry outburst”. After these memories had been successfully processed and resolved, Mitchell chose to address, the one centering around the voices in his head that had caused him to throw the vase. To his great surprise, while preparing this target memory, he felt no distress at all, “without using these!”, he exclaimed, pointing to the buzzers and the headphones on the table.

After the five sessions needed to process these memories, the voices had disappeared and the short visits at his parental home went smoothly. Mitchell became calmer, and his compulsive behaviors decreased. The visits were extended and 6 weeks later he had slept at home three times without any reported difficulties. His problematic behaviors completely disappeared, despite the tumultuous atmosphere of his group home and his mother’s partner leaving her. During the next 6 weeks a systematic phasing out of his medication was completed, and the diagnosis of autism spectrum disorder no longer applied. At another 6 week follow-up, results maintained.

Client 3

Mary is a 53-year old woman with moderate to mild ID (WISC-R: Dutch version of the Wechsler intelligence scale for children-revised [Haassen, 1986; Wechsler, 1974]; Verbal IQ 49; SRZ-P: Dutch social adaptive behaviour scale for individuals with a higher level of intel-

lectual disability (Total score 7 [Kraijer & Kema, 2004]). Together with her partner she lives in a supervised apartment and works in a sheltered workshop for a few hours every week.

About 17 years ago she witnessed her brother-in-law choking her father. Since that event Mary has suffered from panic attacks with increasing intensity and frequency. Given an impaired heart valve, and not wanting to take chances when these events occur, the panic attacks often result in hospitalization. Mary gets angry easily and persistently. She has taken an SSRI for a year and a half to reduce her anxiety. Mary reports suffering from nightmares, states that "it's busy in my head", and experiences a ringing sensation in her ears. She often hears her brother-in-law's voice, saying "I'll catch you!". Additionally she avoids a street where she had seen a well.

During history taking a list of other negative experiences was compiled, including the following: at school her notebook was torn apart by a teacher, which resulted in her detesting school; frequent quarrelling at her parent's home; witnessing her brother and brother-in-law beating mother; witnessing her father struggling to breathe and then dying; two divorces; her mother's death nine years ago; an emergency hospital admission five years earlier, due to pulmonary embolism and heart valve problems, which in turn led to a number of surgeries.

Mary was driven to her therapy sessions by a trusted volunteer, since her caregiver was not able to accompany her. Information exchange with the caregiver before and after each session was facilitated via e-mail. Since Mary had complained about the impact of the fight between her father and brother-in-law, this memory was targeted first. Headphones were used for auditory bilateral stimulation. In choosing the image of the worst moment of the memory, Mary saw herself witnessing her brother-in-law choking her father. As she held this image, the relevant negative thought was "I can't do anything", which was accompanied by a fear that she could identify in her larynx. It took five sessions to process this trauma. Within a couple of weeks, her care giver reported improvements in Mary's functioning, as she appeared more cheerful and was free of panic attacks. According to Mary, it felt better inside her head. On one particular day after the fourth session of working on this trauma, Mary was brought to the hospital. Although nothing appeared to be wrong, the feeling of tightness in her chest had been most distressing, she reported later on. After the traumatic memory was completely processed, her thinking was more peaceful, she could sleep well, and the panic attacks once again disappeared. The most distressing memory left was the image of her brother, punching her mother in the stomach. It took three sessions to process this memory. Throughout the time of this processing Mary's functioning in her daily life continued to improve. At times there was the feeling of tightness of her chest but it did not overwhelm her, nor did it lead to a panic attack. In the last three sessions, the memories of her father's death and of her own heart surgery were processed, leaving no more distressing memories after a total of 13 reprocessing sessions.

At a 6 month follow-up, panic attacks continued to be absent. Mary slept well and felt cheerful. Her anger outbursts had disappeared, social relationships had improved and she was willing to become involved in new activities. She was even able to walk past the well she had feared. In retrospect, it seems evident that this well had triggered the memory of seeing her father's coffin being lowered into the grave. Mary was admitted to the hospital at one point for a week, due to actual cardiac conditions. Noticeably calm, she cooperated with and underwent the required medical treatment.

Seven months after the first follow-up her caregiver reported that Mary still was doing very well. She remained remarkably calm and cheerful. Voices and panic attacks remained absent. Now and then medical problems occurred, which she dealt with appropriately. The phasing out of her medication had been advised, but caregivers forgot this recommendation, leaving her medication regimen at present unchanged.

Client 4

Eve is a 7 year-old girl with mild to borderline ID (Total IQ 71, Verbal IQ 82, Performance IQ 64). At the age of six she was diagnosed with childhood disorder NOS with concomitant diagnosis of obsessive compulsive disorder. Recently she was referred for further specialized assessment which resulted in the diagnosis autism spectrum disorder. Eve suffers from anxiety, compulsive behaviors, outbursts of anger, and frequent mood changes, but most of all from disturbing thoughts about illness, death and knives. Life history was gathered with the help of her parents. No painful memories were identified at that time. Consequently, the diagnosis of autism spectrum disorder was changed to the more specific diagnosis of multiple complex developmental disorder (MCDD; [de Bruin et al., 2007]). Her parents were trained at home on how to deal with Eve's autism in daily life. A psychiatrist educated them regarding the possibility of medication. Simultaneously, Eve was offered an individual training aimed at teaching her to use relaxation techniques to deal with disturbing thoughts. After three such sessions, her symptoms significantly increased after hearing of the death of Michel Jackson. While analyzing that situation, both parents realized that in the past 3 years several overwhelming events had taken place. First of all, Eve experienced a dead body for the first time when a dear family member suddenly died. Secondly, her father's best friend had been missing for several days and was finally found with knife stabs in his body (Eve had not actually seen the knife wounds, but heard the frightening stories concerning that what had happened). Then, another close family member died after a short illness. Finally she saw pictures of her classmate with a life threatening illness, lying in a hospital bed, surrounded by an array of medical equipment.

Given this new information, EMDR treatment was offered in place of the relaxation training. Eve's poor communication skills and her sudden reluctance to follow instructions

became obstacles to the use of the standard protocol. Consequently, the story telling method was used. For the BLS, she held buzzers in her hands. Following a preparation session with her parents, it took three sessions to process the traumatic memories. Her disturbing thoughts disappeared, and at a 7 week follow-up, the effects had lasted. Moreover, she exhibited a positive mood more often, her outbursts of anger had significantly decreased, and, in general, she was more relaxed. Unexpectedly after this progress, Eve's parents called again for help, relating that Eve had become anxious while watching television or a DVD. Upon examining the situation, it became clear that it was not an anxiety, but a reactive stress response, since Eve had not been educated as to what movies were good for her to see. With support and care at home, Eve's parents turned "watching films" into a predictably positive activity for Eve. The stress disappeared, and at a 3-month follow up treatment effects had lasted. The use of medication was ruled out. A psychiatric consultation was arranged, and Eve was ultimately diagnosed with Autistic Disorder.

DISCUSSION AND CONCLUSIONS

The results of the four cases suggest that EMDR can be used as a treatment for people with mild ID as the application of the procedures resulted in a clear reprocessing of the memories related to the traumatic events. Following treatment, none of the four clients fulfilled the diagnostic criteria of PTSD according to the DSM-IV-TR (American Psychiatric Association, 2000) and DM-ID (Fletcher et al., 2007). Despite their intellectual disabilities, it was possible to adapt instructions to clients' cognitive and emotional level. For example, with clients #1, #2 and #3 the protocol for children was used and matched to their cognitive level of functioning. These clients appeared to be able to put images, thoughts, feelings and physical sensations into words. Despite a cognitive level of mild ID, client #4 required story telling, due to the subject's severe communication impairments, a prominent feature of her autistic disorder (Noens & van Berckelaer-Onnes, 2004).

With regard to treatment efficacy, the decrease of PTSD-like symptoms following a relatively small number of EMDR sessions is in line with the previously published findings of the three EMDR case reports of PTSD treatment in subjects with mild ID (Giltaij, 2004; Rodenburg et al., 2009) (see also Table 2). Additionally, the findings of this study demonstrate that in all four cases PTSD-like symptoms that had been present for 3 to even 17 years, dissipated after two to thirteen EMDR treatment sessions. Treatment effects remained at the 3-month and the 2.5 year follow-up. Moreover, depressive symptoms (clients #3 and #4) and physical complaints (client #1 and #3) decreased, developmental growth increased, and social and adaptive skills improved (#1 and #3). The observation that positive growth factors occurred subsequent to treatment has important implications for this population and should be evaluated in future research.

The complete elimination of the symptoms post-treatment that had caused the caretakers to seek treatment for the clients also sheds light on the need to evaluate ID patients for distressing life events that may be foundation pathology whether or not they are Criterion A events, or if the symptoms raise to full diagnostic criteria for full PTSD (Mol et al., 2005; Shapiro, 2001). Specifically, the complete treatment effects were derived after processing memories that might be considered “life-threatening”, and others that distressed the client such as quarrels, and unfortunate acts by teachers or other authority figures. Further, the present findings should be considered in light of the difficulty in establishing a proper PTSD diagnosis in people with ID, as well as the lack of data regarding this population’s treatment responsiveness (Mevisen & De Jongh, 2010). Therefore, feedback for the present study was gathered by interviewing parents and caregivers according to DSM-IV-TR (American Psychiatric Association, 2000) and DM-ID (Fletcher et al., 2007). It emerged that all patients had been exposed to more than one overwhelming event, and at least one of the events for each client seemed to meet PTSD criterion A1 for trauma (DSM-IV-TR [American Psychiatric Association, 2000]). These criteria include experiencing threat to physical integrity of self (client #3), experiencing the threat of death or personal injury (client #1), witnessing an actual death (client # 3), or the threat of death or serious injury to others (client #2, #3 and #4). The second PTSD criterion (A2), DSM-IV-TR (American Psychiatric Association, 2000) includes a response involving intense fear, helplessness or horror. Of the four cases, only clients #2 and #3 were able to report emotional awareness while experiencing or witnessing the overwhelming event. This seems to be the core problem with diagnosing people with ID with PTSD, as they often are unable to communicate feelings of helplessness or horror, particularly verbally. Clients with autism, in particular, tend to express their emotions in atypical ways. Consequently, the emotional impact of an event might be concealed even from trusted persons (client #4). Another complicating factor is that, in comparison with the general population, differences may occur in the expression of symptoms, and in the interpretation of distressing experiences (Mevisen & De Jongh, 2010). Based on patients’ complaints (see Table 3), re-experiencing of trauma, PTSD criterion B (DSM-IV-TR [American Psychiatric Association, 2000]), appears to be the most recognizable symptom in all four subjects: nightmares, hearing voices (client #3), being frightened by trauma-related stimuli (client #1), voices (clients #2 and #3), fantasies (client #2), and disturbing thoughts (client #4). The difficulty in diagnosing PTSD in clients with ID is perhaps best illustrated when considering PTSD criterion C (DSM-IV-TR [American Psychiatric Association, 2000]), which lists seven signs of avoidance, at least three of which have to be present. This criterion seems hardly applicable to clients with mild ID, because it relies strongly on verbal, subjective reporting. Consequently, with respect to this criterion, the DM-ID (Fletcher et al., 2007) places great significance on reports from parents and caregivers regarding signs of “non-compliance” and self-isolation. It is important to note that it was after treatment that the primary caregivers of all clients in

this study, except for the one with autism, reported remarkably positive changes in terms of “taking up activities”, “improving independence” and “learning new skills”. Thus, only with hindsight were the symptoms of avoidance noted. With regard to the client with autism (#4), it was difficult to notice symptoms of avoidance at all. After treatment however, parents reported that activities were taken up without aggression. Concerning criterion D, the situation is different. In 3 of 4 patients (clients #1, #2, and #3) PTSD criterion D (DSM-IV-TR [American Psychiatric Association, 2000]) appeared to be recognizable when considering the presenting complaints at the time of referral. Subject #4 reported only one of two required symptoms of arousal (i.e. anger outbursts). It is not clear whether other symptoms were really absent or just had not been noted by the caregivers. Remarkably, excessive anger was mentioned in all four patients. In subjects #2 and #4, traumatic re-experiencing was misinterpreted as a psychotic symptom, resulting in a diagnosis of multiple complex developmental disorder (MCDD; [de Bruin et al., 2007]). It should be noted that in subject #2 treatment results maintained after phasing out anti-psychotic medication. Moreover, due to the mistake of diagnosing ‘autism’ in subject #2 other PTSD symptoms seem to have been overshadowed. These assessment failures underscore the notion that until now the psychological impact of negative emotional events on people with ID has received little attention by professionals. This is particularly striking, given that people with ID seem to have a predisposition to the development of PTSD (Mevisen & De Jongh, 2010).

In conclusion, the results of the four single cases presented here show that PTSD symptoms can be identified with cooperation from parents or trusted caregivers. In all instances, PTSD symptoms decreased with results that were maintained at 3 months to 2.5 year follow-up. Moreover, depressive symptoms and physical complaints subsided and developmental growth increased, which included the improvement of social and adaptive skills. Given the length of the baseline period and the fact that treatment was limited to a maximum of 13 sessions, the improvements clearly suggest the applicability and potential effectiveness of EMDR in treating PTSD in clients with mild ID. Nevertheless, the application of evidence based treatment procedures for psychotrauma, such as EMDR and cognitive behavioral treatment (CBT), to the treatment of people with ID requires further and more rigorous investigation.

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3.2

EMDR treatment in individuals with moderate ID

Do persons with intellectual disability and limited verbal capacities respond to trauma treatment?

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ABSTRACT

Background There is not one case report of successful trauma treatment with the use of an evidence-based treatment method in people with substantially limited verbal capacities. This paper assessed the applicability of eye movement desensitisation and reprocessing (EMDR) in two clients with moderate ID, serious behavioural problems, and histories of negative life events.

Method The 8-phase protocol of EMDR, a first-line treatment for psychological trauma, was applied.

Results In both cases, posttraumatic stress disorder (PTSD)-like symptoms decreased in a total of only 6 and 5 sessions, respectively. Gains were maintained at 32 and 10 months' follow-up.

Conclusions EMDR seems to be an applicable psychological trauma treatment for persons with limited verbal capacities. Considering the importance of these findings, further and more rigorous research is required.

INTRODUCTION

In the general population posttraumatic stress disorder (PTSD) is known as a disorder with high prevalence rates (5-10%; Kessler, Chiu, Demler, & Waters, 2005) and disruptive effects on a person's daily life functioning (van der Kolk & McFarlane, 1996). Fortunately, effective treatment methods are available with trauma-focused cognitive behavioural therapy (TFCBT) and eye movement desensitisation and reprocessing (EMDR) having the strongest empirical support (Bisson et al., 2007; Rodenburg, Benjamin, de Roos, Meijer, & Stams, 2009).

People with intellectual disability (ID) have been found to be more likely to experience traumatic events and negative life events than those without intellectual disability (Tsakanikos, Bouras, Costello, & Holt, 2007). There is also tentative evidence for a causal role of life events with regard to psychological problems (Hulbert-Williams & Hastings, 2008). However, a recent review of the literature revealed that (1) there are no reliable and valid instruments for assessing PTSD in this population, (2) prevalence data on PTSD in people with ID are lacking, and (3) there are no evidence-based treatment methods for people with ID who suffer from PTSD (Mevisen & De Jongh, 2010). Because of its importance, PTSD is assigned its own chapter in the *Diagnostic Manual – Intellectual Disability* (DM-ID; Fletcher, Loschen, Stavrakaki, & First, 2007), including recommendations for adapted PTSD symptom descriptions in people with various levels of ID. Thus, PTSD in this population is an underdiagnosed, as well as an undertreated, disorder.

To date, four case reports of PTSD treatment of clients with ID using TFCBT and 13 using EMDR have been found in the literature (Barol & Seubert, 2010; Mevisen, Lievegoed, & De Jongh, 2011). Of these, 14 clients had mild ID and one had moderate ID. Since the latter person, treated with EMDR, was described as very articulate and able to reflect on feelings verbally, the question remains whether this case was representative of this population. Because of EMDR's largely nonverbal character, the purpose of the present case report was to extend aforementioned findings and to examine whether EMDR would be an applicable and effective treatment method for clients with substantial limited verbal capacities.

METHOD

The study was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all clients who agreed to participate after the procedures were explained. Ethical approval was not obtained from a medical ethical body because none of the participants had been restricted from participating in treatment; moreover,

there is no alternative treatment method available for PTSD-like symptoms with a similar evidence base for this group of people. In this case, under Dutch law and regulations, it is not necessary to seek ethical approval.

Participants

Participants were four clients with moderate ID and substantial limited verbal capacities. They were referred for outpatient treatment by their psychiatrist or other mental health professional as it was assumed that there was a relationship between their problem behaviours and a number of traumatic life events to which they had been exposed.

The first author, a clinical psychologist and EMDR practitioner with more than 30 years' experience with persons with ID and mental health issues, conducted clinical interviews with the participants and their trusted caregivers and examined their records. All participants seemed to experience PTSD-like symptoms, according to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR; American Psychiatric Association, 2000) and DM-ID (Fletcher et al., 2007). Given that these participants had a close relationship with at least one family member (and/or a trusted staff member), they were considered to be eligible for EMDR treatment. The legal representatives were informed about the study and invited to participate. All four agreed with EMDR treatment of their relative, but only two signed an informed consent form giving the researchers permission to include the treatment findings in their study.

Procedure

The first author administered treatment. Treatment and related procedures were explained in detail to the caregivers who supported the participants during the treatment sessions. The participants themselves underwent weekly therapy sessions of one hour each. The total number of sessions was based on their individual needs. The caregivers were asked to observe participant behaviour in daily life and to make notes about observed changes, especially with regard to the complaints for which they had been referred. All sessions were videotaped with written consent. The therapist analysed the tapes with regard to the most significant aspects of the trauma processing. Due to the participants' cognitive disabilities and poor verbal capacities, complaint-related changes had to be reported by the caregiver at the beginning of each session.

Treatment

EMDR is a protocolised, eight-phase psychotherapeutic approach, developed to resolve symptoms resulting from disturbing and unprocessed life experiences (Shapiro, 2001). 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 develop-

ment are typically 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 her¹ fingers back and forth in front of the client, asking the client to track the movements while keeping his head still), while concentrating on the trauma memory (Shapiro, 2001). 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 her 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 internal 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 (Shapiro, 2001). Phase VII is dedicated to closing down the session and preparing the client for the interim between sessions. Phase VIII consists of re-evaluation and integration.

EMDR practice is guided by a theory of adaptive information processing (Shapiro, 2007) which 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, 2001). The results of clinical outcome studies are corroborated by a large array of experimental studies showing that eye movements during recall of aversive memories reduce their vividness and emotionality (e.g., Engelhard, van den Hout, & Smeets, 2011; Gunter & Bodner, 2008). During recall, emotional memories become “labile,” (i.e., liable to change) and their reconsolidation is affected by experiences during recall (Baddeley, 1998). Recalling a traumatic memory is assumed to depend on working memory resources that are limited. If another task is executed during recall, fewer resources will be available for recalling an episode and the memory will be experienced as less vivid and emotional. Eye movements are held to serve as such a “secondary” task that taxes working memory (Engelhard et al., 2011; Gunter & Bodner, 2008). The needs of clinical practice have led to task variations. With children, for instance, the therapist might put stickers on her fingers to facilitate the child’s tracking. With even younger children, buzzers can be used to vibrate alternately between their right and left hand, or the therapist can provide tactile bilateral stimulation by tapping on the child’s hands or knees (Adler-Tapia & Settle, 2008). Auditory stimulation can also be employed, such as the use of alternating tones via a headphone or audio speakers placed on either side of the client.

Instructions as to how to activate the trauma memory, and how to support the client during the desensitisation and reprocessing phase, are age-related and adjusted to the person's mental age, taking into account any associated conditions such as autism (Adler-Tapia & Settle, 2008; Barol & Seubert, 2010; Greenwald, 1999; Mevissen et al., 2011; Tinker & Wilson, 1999). In Phase III, for example, children with a mental age between 4 and 8 are asked to draw the target image instead of describing it verbally. The negative and positive cognition are omitted with clients younger than 5, and in Phase IV the level of distress is measured in a concrete, visual way with the use of facial images or spreading hands. The Story Telling Method (Lovett, 1999) is of great use when applying EMDR to the youngest children (< 3 years). Typically, parents or caregivers tell the story of the traumatic event. The story has a positive beginning, followed by the relating of the traumatic event, which includes the distressing details as to what was seen, heard, felt (emotionally and somatically), thought, or smelt. Occasionally, photos, drawings, or physical objects are employed to engage the senses and to activate the trauma memory. The story also includes the way the person responded, but the ending is always positive, including a positive self-belief.

RESULTS

A description of the two clients, including a summary of the results of their treatment is provided in Table 1.

Case 1

Maria could be described as a young woman living with her family who was sexually abused by two perpetrators. She has moderate ID (WISC-R; IQ = 44) and symptoms of autism. Maria had become restless, had sleep problems, and was often tearful. She displayed aggressive outbursts and obsessive behaviour. Her personal hygiene deteriorated, and she was quite demanding of her mother. These problems started three months after she had been sexually abused. Play therapy was ineffective, and her complaints worsened. An antipsychotic medication (risperidone) was administered, but with no positive results. Maria then had to be placed in a crisis unit, since her parents could no longer manage her behaviours.

Since Maria was neither able to speak nor create drawings about the abuse, the Story Telling Method was employed. In terms of general description, her mother narrated the events, including the forced move to the crisis unit. Maria could not tolerate headphones, buzzers, or eye movements. Consequently, external audio speakers were chosen. In the first session, Maria reacted emotionally, rage slowly changing to anger and ending with

Table 1. EMDR treatment of two patients with poor verbal capacities

Case	Level of ID & comorbidity	Complaints	Trauma/life events	Number of sessions	Results	Follow-up
Maria (young woman)	Moderate Symptoms of autism	Restless Possessive of mother Sleep problems Aggressive outbursts Tearful Bad personal hygiene Obsessive behaviour	3 months ago sexual abuse by two perpetrators Outplacement in crisis unit recently (parents could no longer handle behavior problems) Parents divorced years ago	6	No longer restless Obsessive behaviour disappeared Sleeping pattern normalised Positive mood returned Aggression disappeared Personal hygiene normalised	4 months: Results maintained 32 months: Results maintained with increased self-sufficiency
Simon (middle-aged man)	Moderate	Since 10 months: Aggressive outbursts; e.g., threatening with knife Complaining Shaking Possessive of caregivers and girlfriend Eating too much/ stuffing food in mouth	10 months ago mother died In his late adolescence father died of heart attack 10 years ago outplacement; family's farm was sold, mother moved Courtship broken up, forced by others	5	Self-sufficiency increased Able to talk about mother in an appropriate way More relaxed Excessive rage disappeared Asked for help when in trouble Able to talk about thoughts and feelings	10 months: Results maintained
			After 4 EMDR sessions: Lost his way during trip abroad, was found after 2 days and brought to police station			

sadness. During the second session, she was able to verbalise to some extent what the perpetrators had done to her and could tolerate buzzers in her hands. Complaints decreased overall and visits to her parents' home were re-established. In the fifth session, Maria created sequential drawings of what had happened. Each of nine drawings was regarded as a separate target (being kissed, in the shower, touching breasts, etc.) and was processed separately. Each target still elicited some emotional disturbance, but they were all fully reprocessed. Finally, a future template was installed; for example, a fearful situation that she typically avoided after the traumatic event was imagined and accompanied by a positive belief. Maria successfully imagined meeting the perpetrators, while telling herself, "Yes, I can!"

After six 1-hour sessions Maria was no longer restless, the obsessive behaviours had disappeared, her sleeping patterns returned to normal, and her positive mood returned. Aggression ceased, and her personal hygiene improved to its former status. Effects of treatment were maintained after four months. Maria's only remaining difficulty was being alone at home.

During a 32-month follow-up, her mother reported that Maria was still doing very well. In the interim, she had moved voluntarily to her own apartment, with the support of caregivers. Her independence continued to increase. She had a job, and in her leisure time she was taking a course in reading and writing. The only difficulty, according to the mother, was in getting Maria to curb her enthusiastic phone calls to her parents. Importantly, she eventually ran into the perpetrators without becoming upset.

Case 2

Simon is a middle-aged man with moderate ID (WPPSI-R; average developmental level 4.9 years)² living in a group home. Ten months ago Simon's mother died. Subsequently, he became aggressive, threatened someone with a knife, and was suspended from work. Caregivers and family members feared he would attack others. He developed an ongoing physical shaking and he began to overeat, actually stuffing food in his mouth. Simon knew Ann, his girlfriend, a woman with mild ID and autism, from childhood. They were in fact colleagues, and Simon was quite possessive of her and his caregivers in general. Yet, he began to continuously complain about Ann.

The first session was used to initiate preparation for treatment with a trusted family member and caregiver. In taking his history, other traumatic events surfaced. When Simon was in his late adolescence, he experienced several profound losses. His father suddenly died of a heart attack. Simon was left behind at the farmhouse with the other members of the family. Simon and his father had been close. Each day when Simon returned from school, he assisted his father in the cowshed. After his father's death, the farm work had to be maintained, so Simon became his mother's helper. During that same period, he

changed from school to a workshop. Ann got a job elsewhere, so they met less frequently. Approximately 20 years later, the farmhouse was sold and his mother moved into an apartment, and Simon was placed in a group home. Simon became passive, was often in a bad mood and was very possessive of Ann. Caregivers decided that their relationship needed to be dissolved. About two years after his placement in the group home, Simon received a psychiatric evaluation, yet no diagnosis was established. The only recommendation was to arrange for meaningful activities for Simon. Gradually, he improved and stabilised.

A close family member was present for each EMDR session. It took four 1-hour sessions to treat Simon's traumatic memories. The first memory targeted in the session was his mother's death. Simon drew an image representing the memory: Simon himself, his mother, and an empty house. He felt "a pity," and reported "a lot of" disturbance in his "belly." This memory was fully processed with using buzzers as a secondary task. However, with regard to the memory of his father's death, Simon was not able to talk about what had happened, nor could he draw the memory. His facial expression, however, revealed emotional stress, so bilateral stimulation (using buzzers in his hands) was initiated. At the end, to be sure that all aspects of the memory were reprocessed, the therapist narrated the entire story of the father's death, while administering the buzzers, until there was no distress left. The forced break-up of his relationship with Ann was treated in a similar manner.

As a result of treatment, Simon became more relaxed. He still became frustrated when teased about Ann by his peers, but his extreme rage responses disappeared. His dependence on Ann and his caregivers decreased, whereas self-reliance increased, and he could now talk about Ann and about his mother more calmly.

Shortly after his fourth treatment session, another overwhelming event occurred. Simon and Ann joined a trip abroad with their peers. They were separated from the group at one point, and subsequently lost their way. Unable to find them, an international search effort was initiated. At the end of the second day, the search team found them and brought them to a police station, where their families could retrieve them. Within a week, an EMDR session was arranged to help Simon reprocess the event and, at a 10-week follow-up, his improved functioning maintained. Simon was doing well at work, and his swearing and threatening behaviours ceased. He was able to simply talk about his thoughts and feelings, and he consulted his caregivers whenever he experienced difficulties.

At a 10-month follow-up, Simon's caregiver reported that problems in the relationship between Simon and Ann continued at their sheltered workshop, involving aggressive behaviours on both parts. A change of workplace for Simon was set in motion. Ann's autism and Simon's cognitive limitations together seemed to create insurmountable obstacles to mutual satisfaction in their relationship, but he could now accept the help of his relatives and caregivers in managing his problems with Ann. Simon no longer showed any signs of

disturbance, either with regard to the death of his parents or to the experience of being lost. His growth in independence continued, and he continued to do well in his group home, as well as with his family members.

DISCUSSION

These case descriptions suggest that EMDR is a potentially applicable psychotherapeutic treatment method for clients with ID, even if they have substantially limited verbal capacities. The results are congruent with research findings when employing EMDR with people with mild intellectual disability (Barol & Seubert, 2010; Mevissen et al., 2011). Both participants met PTSD criteria as described in the DM-ID, particularly when one considers their trauma histories and the behavioural changes that occurred after treatment.

The two clients were unable to express themselves with regard to (some of) the traumatic events, neither in simple words nor in a drawing. In the absence of such communication, it was necessary to use a trusted caregiver's report regarding what had happened to create a narrative, which then activated the trauma memory. In both clients it was possible to bring back the SUD level comparable to zero, according to the observations made by the family members who accompanied them during treatment. The serious and increasing behavioural problems were resolved after five 1-hour EMDR treatment sessions and were maintained at 10 months' follow-up; extreme aggressive outbursts were solved after six sessions without any homework and maintained at the 32-month follow-up. Moreover, in both cases personal functioning improved and the results were maintained at 10- and 32-months' follow-up, respectively.

The findings highlight the need for further exploration of EMDR's applicability in people with severe ID and to assess the scope of its utilisation within people with ID and mental health issues. Although there may be concern for the safety of the clients undergoing treatments that may involve emotionally charged materials in this population, our experiences suggest the opposite. None of the clients we treated thus far showed any exacerbation of symptoms due to the treatment.

With regard to the methodological shortcomings of this preliminary study more rigorous research is needed, particularly with regard to the effectiveness and efficacy of EMDR in people with various levels of ID, for instance by using multiple baseline designs. This also requires the development of a valid and reliable instrument for the assessment of PTSD in people with ID, as well as well-trained, certified EMDR therapists, who also possess expertise in working with this population. To this end, awareness of PTSD and potential triggers in persons with ID is a prerequisite for treatment. The more limited a person's verbal capacities are, the more difficult assessment will be. Therefore, awareness of this

deficit among medical and mental health professionals, family members and caregivers is important. It will alert them more immediately to behavioural changes that follow negative life events and, consequently, increase the possibility of successful treatment.

AUTHOR NOTE

No research funding was involved and there was no conflict of interest.

NOTE

- 1) For clarity in this report, the female pronoun is used to denote the therapist and the male pronoun the client.
- 2) The level of functioning is reported as described in the participant's file.

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3.3

EMDR treatment in individuals with severe ID

**Treatment of PTSD in people with severe intellectual
disabilities: A case series**

L. Mevissen, R. Lievegoed, A. Seubert, & A. de Jongh

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ABSTRACT

Objective There is a dearth of information regarding the treatment of PTSD in people with severe intellectual disabilities (ID). The purpose of the present case studies was to assess the applicability and effects of an evidence-based treatment method for psychological trauma with this population.

Methods The treatment of four single cases with Eye Movement Desensitization and Reprocessing (EMDR) was evaluated. Participants included adults and children with a variety of symptoms, as well as different histories of negative life events.

Results In all cases PTSD symptoms decreased. In all but one case, the gains were maintained at 15.5 months to 2.5 years following treatment. Depressive symptoms and physical complaints diminished, and social and adaptive skills improved.

Conclusion EMDR seems to be an applicable treatment method for clients with severe ID. Reduction and maintenance of PTSD symptoms in individuals with severe ID appears to be both desirable and obtainable.

INTRODUCTION

Individuals with intellectual disabilities (ID) are more likely to experience traumatic and negative life events than individuals with normal development (Ryan, 1994; Tsakanikos, Bouras, Costello, & Holt, 2007). Furthermore, people with ID seem to be at greater risk of suffering from the disruptive effects of trauma, including posttraumatic stress disorder, or PTSD (Mevisen & De Jongh, 2010).

Although persons with ID may be more susceptible to the development of PTSD, those who work with this population often lack this awareness (Mevisen & De Jongh, 2010). Moreover, it is not clear to what extent individuals with ID suffer from the same PTSD symptoms as non-disabled persons. To this end, recommendations for adapted PTSD symptom descriptions in people with ID have been proposed (Fletcher, Loschen, Stavrakaki, & First, 2007). For example, there is evidence to suggest that a traumatic experience manifests itself in disorganized or agitated behaviour, while re-experiencing the trauma in people with ID often takes the form of behavioural acting out of traumatic experiences, self-injurious behaviour, frightening dreams without recognizable content and trauma-specific re-enactments that can appear as symptoms of psychosis in adults (Fletcher, Loschen, Stavrakaki, & First, 2007; Focht-New, Clements, Barol, Faulkner, & Pekala, 2008). This difference in response to a trauma trigger may explain why reliable and valid instruments for assessing PTSD in people with lower levels of ID are lacking, why there are no data on the prevalence of PTSD in the ID population, and why there are no evidence-based treatment methods for people with ID who suffer from PTSD (Mevisen & De Jongh, 2010, Wigham, Hatton, & Taylor, 2011a; Wigham, Hatton, & Taylor, 2011b).

Regarding PTSD treatment, several evidence-based treatment methods are available, with Trauma-Focused Cognitive Behavioral Therapy (TF CBT) and Eye Movement Desensitization and Reprocessing (EMDR) having the strongest empirical support (Bisson, Ehlers, Matthews, Pilling, Richards, & Turner, 2007; Cloitre, 2009; National Collaborating Centre for Mental Health, 2005; Rodenburg, Benjamin, De Roos, Meijer, & Stams, 2009). In contrast to the treatment of non-disabled, reports on treatment of PTSD symptoms in people with ID are rare (Mevisen & De Jongh, 2010). To date, 20 case reports of PTSD treatment of individuals with ID could be found in the literature (Barol & Seubert, 2010, Fernando & Medlicott, 2009; Mevisen & De Jongh, 2010; Mevisen, Lievegoed, & De Jongh, 2011a; Mevisen, Lievegoed, Seubert, & De Jongh, 2011b; Rodenburg, Benjamin, De Roos, Meijer, & Stams, 2009a). In 19 of these case reports, either CBT (4) or EMDR (15) was employed. In all but two of them positive results with regard to PTSD symptoms were reported. It is noteworthy that only one case description pertained to PTSD treatment of clients with severe ID. In this case the clinician employed EMDR to treat the current problem that the client presented in session. The authors noted that it was impossible, however, to address

earlier, core traumatic memories that gave rise to the client's immediate difficulties (Barol & Seubert, 2010). The few other published case reports of trauma treatment in people with severe ID mainly involved psycho-dynamic treatment of sexual abuse (Beail, 1998; Cottis, 2008; Sinason, 1992). Although these case reports suggest positive treatment effects, the focus was not specifically on the treatment of PTSD symptoms, and the treatment was not protocolized. Thus, treatment reports regarding people at lower developmental levels in which PTSD symptoms were treated with an evidence-based treatment are scarce.

The present study, therefore, focuses on examining the applicability and effectiveness of Eye Movement Desensitization and Reprocessing (EMDR) in a sample of 4 people with severe ID and a variety of complaints, ages and types of overwhelming events.

METHODS

The method used in this study is comparable to the method used in a previous study by the same authors regarding the applicability and efficacy of EMDR in subjects with moderate ID (Mevissen, Lievegoed, Seubert, & De Jongh, 2011).

Participants

Nineteen clients, assumed to be suffering from complaints related to one or more overwhelming life events, were referred for outpatient treatment. The four clients with severe ID and PTSD-related symptoms according to DSM-IV TR (American Psychiatric Association, 2000) and DM-ID criteria (Fletcher, Loschen, Stavrakaki, & First, 2007), who participated in this study were referred by a psychologist (Patient #1, #2, and #4) or a psychiatrist (patient #3). The first author determined the appropriateness of each participant for EMDR treatment based on client files and by means of a clinical interview with the client and caregiver. Because of the severe cognitive impairment of the clients, participation by a family member or a trusted staff member who knew the client's history, was supposed to be necessary. The determination of each client's functioning level was based upon client records. Information about treatment and related procedures were explained in detail to the caregivers, who were also given printed treatment information to be read at home. The legal guardians of all four clients agreed to EMDR treatment for their wards and to their participation in the present study, and signed an informed consent form. None of the clients received any other form of treatment concurrent with this study.

Procedure

All treatments were administered by the first author, a clinical psychologist and a registered EMDR practitioner with more than 30 years experience with persons with ID. Treat-

ment was provided in weekly sessions of 60 minutes each, the number of sessions being based on the client's individual needs. During treatment, all clients were accompanied by the trusted person in order to provide a sense of safety, to overcome communication disabilities, to facilitate an integration of the therapeutic process with daily life, and to function as a co-therapist. All sessions were videotaped with written consent. The therapist analyzed the tapes with regard to the most significant aspects of the trauma processing. In each session the trusted persons were asked to report observed changes in daily life functioning, with specific attention to complaint-related behaviours.

Treatment

All participants were treated with EMDR, a protocolized, 8-phase psychotherapeutic approach, developed by Shapiro (Shapiro, 2001), aimed to resolve symptoms resulting from disturbing and unprocessed life experiences. 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 are typically 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 (Shapiro, 2000). 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 re-evaluation and integration.

The underlying adaptive information processing theory (Shapiro, 2007) 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, 2001). Various experimental studies support this theory by showing that eye movements during recall of aversive memories reduce their vividness and emotionality (Engelhard, van den Hout, & Smeets, 2011; Gunter & Bodner, 2008). 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 (Engelhard, van den Hout, & Smeets, 2011; Gunter & Bodner, 2008). With children task variations are employed, for instance, the therapist might put stickers on his fingers to facilitate the child's tracking, while with even younger children, buzzers can be used to vibrate alternately between their right and left hand, Other modalities used to tax working memory are alternating tones administered via a headphone or audio speakers placed on either side of the client (van den Hout, Engelhard, Rijkeboer, Koekebakker, Hornsveld, Leer, Toffolo, & Akse, 2011) or tapping on the child's hands or knees (Adler-Tapia & 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 mental age, taking into account any co-morbid disorders such as autism (Adler-Tapia & Settle, 2008; Barol & Seubert, 2010; Greenwald, 1999; Mevissen, Lievegoed, & De Jongh, 2011; Mevissen, Lievegoed, Seubert, & De Jongh, 2011). In Phase III, for example, children between a mental age of 4 and 8 are asked to draw the target image instead of describing it verbally. The negative and positive cognition are omitted with clients younger than 5 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 somatically), thought or smelled. Sometimes photo's, drawings, or physical objects are employed to engage the senses and to activate the trauma memory. The story further involves the way the person responded, but the ending is always positive. The story is repeated until it evokes no stress at all according to the trusted person's observations (Subjective Unit of Disturbance = 0).

RESULTS

The results are summarized in Table 1.

Patient 1

Jane is a 49-year old woman with severe ID and Down syndrome. She lives in a group home and visits a day care centre. 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 seven 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 couldn't 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, 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 this 15.5- month follow-up.

Patient 2

Melissa is a 10-year old girl with severe ID (cognitive developmental age: 3 years) with Marshall Smith Syndrome (MSS). MSS is a rare genetic syndrome that includes physical abnormalities, severe medical problems, and a short life expectancy. She is an only child, lives with her parents and attends a special school. In every day life, Melissa is anxious, avoiding people as well as activities. Parents and teachers report that she has poor concentration, is volatile, easily upset and constantly physically tense. From early on, Melissa had experienced life threatening circumstances, had been repeatedly hospitalized, undergoing a series of painful examinations and operations. Consequently, Melissa suffered panic attacks whenever required to have medical check-ups or treatment. Undergoing anesthesia typically resulted in some of her most severe experiences of panic.

The Story Telling Method was used, with mother narrating the stories. Vivid recollection of disturbing memories was enhanced with the aid of trauma related drawings, objects and other sensory cues such as noises, smells and physical sensations. Since Melissa could not tolerate any form of touch nor follow hand movements visually, EMDR was administered with auditory bilateral stimulation via audio speakers placed on either side of her. Melissa's mother was able to take part in this treatment without being upset herself, thanks to her own prior EMDR treatment, in which disturbing memories of Melissa's birth and life-threatening medical problems were reprocessed.

Various overwhelming events were reprocessed successively: being examined by the ear doctor, hearing a siren, the orthopaedist making plaster moulds of both feet, visiting the dentist, having her nails cut, receiving injections, and, most difficult of all, being anaesthetized. The order of treatment was determined by the intensity of Melissa's reactions to the various events. After two sessions, she was more relaxed at home and began to draw and talk about her painful experiences. After five sessions, her habit of crying 'no doctor' every time she left home to travel by car ceased. Panic decreased, and, after 14 sessions of EMDR, she was able to tolerate medical check-ups and treatment. In her daily life she became involved in a variety of activities. Her concentration improved, she began to learn new skills (e.g. toilet-training), and she enjoyed positive mood states more frequently. These effects have maintained at a 2.5-year follow-up.

Patient 3

Peter is a 10-year old boy with severe ID and Down syndrome. He lives at home with his parents and his younger sister, while attending a special school. Peter was referred for EMDR treatment because of eating problems. Additionally, he experiences aggressive outbursts, primarily directed at his younger sister. Peter refuses to eat solid food independently, requiring that someone else feed him. He refuses to join the family at the

dinner table and will only eat when eating is combined with various forms of distraction. No medical explanation for his condition could be determined.

This pattern began when he was about three months old and had developed severe heart problems. He typically refused to drink any liquids during that time, something required for his cardiac treatment. Consequently, at 4 months of age, he underwent heart surgery and had to be fed liquids intravenously. Upon his return home, the drip-feed was discontinued, and from that time on any form of eating turned into a fight. His parents were at their wits' end, which resulted in Peter's placement in a specialized eating-clinic for 1 year at the age of 3. There he learned to eat a piece of bread independently, as well as other kinds of food when spoon-fed. The situation at home, however, improved very little.

While preparing the mother for EMDR treatment, it became clear that she was not capable of participating. She herself was traumatized by the birth of her handicapped child, by his life threatening illness, as well as her ongoing failure to feed him adequately (mother herself was a dietician). It became clear that she considered herself an inadequate mother. To make matters worse, from the time Peter was born, her marriage began to deteriorate. She and her husband underwent marital therapy, but, unfortunately, without success.

Consequently, EMDR treatment was offered to the mother. After four sessions she felt less stressed and much less angry towards her children and husband. The father noticed these improvements and began to reveal his own difficulties in dealing with Peter's birth, illness and eating problems. EMDR treatment was then offered to the father. After 5 sessions, he felt more positive, was more capable of sharing his experiences with his wife, and felt more able to set appropriate limits with his children.

When it seemed time to begin Peter's EMDR therapy, both parents expressed concern for their daughter who had developed PTSD symptoms of her own due to unresolved grief. The parents requested that we treat their daughter before beginning with Peter. In four sessions, the daughter's experiences of loss were processed, as well as the most disturbing memories of conflict between her parents, as well as those between herself and her brother.

EMDR was finally offered to Peter. Both parents took turns in telling his story. At first, buzzers were used, but Peter soon rejected them. He seemed to associate them with negative emotions. Fortunately, he did accept tapping on his knees and the use of audio speakers as well. In the third session, he was able once again to tolerate the buzzers, and in this last session he succeeded in listening to the entire story without disturbance.

At a 3-month follow-up, his mother reported that family relationships were much better. They had begun a home training program in order to find new ways of handling Peter's eating problems. Once the parents began to overcome their own emotional difficulties,

they were willing, albeit with some trepidation, to introduce new eating routines. Peter was able to adapt to these new procedures, his aggressive outbursts towards his sister faded, and he began to display a greater ability to eat on his own. Additionally, he learned various new skills and his self-sufficiency increased. At a two-year follow up, his father reported that Peter was able to eat solid food independently. His sister was doing very well, and their marital relationship had improved significantly.

Patient 4

Joany is a 32-year old woman with severe ID (average developmental level 2 to 3 years) and symptoms of autism spectrum disorder. She lives presently at home with her elderly mother and attends a day care centre. Because of serious behavioural problems, she had to leave the group home where she had been placed about a month earlier.

As a child, Joany was relaxed, cheerful and related to people around her. She moved to a group home when she was 20 years old. The first two years she did very well. Unfortunately, the past ten years of her life have been characterized by severe behavioural problems, typically resulting in a new placement. Joany is generally anxious, has an exaggerated startle response, and has a panic attack whenever she hears someone sneezing or coughing. She is also restless, often in a bad mood, tired and passive, with unpredictable, aggressive outbursts.

Behavioural changes began after Joany was repeatedly sexually and physically abused by a group member for at least half a year. During that period she sustained neck wounds, and personal belongings in her bedroom were found in pieces and her bed broken. Subsequently, she became afraid of the dark, began to attack other people and threw a photo album of her group home out of the window. After a visit to her parent's home, she refused to return to the group home. She became demanding of her mother's attention, exhibited unusual sexual behaviours, slept sitting up, and, when asked to lie down, said 'I choke'. She suffered from nightmares and could not tolerate being touched. Then Joany's father became ill and died. Recently, the abuse was discovered. Temporary antipsychotic medication was administered, but without results.

As a working memory demanding task auditory bilateral stimulation was administered with the use of audio speakers. The Story Telling Method was employed, with mother narrating the story. Three events were targeted: the abuse (being in her bedroom alone with the perpetrator, caregivers not present to offer help), father's dying (initially he was very ill, suffering from pain and unable to play with his daughter, his death, funeral, leaving Joany with her mother), and the most recent incident of aggression (panic attack while riding on a tandem bicycle with her caregiver), which resulted in another placement.

The story of the abuse was told in spite of missing information about what exactly had happened in her bedroom. Memory access was facilitated with photos of the group home

Table 1. EMDR treatment in 4 patients with severe ID

Case no	Age, years	Sex	Level of ID & comorbidity	Complaints	Trauma's/life events	No of sessions	Results	Follow-up	
1	Jane	49	F	Severe Down syndrome	Since 2 years: Screaming every midnight Physical problems↑ Adaptive skills↓ Isolation	2 years ago trapped with head in bars of bed and rescued by a fireman	4 (first treatment)	Sleep problems disappeared Physical complaints↓ Muscles more relaxed Cooperative when going to bed More frequent cheerful mood; the once weekly sad mood persisted	7 months: results maintained 14 months: results maintained
				14 months after treatment "bed-trauma": Tearful Unable to stop talking about mother	4 people in personal environment died recently Father died 8 years ago Mother died 5 years ago	3(second treatment)		6 weeks after second treatment (15,5 months after first treatment): Mood problems completely disappeared More able to "talk" about feelings Results first treatment maintained	

Table 1. EMDR treatment in 4 patients with severe ID (continued)

Case no	Age, years	Sex	Level of ID & comorbidity	Complaints	Trauma's/life events	No of sessions	Results	Follow-up	
2	Melissa	10	F	Severe Marshal Smith Syndrome	From early life: Panic attacks with medical procedures Anxiety in daily life situations Avoiding places and people Poor ability to focus Volatile Easily upset Always physically tense	Life threatening medical problems from birth; repeatedly hospitalized with painful examinations and operations	14	Allows medical controls and treatment without panic Takes up all kinds of activities Concentration improved Learning new skills Often in a cheerful mood	2.5 years: results maintained
3	Peter	10	M	Severe Down syndrome	Eating problems from the age of 3 months Since 7 years: Refusing to eat solid food Has to be fed Unable to eat together with family members Unable to eat without distracting stimuli Aggressive outbursts	Heart surgery at the age of 3 months and forced to eat when back home Outplacement into an eating clinic at the age of 3	3/16* (*including individual EMDR treatment of all 3 other family members)	Parents accept professional educational support Patient is learning new skills Aggressive outbursts decreased	2 years: Is able to eat fast food independently Aggressive outburst disappeared

Table 1. EMDR treatment in 4 patients with severe ID (continued)

Case no	Age, years	Sex	Level of ID & comorbidity	Complaints	Trauma's/life events	No of sessions	Results	Follow-up
4 Joany	32	F	Severe Symptoms of autism	<p>Since 10 years: Initially: Afraid of darkness Attacking other people Throwing away photo's symbolizing trauma--aspects Refusing to return to group home after visiting parents Possessive of mother Sexually unusual behavior Sleep problems/night-mares Could not be touched Later on: Unpredictable aggressive outbursts Anxious in daily life situations Exaggerated startle response In panic when someone is sneezing/coughing Restless Often in bad mood Passive</p>	<p>10 years ago 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 Meanwhile serious illness and death of father</p>	17	<p>Better tolerating being touched in support of personal hygiene More cheerful Energy level increased Tolerating crowded environments Aggressive outbursts decreased</p>	<p>3 months: Had returned to former group home ; Occasional aggressive outbursts 16 months: Aggressive outbursts increased followed by another outplacement</p>

and the perpetrator. The emotional distress that accompanied the memory manifested somatically: fiddling with hands, crossing legs, fixed facial expression, perspiring. When asking where she could feel the disturbing feelings, she pointed to her throat, neck, and shoulders. Her neck reddened during the processing. After the sessions, Joany would experience tiredness, and the processing would continue at home. For example, for several days after a session, she would awake in the middle of the night, shouting at the perpetrator, and barricade her bedroom with pieces of furniture. After several sessions, she displayed anger, as well some happiness, and could tolerate being touched. Administering personal care to her consequently became easier. After 10 sessions others began to observe a positive change. She was more cheerful, her energy increased, and she began to tolerate crowded environments.

Treatment ended after 17 sessions. Joany was able to look at all the photos without any sign of distress. At three months' follow-up, Joany returned to her former group home. Aggressive outbursts, however, reappeared, triggered by the caregiver with whom she had experienced the panic attack. At 16 months' follow-up, Joany's mother reported that her daughter had come back home ten months after the last treatment session.. Severe conflict with the same caregiver had returned, requiring a new placement.

DISCUSSION

The present single case series was carried out to assess the applicability and effects of a treatment, particularly aimed at alleviation of PTSD symptoms, among four individuals with severe ID and who met PTSD criteria. With every client who met PTSD criteria (DSM-IV-TR and DM-ID), significant positive changes in trauma symptoms were observed, while their personal functioning improved. In three of four clients, results maintained at a 15.5 month to 2.5 year follow-up. As this was achieved in a limited number of sessions, patients' improvements converge to suggest the applicability, efficacy, and efficiency of the EMDR procedure with this population.

To the author's knowledge, these results represent the first report to examine the applicability of an evidence-based, psychological trauma-treatment approach for individuals with severe ID. It was necessary and possible to adapt instructions to the cognitive and emotional level of the clients. In all four participants the EMDR Story Telling Method (Lovett, 1999) was used with a family member supporting the client and narrating the story. However, in some instances, when the parents themselves were traumatized by the event(s), it became necessary to treat them first, in order for them to be emotionally stable enough to participate in treatment.

With regard to the efficacy of EMDR, the results are promising. With only client #4 a relapse of anger outbursts occurred. This client was reassigned to the group home where she developed serious behavioural problems. Here she was supervised by the same caregiver with whom she had previously experienced an intense blow-up. EMDR treatment of this caregiver and/or environmental changes, including staff training, might have prevented the relapse, particularly given the limited coping skills of this client due to her severe ID and autistic features. Finally, it should be noted that besides PTSD-like symptoms, other improvements were reported. Several clients experienced improved mood, and several learned new skills and had increased self-sufficiency. Another was more able to express simple thoughts and feelings, while in one client severity of medical problems decreased.

Despite the difficulties regarding PTSD assessment in people with ID (Mevisen & De Jongh, 2010), in all cases presented above, the clients had been exposed to more than one overwhelming event, at least one of which met PTSD criterion A1 for trauma (DSM-IV-TR). Specifically, they experienced either the threat of death or serious injury, or some other threat to physical integrity. Moreover, three of these four clients had been traumatized repeatedly over a period of time.

Application of PTSD criterion A2 (DSM-IV-TR), however, was more difficult, given the fact that all participants in this study were unable to self-report their feelings in the face of traumatic events. In two cases, caregivers were present when the trauma occurred and were able to observe the behavioural manifestations of intense fear, helplessness or horror.

Another complicating factor regarding PTSD assessment in people with ID is that the manifestation of possible PTSD symptoms seems to vary with the level of ID (Mevisen & De Jongh, 2010)]. Given the clients' complaints (see Table 1), it is difficult to translate them into PTSD Criterion B symptoms. In two clients, it might be hypothesized that the trauma was being re-experienced when caregivers noticed fear, resistance or aggression after the clients experienced triggers, such as meeting doctors and being forced to eat. In spite of their severe ID, two clients exhibited easily recognizable behavioural symptoms of traumatic re-experiencing, such as daily recurrent screaming at 'trauma time', nightmares, and being triggered by coughing and sneezing.

Limited verbal capacities also made for difficulties when considering PTSD criterion C (DSM-IV-TR). For the client to meet C criteria, the client must report three of seven symptoms of avoidance. Taking into account these criteria as put forth in the DM-ID, symptoms of 'non-compliance' and isolation, as reported by caregivers, were very significant. In all clients in this study, these symptoms were reflected either in the complaints reported prior to treatment or in observable, positive changes following treatment, such as 'taking up all kinds of activities', 'growing independence', 'learning new skills', and 'tolerating crowded places'.

Finally, with regard to PTSD criterion D (DSM-IV-TR), the situation is somewhat different. In three of four clients two signs of hyperarousal were observed at the time of referral. In participant #3 however, only one sign of hyperarousal was reported, specifically anger outbursts. In this case, it was not clear whether other symptoms of hyperarousal were absent or were overlooked by the caregivers. Additionally, anger outbursts were observed in two of four clients.

In conclusion, the results of this case review suggest that EMDR can be an applicable and effective treatment method, not only for people with mild and moderate ID (Barol & Seubert, 2010; Giltaij, 2004; Mevissen et al., 2011a; Mevissen et al., 2011b; Rodenburg, Benjamin, Meijer, & Jongeneel, 2009), but also for clients with severe ID who suffer from PTSD-like symptoms.

For purposes of future research, it will be important to overcome the methodological shortcomings of the present study, particularly the fact that the same person performed the therapy, assessed the therapeutic process, including the outcome-observations of the clients' parents or caregivers. Yet, given the length of the baseline period, the wide variety in improvements, and the fact that treatment entailed a maximum of 17 sessions in total, the results are promising. Therefore, it will be necessary to further examine the cognitive, emotional and behavioral changes over time in a more reliable way and to determine the extent to which the present results can be generalized to routine clinical practice, thereby, informing healthcare decisions (Schnurr, 2007). To this end, a study with a multiple baseline design across persons might be a first step. Awaiting this, the findings should encourage other clinicians who are involved in the care of patients with limited intellectual capabilities to screen for PTSD symptoms and to identify those individuals that could benefit from an evidence-based psychological treatment, such as EMDR.

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4

**Development of the *Adapted ADIS-C section PTSD* for the
clinical assessment of PTSD in children and adolescents
with mild to borderline ID**

4.1

Investigation of the feasibility of the *adapted ADIS-C section PTSD* and exploration of manifestations of PTSD in children with mild to borderline intellectual disabilities

Clinical assessment of PTSD in children with mild to borderline intellectual disabilities: A pilot study

L. Mevissen, E. Barnhoorn, R. Didden, H. Korzilius, & A. de Jongh

ABSTRACT

Objective There are few studies regarding assessment and treatment of trauma-related disorders in people with intellectual disabilities (ID). The aims of this study were to determine (1) the feasibility of an adapted version of a Posttraumatic Stress Disorder (PTSD)-clinical interview, and (2) to what extent manifestation of PTSD in a sample of children with mild to borderline ID corresponds with four existing PTSD algorithms.

Method Fifteen children who visited a special need school were interviewed.

Result In all children, the full interview could be completed. Potentially traumatic events (A1 criterion), and PTSD symptoms for children with mild to borderline ID were similar to those observed in children without ID.

Conclusions The manifestation of PTSD in children with mild to borderline ID corresponds with the manifestation of PTSD in children without ID. The data provide no reason to broaden PTSD criterion A1 for children with mild to borderline ID.

INTRODUCTION

Most people experience a devastating or life-threatening stressor event such as a serious accident or the sudden loss of a loved one, at some time during their lives (Bonanno, 2005; Breslau, 2001). Typical reactions to such an event are distress, anxiety, and fear (Breslau, 2001). It is generally assumed that the memories about the distressing event are geared towards providing the individual with information to help to survive a next similar event (Gazzaniga & Heatherton, 2006; Tronson & Taylor, 2007). The personal responses to an emotionally arousing experience give rise to the storage of emotionally-charged memories of the event (Cahill, 2003; Van Stegeren, 2008), which in some instances can lead to the development of Posttraumatic Stress Disorder (PTSD) (Breslau, 2001). Following the DSM-IV-TR (American Psychiatric Association, 2000), PTSD criteria are met when a person witnessed, experienced or was confronted with an event that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others (Criterion A1). In addition, the individual's response has to be one of intense fear, helplessness, or horror (Criterion A2). To meet the full criteria of a PTSD diagnosis, exposure to the traumatic stressor should also involve symptoms of re-experiencing, avoidance and arousal. Finally, these symptoms need to be present for at least one month and should cause impairment in functioning, and significant distress (American Psychiatric Association, 2000). The estimated lifetime prevalence of PTSD in the general population is about 8% (Kessler, Chiu, Demler, & Walters, 2005).

Since PTSD was first mentioned in the DSM there is an ongoing controversy about how to diagnose and classify PTSD (Brewin, Lanius, Novac, Schnyder, & Galea 2009; Gold, Marx, Soler-Baillo, & Sloan, 2005; McNally, 2003; Rosen & Lilienfeld, 2008). For example, studies have shown that people who have been exposed to an event fulfilling the DSM-IV-TR criterion A1 report significantly less symptoms of PTSD following this event than those who have experienced an event that is not subsumed under the DSM-IV-TR's definition of a traumatic event (e.g. Gold et al., 2005). Furthermore, with regard to the value of the DSM-IV criterion A2, it has been found that persons who did not experience intense fear, helplessness, or horror during the trauma, still fulfilled the criteria for PTSD as based upon their symptom scores on the PTSD Symptom Scale (Brewin, Andrews & Rose, 2000).

For the DSM-5 several changes have been proposed, including a sharpened criterion A1 and the elimination of criterion A2 (Friedman, Resick, Bryant, & Brewin, 2011). Another prominent proposed change based on reviews (Elhai, Carvalho, Miguel, Palmieri, Primi, & Frueh, 2011; Yufik & Simms, 2010) is the addition of a fourth cluster of symptom criteria pertaining to negative alterations in mood and cognitions associated with the traumatic event(s). This includes, for example, persistent and exaggerated negative beliefs or expectations about oneself, others or the world, a persistent negative emotional state, and markedly diminished interest or participation in significant activities (Friedman et al., 2011).

Different suggestions have been made for the DSM-5 PTSD diagnosis in children. Based on the assumption that developmental differences affect presentation of PTSD symptoms, Scheeringa, Meyers, Putnam, and Zeanah (2012) examined four diagnostic criteria sets in trauma-exposed children younger than 7 years old: (1) DSM-IV, (2) PTSD-AA (alternative algorithm), (3) the proposed DSM-5 posttraumatic stress in preschool children, and (4) DSM-5-UC (DSM-5 'with two symptoms under condition'). Three of the criteria sets [i.e. (2)-(4)] resulted in significantly more PTSD-cases compared to using the DSM-IV criteria. Moreover, all these extra cases were highly symptomatic and impaired, suggesting that DSM-IV criteria are insensitive for diagnosing PTSD in young children. The data support the adoption of a developmental subtype of PTSD for preschool children in the DSM-5 (Scheeringa et al., 2012). The most important additional change in this developmental PTSD subtype is the reduction of the total number of criterion C (avoidance) and D (negative mood and cognitions) symptoms, from at least three symptoms to at least one symptom. Data regarding an alternative algorithm for school-aged children seemed to be more limited and less consistent compared to data with regard to the proposed DSM-5 subtype for preschool children (Scheeringa, Zeanah, & Cohen, 2011).

One group of individuals that seems to be particularly vulnerable to exposure to distressing (traumatic) events are people with intellectual disabilities (ID), a population in which the frequency of psychiatric disorders is estimated to be two to four times higher than in the general population (Einfeld, Ellis, & Emerson, 2011; Hatton & Emerson, 2004; Mitchell & Clegg, 2005). People with ID experience more often sexual or physical abuse (McCarthy, 2001; Reiter, Bryen, & Schachar, 2007; Ryan, 1994; Turk, & Brown, 1993), emotional abuse (Reiter et al., 2007), life threatening illness or injury and parental divorce (Hatton & Emerson, 2004), than people without ID. It has been stated that even having an ID can be traumatic in itself (Hollins & Sinason, 2000). Furthermore, it is assumed that people with ID are more vulnerable to develop PTSD than people without ID, due to limited skills to cope with traumatic events (Tomasulo & Razza, 2007). Moreover, it has been argued that language problems impede sharing overwhelming experiences with others (Tomasulo & Razza, 2007).

PTSD often goes undetected in people with ID (Mevisen & De Jongh, 2010). Although in research associations have been found between adverse life events and psychopathology in this particular population, evidence for a relationship between life events and specific types of psychopathology such as anxiety and mood disorders in people with ID is scarce (Hatton & Emerson, 2004). Furthermore, in this clinical field it is not uncommon practice to ascribe emotional and behavioral problems to the ID itself, termed "diagnostic overshadowing" (Fletcher, Loschen, & Stavrakaki, 2007). The release of the DM-ID (Fletcher et al., 2007), an adapted version of the DSM-IV, was an attempt to enhance the reliability of psychiatric diagnoses in people with ID. Because of its alleged importance, PTSD is assigned its own chapter in the DM-ID (Fletcher et al., 2007). Mainly based on

clinical practice, recommendations were given for adapted PTSD symptoms in people with ID (Tomasulo & Razza, 2007). It has been argued that PTSD symptoms in adults with mild ID do not differ from those seen in adults without ID, while adults with more severe ID report PTSD symptoms that are more similar to those seen in children (Tomasulo & Razza, 2007). With regard to the PTSD traumatic stressor criterion, as applied in the DSM-IV, the DM-ID takes into account that also events that the DSM-IV-TR would not classify as traumatic (e.g. an outplacement engineered by others or developmentally inappropriate experiences including “voluntarily” engaged sexual experiences) can be considered traumatic in people with ID (Tomasulo & Razza, 2007). According to the DM-ID, symptoms of re-experiencing and arousal will be manifested in overt and behavioral form, such as in self-injury, aggression, and outbursts of anger, while symptoms of avoidance might be seen as noncompliance (Tomasulo & Razza, 2007).

However, despite the growing interest in “trauma” and the negative effects of “life events” in people with ID (Martorell & Tsakanikos, 2008), there is still a limited number of studies on assessment and treatment of PTSD in people with ID (Mevisen & De Jongh, 2010; Wigham, Hatton, & Taylor, 2011). In addition, in the aforementioned studies by Scheeringa and his colleagues (Scheeringa et al., 2011; Scheeringa et al., 2012) on PTSD in children, those with ID were excluded, while in the few studies that did assess the effects of traumatic events on people with ID, diagnostic instruments were used that were not validated for people with ID (Mevisen & De Jongh, 2010; Wigham, Hatton, & Taylor, 2011a). The question as to how PTSD manifests itself in people with ID is still under researched.

The first aim of this study was to investigate the feasibility of a clinical interview (ADIS-C PTSD section, adapted for children with mild to borderline ID; Mevisen, Didden & De Jongh, 2012) developed to assess PTSD in children with mild to borderline ID. The second aim was to explore to what extent the manifestation of PTSD in children with mild to borderline ID corresponds to the manifestation of PTSD in children without ID. Two hypotheses were tested with regard to trauma exposure in children with mild ID: (1) events not specifically meeting PTSD stressor criterion (A1) are associated with the development of PTSD symptoms, and (2) a greater level of exposure to potentially traumatic events is associated with more PTSD symptoms.

MATERIAL AND METHODS

Participants and Setting

Participants were 15 children, 8 girls and 7 boys, of a special need school in the eastern part of the Netherlands. All participants lived at home with their parent(s). Their mean

age was 10.0 years (range: 8.0-13.1; *SD*: 1.09). The mean intelligence quotient (IQ) of the participants was 74 (range: 64-84; *SD*: 7.5).

Materials

Interview. An adapted version of the section PTSD of the Dutch translation of the child interview of the ADIS-C (Anxiety Disorders Interview Schedule of DSM-IV – Child version; Siebelink & Treffers, 2001a) was used. Because the ADIS-C is based on the DSM-IV, for this adapted clinical interview the ADIS-C was complemented with questions about traumatic events and symptoms of PTSD corresponding with three other classification systems (PTSD-AA [Scheeringa et al., 2011], proposed DSM-5 criteria [Friedman et al., 2011], and proposed DSM-5 criteria for preschool children [Friedman et al., 2011], literature about PTSD in people with ID [Brackenridge & Morrissey, 2010; Mehtar & Mukaddes, 2011; Mevissen & De Jongh, 2010; Wigham et al., 2011a; Wigham, Hatton, & Taylor, 2011b]), clinical trauma treatment experience using Eye Movement Desensitisation and Reprocessing (Barol & Seubert, 2010; Mevissen, Lievegoed, & De Jongh, 2011; Mevissen, Lievegoed, Seubert, & De Jongh, 2011; Mevissen, Lievegoed, Seubert, & De Jongh, 2012) and open-ended questions. The first part of the adapted version of the interview consists of 25 questions addressing different types of traumatic events (Table 1). The response format for each question is ‘yes’, ‘no’ or ‘otherwise’. When the child responds to the question about one of the traumatic events in the affirmative, the child is asked three more questions: ‘What happened?’, ‘How did you react to that?’ and ‘How old were you when it happened?’ Next, the child is asked which event actually is the worst to think about. The second part of the interview consists of 37 questions about PTSD-symptoms (Table 2). For these questions the response format is ‘yes’, ‘no’ or ‘otherwise’. Seven of the 37 questions pertain to symptoms not subsumed in one of the four PTSD algorithms (Table 3). In these seven questions, the child is asked to provide an explanation when responding in the affirmative. Two questions are open ended. The child is asked whether he or she has noticed anything else since the events, and in case the answer is “yes” s/he is also asked to provide an explanation. In all other 30 questions no further explanation is required, irrespective of the child’s response. The final interview question refers to the interference in daily life functioning: ‘To what degree do you think your daily life functioning actually is impaired by the event(s) you have experienced?’ The ADIS-C thermometers card (see below) was used to facilitate this.

Thermometers card. The child had to indicate the interference by naming or pointing to a scale consisting of nine thermometers with 0 referring to ‘totally not’, 2 ‘a little bit’, 4 ‘somewhat’, 6 ‘a lot’ and 8 ‘very much’. The other thermometers were in between (Siebelink & Treffers, 2001b).

Timeline. A timeline was used to get a picture of all the traumatic events the child ever had experienced, and to support the child in a visual way. The timeline was a piece of paper on which a horizontal line was drawn, which represented the child's lifetime from birth to present age, and which was divided in equal pieces of one year corresponding with the child's age. The interviewer assisted the child in writing or drawing each of the experienced events on the matching timeline point. While assessing the symptoms the interviewer pointed at the timeline with the experienced event(s) to make sure that if 'yes' was answered, the child felt as if there was a straight relationship between the negative event(s) and the reported symptoms.

Procedure

Eleven special needs schools around Nijmegen, a college town in the eastern part of the Netherlands, were invited to participate. None of school staff expressed willingness to participate. Those who gave a reason argued that being questioned about traumatic events might emotionally affect the children in a way that could not be handled by the school. The first author approached a school of special needs in Deventer, a city in the eastern part of the Netherlands. Its director, psychologist and intern supervisors gave their permission to participate. It was agreed that, if needed, the nearby center for child and adolescent psychiatry (i.e. Accare) would provide outpatient trauma treatment. The psychologist and intern supervisors of the school designated 30 children, taking into account the following criteria: (1) aged between six and eighteen years, (2) IQ between 50 and 85, and (3) ability to answer questions during a one-hour interview. Five successive class-levels were included. Sixteen parents gave their written informed consent. Each interview was videotaped. The children were interviewed by the second author in a separate room during school time. At first, a number of questions were asked to comfort the child, such as 'Do you have any brothers or sisters?' and 'What are your plans for the holidays?' Next, the interview was introduced. At the end of the interview the child was asked about his or her opinion about the interview. The session was always closed in a positive way. Of one child the IQ data appeared unavailable, as a consequence only the data of the other fifteen participants were analyzed.

Reliability

To determine the reliability of the interview, 4 of the 15 randomly chosen videos were examined by a second observer who independently scored the participants' answers to all questions. Reliability was calculated on a question-by-question basis, and results were corrected for chance. Kappa's (κ) were calculated which varied between .87 to .95, suggesting that the interobserver agreement of the interview was excellent ($\kappa > .75$; [Cicchetti, 1994]). The interviewer and second observer independently coded participants'

scores according to the different PTSD algorithms. In case of disagreement the final decision was made by the last author based upon his interpretation of the criteria of that specific PTSD algorithm.

Statistical analyses

Frequency analyses were used for exposure rates of trauma and life events and standard as well as additional PTSD symptoms. *t*-Tests for independent samples (two-tailed) were employed to analyze differences between the thermometer scores of children who did and those who did not fulfill the other PTSD symptom criteria, and to determine the difference between the number of potentially traumatic events of those meeting PTSD symptom criteria and those who did not. Mann-Whitney *U*-tests were used in case the assumption of normal distribution of the data was violated. Outcomes were corroborated with Mann-Whitney *U*-tests. Fisher's exact test was employed with regard to meeting PTSD A1 criterion and occurrence of PTSD symptoms. The level of significance was set at 0.05.

RESULTS

Feasibility of the interview

For all children the full interview could be completed. They answered all questions and seemed to understand them. Incidentally, a child asked for explanation or the interviewer asked another question to make quite sure the child did not misinterpret the question. Only one child needed a break during the interview. None of the children got upset as a result of being interviewed. When asked "What do you think about the interview?" 10 of the 15 children were positive (e.g. "fun", "good", and "relieving"), two were negative (e.g. "a lot of the same questions" and "talk about the events feels uncomfortable"), two were neither negative nor positive about the interview and one participant did not answer the question.

Manifestation of PTSD and its relationship with the different PTSD algorithms

Table 1 presents the exposure rates by type of trauma or life event.

The most frequently experienced events were death or serious injury of a person or a pet, witnessing an accident or a fire, and being confronted with bullying. None of the children reported any kind of sexual abuse, near death experiences because of an accident or fire, nor being outplaced.

Table 1. Exposure rates by type of trauma or life event (n = 15)

Type of trauma or life event	Yes	No	Other ¹
- Did you ever experience that a beloved pet died or got seriously injured?	12	3	0
- Did you ever experience that somebody died or got seriously injured?	12	3	0
- Have you ever seen an accident or a fire?	10	5	0
- Were you ever in hospital or did you have horrible medical surgeries or treatments?	11	4	0
- Have you ever been severely harassed or have you seen someone else being severely harassed?	9	6	0
- Have you ever been sent away from school or have you been forced to change school?	7	8	0
- Did you ever experience a flood or an earthquake, or has there been a very serious storm close to your home?	6	8	1
- Did you ever hear horrible stories at the computer or the television or from other people or have you ever seen awful pictures (for example about disasters, war, accidents, deaths, maltreatment, serious illness, sexual abuse, frightening medical surgeries or treatments, ghosts or monsters)?	6	8	1
- Did someone ever hit you repeatedly or hurt you severely?	7	8	0
- Have you ever seen someone being threatened or maltreated (beating, kicking, shooting, stabbing, going at someone's throat), within your family or somewhere else?	7	8	0
- Have your parents been divorced?	7	8	0
- Did you ever experience a burglary?	5	10	0
- Did you ever get lost?	5	10	0
- Have you or someone you know very well ever been in prison?	4	11	0
- Did someone ever touch your body even though you didn't want this?	3	10	2
- Have you ever been robbed or attacked by somebody?	3	12	0
- Have you ever been picked up or questioned by the police?	2	13	0
- Did you ever have very serious problems with someone within your family or with a friend or girlfriend?	2	13	0
- Were there ever adults who didn't tolerate anything and punished you harshly?	0	14	1
- Did you ever see someone else being forced to have sex?	0	14	1
- Did you ever experience a serious accident or a fire in which you nearly died?	0	14	1
- Have you ever been outplaced or were you in a crisis centre for a short while?	0	14	1
- Have you ever been forced to touch someone's body parts when you really didn't want to?	0	15	0
- Did someone ever do something else to you or forced you to do something you really didn't want to?	0	15	0

¹ The child answers e.g.: "I don't know", "sometimes" or any other unclear answer.

On 12 accounts the open-ended question was answered affirmatively (not shown in Table 1). Four of the events that were reported could not be classified. In one case this was because the answer was not specific enough. The other answers (i.e., being exposed to a group member shattering a window pane; a duck that was run over by a car; grandfather who was carried into an ambulance) could not be classified under the given categories. Most frequently reported events as being actually the most distressing were: death of a loved one (four times), parental divorce (three times), and witnessing or learning about an accident (three times).

Table 2 shows the frequency rates of all PTSD symptoms included in the four different diagnostic systems (i.e., DSM-IV, PTSD-AA, DSM-5, and DSM-5 for pre-school children) as reported by the participants.

Symptoms most frequently reported were: being seriously frightened when something happens unexpectedly and getting angry more often (hyperarousal), trying to avoid thinking of the event(s) (avoidance) and having nightmares (re-experiencing). None of the children suffered from blaming themselves for what happened.

Table 2. Frequency rates of potential PTSD symptoms, included in DSM-IV, PTSD-AA, DSM-5 & DSM-5 for pre-school children (n= 15)

Symptoms	Yes	No	Other ¹
- Are you seriously frightened when something happens unexpectedly or suddenly, for example if all of a sudden you hear a loud noise or if someone touches you unexpectedly?	11	4	0
- Do you frequently have nightmares or horrible dreams about what has happened?	8	5	2
- Do you try as hard as you can, not to think of those event(s)?	9	4	2
- Do you have nightmares or horrible dreams about other things?	7	7	1
- Do you get totally upset if something reminds you of those event(s)	7	6	2
- Do you always watch out very carefully because you think something bad might happen again?	7	8	0
- Do you get angry more often since those event(s) happened?	7	7	1
- Do you still often think of the event(s) even though you really don't want to?	6	8	1
- If something reminds you of the event(s), do you get awful feelings in your body? For example does your heart start to beat much faster, do you start to sweat or shake?	6	7	2
- If something reminds you of the event(s) do you get stomach ache or headache?	6	7	2
- Since the event(s), has it become more difficult for you to show other people how you feel? For example, do you avoid showing someone else how you are feeling and do you keep your feelings to yourself?	6	7	2

Table 2. Frequency rates of potential PTSD symptoms, included in DSM-IV, PTSD-AA, DSM-5 & DSM-5 for pre-school children (n= 15) (continued)

Symptoms	Yes	No	Other ¹
- Are you unable to sleep well, for example; is it difficult to fall asleep, do you often wake up during the night or do you wake up too early in the morning?	5	4	6
- Has it become more difficult to trust other people since the event(s)?	5	8	2
- Is it difficult to keep your mind on things, do you have difficulties concentrating?	5	8	2
- Do you often feel bad? Do you, for example, often have feelings of anxiety, blame, or shame or do you often think things are very awful?	4	8	3
- Since those event(s) happened, did you stop doing things you really liked to do before, for example, playing games or going out, hobbies? Or do you no longer like to do those things?	4	9	2
- Are there some some parts of the event(s) you no longer remember?	2	11	2
- Do you have serious outbursts of anger?	3	10	2
- Do you try to stay away from things that remind you of the event(s)? For example situations, places, noises, smells?	3	12	0
- Do you no longer feel like seeing your friends or girlfriends since the event(s)?	2	11	2
- Do you feel lonely or isolated more often since those event(s)?	2	12	1
- Cannot you feel happy anymore since those event(s)?	1	9	5
- Do you sometimes hurt yourself or others or do you break things?	1	12	2
- Is it as if you can't feel anything anymore since those event(s)?	1	13	1
- Did you start doing things again you didn't do since you were a little child, for example wetting your pants again, sucking your thumb or always trying to stay close to your father and mother or caregivers?	1	14	0
- Do you always blame yourself or others about what has happened while in fact this is not with good reason?	0	14	1
- Do you no longer watch out for what you're doing; do you act dangerously?	0	14	1
- Do you think that if you are grown up, you are able to do anything you would like to do for example receive training, get married, find a job, raise children or any of these types of things?	12	0	3

¹ The child answers e.g.: "I don't know", "sometimes" or any other unclear answer.

Three children could be diagnosed with PTSD based on the DSM-5 criteria, four children following the DSM-IV criteria, and six children according to the PTSD-AA and the DSM-5 criteria for preschool children. Three of the fifteen children could be diagnosed with PTSD based on all criteria of all systems (DSM-IV, PTSD-AA, DSM-5, and DSM-5 for pre-school children).

Table 3 displays the frequency scores for the seven potential symptoms of PTSD, which might be characteristic for children with ID, but are not included in one of the four differ-

ent PTSD algorithms. The two open-ended questions (“When something reminds you of the event(s), do you notice anything else in yourself?”, and “Did you notice anything else since those events?”) that were included in the symptom section (not depicted in Table 3) were only once answered with “yes”. This participant described his/her symptom as “becoming hyperactive”.

Table 3. Frequency rates of other potential PTSD symptoms (n = 15)

Symptoms	Yes	No	Other ¹
- Do you sometimes have the feeling it could easily happen again?	7	7	1
- Since the event(s), did you change eating behaviour, for example, eating too much or too little?	6	7	2
- Since those events, is it harder to accept when things go different than expected, for example, if an appointment has been cancelled or if you suddenly have to do something unexpected?	5	9	1
- Do you sometimes hear voices in your head with regard to the event(s)?	4	10	1
- Do you have to do some things again and again or always in the same order?	1	14	0
- Do you no longer take care of yourself as well as you did before, for example, has it become more difficult to wash yourself and dress and do you no longer succeed in brushing your teeth well?	0	14	1
- Do you start to behave exaggeratedly happy if you have to think about the event(s)?	0	15	0

¹ The child answers e.g.: “I don’t know”, “sometimes” or any other unclear answer

Table 4 presents mean number of additional potential PTSD symptoms (range 0-7) that were not included in the four different PTSD algorithms (see also Table 3) for children who did and those who did not meet PTSD symptom criteria according to the different diagnostic systems. For all four systems the mean number of additional potential PTSD symptoms was significantly higher in participants who met PTSD symptom criteria than in participants who did not meet these symptom criteria.

Table 5 presents mean thermometer scores of participants fulfilling the criteria of the different sets of PTSD symptom criteria and participants who did not fulfill the set of PTSD symptom criteria. Children who met the PTSD symptom criteria of DSM-IV, DSM-5 and DSM-5 for pre-school children reported a significantly higher mean thermometer score than those who did not meet the appropriate set of PTSD symptom criteria.

Table 4. Difference in mean number of additional potentially PTSD symptoms between participants who met and did not meet PTSD symptom criteria according to the different diagnostic systems ($n = 15$).

Diagnostic system	PTSD symptom criteria	<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i> (13)	<i>p</i>
DSM-IV	yes	4	3.00	1.16	3.09	0.009*
	no	11	1.00	1.10		
PTSD-AA	yes	6	2.67	1.21	3.35	0.005*
	no	9	0.78	0.97		
DSM-5	yes	3	3.33	1.16	3.18	0.007*
	no	12	1.08	1.08		
DSM-5 for pre-school children	yes	7	2.57	1.13	3.68	0.003*
	no	8	0.63	0.92		

* $p < 0.05$

Table 5. Differences of thermometer scores between participants who fulfilled and did not fulfill PTSD symptom criteria, following the different diagnostic systems ($n = 15$).

Other symptom criteria		<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>
DSM-IV	yes	4	7.75	0.50	4.43	11.28 ^a	0.001*
	no	11	3.45	3.11			
PTSD-AA	yes	7	6.14	2.55	1.84	13	0.089
	no	8	3.25	3.41			
DSM-5	yes	3	8.00	0.00	4.69	11	0.001*
	no	12	3.75	3.14			
DSM-5 for pre-school children	yes	7	6.86	1.22	3.38	9.09 ^a	0.008*
	no	8	2.63	3.30			

Note. ^a As the assumption of equal variances was not met (tested with Levene's test) t-test for unequal variances are reported. * $p < 0.05$

Table 6 presents results of Fisher's exact tests on the association between meeting criterion A1 and fulfilling PTSD symptom criteria for each of the diagnostic systems. When full PTSD symptom criteria were present, in all but one case a criterion A1 event had been reported. Only for DSM-IV a significant association was found between having experienced a criterion A1 event and meeting PTSD symptom criteria.

Table 6. PTSD Criterion A1 and PTSD symptom criteria for the different algorithms ($n = 15$).

Criterion A1		Symptom Criteria		p
		Yes	No	
DSM-IV	Yes	4	3	0.026*
	No	0	8	
PTSD-AA	Yes	6	8	1.00
	No	0	1	
DSM-5	Yes	3	8	0.52
	No	0	4	
DSM-5 for preschool children	Yes	6	5	0.57
	No	1	3	

*Note. Tested with Fisher's exact test. * $p < 0.05$*

Table 7 displays the mean number of events in the children fulfilling A1 criterion according to the different PTSD algorithms for children meeting PTSD symptom criteria and children who did not meet PTSD symptom criteria. It appears that for DSM-5 as well as the DSM-5 version for pre-school children, children who met A1 criterion and PTSD symptom criteria had been exposed to a significantly higher number of negative events than children who did not meet both of these criteria.

Table 7. Differences in mean number of events in children meeting A1 criterion, between children who fulfilled and did not fulfil PTSD symptom criteria, according to the different algorithms.

Diagnostic system	PTSD symptom criteria	<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>
DSM-IV	yes	4	12.50	2.38	0.79	5	0.466
	no	3	11.00	2.65			
PTSD-AA	yes	6	11.00	2.97	0.19	12.	0.152
	no	8	8.50	3.55			
DSM-5	yes	3	13.67	0.58	2.61	9	0.028*
	no	8	8.38	3.38			
DSM-5 for pre-school children	yes	6	11.83	2.64	2.34	9	0.044*
	no	5	7.40	3.65			

* $p < 0.05$

DISCUSSION

To our knowledge, this study is the first to provide a detailed examination of the feasibility of a PTSD clinical interview. It is also the first study that investigated how PTSD is manifested in children with mild to borderline ID. The findings suggest that the clinical interview is applicable for children with mild to borderline ID. This is supported by the finding that the full interview could be completed in all participants, and that none of the children showed any signs of adverse reactions to being interviewed on this topic.

The second aim of the study was to investigate to what extent manifestations of PTSD corresponded with the four PTSD algorithms. The results suggest that the consequences of trauma in children with mild to borderline ID are similar to those in children without ID. This holds true with regard to the (a) reported PTSD symptoms, (b) impact on daily life functioning, and (c) proportion of frequencies of PTSD diagnoses across the different algorithms.

Reported PTSD symptoms

The high frequencies of posttraumatic nightmares (i.e. eight), intrusive thoughts (i.e. six) and alertness to danger (i.e. seven) (also see Table 2) are in line with findings pertaining to PTSD symptoms in traumatized children without ID (McCarthy, 2001). The symptoms that were supposed to be distinctive of people with ID, and were added to

the original interview as these were derived from the literature on trauma in children with ID (Table 3), seem to be redundant. The analysis suggests that it is not necessary to collect additional information about these potentially relevant PTSD symptoms, since reporting a high frequency of these symptoms was highly associated with (already) meeting the symptom criteria of the four existing PTSD algorithms. Moreover, none of the children mentioned PTSD symptoms that were different from the symptoms included in the algorithms for children without ID. Twice the children were asked if they suffered from complaints, other than those the interviewer explicitly had asked for. This appeared to be not the case, suggesting that no additional questions relating to other symptoms are necessary for children with mild to borderline ID.

Impact of PTSD symptoms on daily life functioning

Not only manifestations of PTSD in children with mild to borderline ID correspond with PTSD seen in children without ID, but also regarding the impact on daily life functioning. The interference question showed that for all diagnostic systems, except PTSD-AA, children who met PTSD-symptom criteria reported a significantly higher mean thermometer score than those who did not meet these criteria. This would suggest that, similar to children without ID, PTSD symptoms cause severe impairment and distress in children with mild to borderline ID.

Proportion of PTSD frequencies across diagnostic systems

With regard to the distribution of the frequencies of PTSD diagnoses across the different diagnostic systems (i.e. $n = 3, 4, 6,$ and 6), the manifestation of PTSD in children with ID also appeared to be in accordance with that of children without ID. It is understandable that the number of DSM-5 diagnoses ($n = 3$) in our study is lower than that of DSM IV diagnoses ($n = 4$) considering that it is more difficult to meet all PTSD-5 criteria because of the sharpened A1 criterion of DSM-5, and the addition of a new symptom cluster in the proposed diagnostic criteria for this DSM edition (Friedman et al., 2011). By contrast, fulfilling the PTSD criterion according to the PTSD-AA and DSM-5 for pre-school children is much easier. This explains the high frequency ($n = 6$) of such PTSD diagnoses. Both algorithms, having few internal differences, are developed for children aged six or younger. Because of the developmental level of this age group less symptoms of avoidance/numbing are required in order to meet all symptom criteria for a PTSD diagnosis. Furthermore, the A2 criterion is removed as pre-school children are unable to reliably self-report initial responses of fear, helplessness or horror, and adults are not always present to observe the child's reaction (Scheeringa et al., 2012). In our sample, considering participants' mild to borderline ID, and their ages (at least eight years), more than 50% of the sample might have had a mental age higher than 6 years. This would mean that, in fact, it was not appropriate using the PTSD-AA and DSM-5 for pre-school children when diagnosing PTSD.

in our sample. Therefore, a total of 6 PTSD diagnoses in this study sample might reflect an overestimation as a result of using the latter diagnostic systems.

The results also show a remarkably high prevalence rate of PTSD in our sample (i.e. 27% for the PTSD DSM-IV diagnoses) in comparison with outcomes of PTSD DSM-IV prevalence rates in children without ID. In children without ID the estimated lifetime prevalence rate of PTSD ranges between 1% and 14% (Stallard, 2006), and approximately one of three children is likely to develop PTSD following trauma exposure (Alisic, Jongmans, Van Wesel, & Kleber, 2011). Although it is difficult to draw any firm conclusions on small study samples, the relatively high frequency of DSM-IV PTSD diagnoses may be explained by the fact that people with ID are more frequently exposed to traumatic and negative life events than people without ID (Mevisen & De Jongh, 2010).

Our hypothesis that in children with ID less overwhelming events, not specifically meeting A1 criterion (e.g., being harassed, being sent away from school, death of a pet) are associated with having a PTSD diagnosis, was not supported by the current data. All children (except one) who fulfilled PTSD symptom criteria also fulfilled criterion A1. The opposite was not true; that is, regarding DSM-5, PTSD-AA and DSM-5 for pre-school children, experiencing a criterion A1 event was not found to be associated with meeting PTSD symptom criteria. This finding is supportive of the general notion that only a minority develops PTSD after having been exposed to a traumatic event. Accordingly, no support was found for the view that criterion A1 should be broadened for children with mild to borderline ID.

Our hypothesis, that a greater level of exposure to potentially traumatic events would be associated with the report of more PTSD symptoms, was only partly supported. Only for the DSM-5 and DSM-5 for pre-school children, those who met A1 criterion as well as PTSD symptom criteria had been exposed to a significantly higher number of negative events than those who did not meet both of these criteria (Table 7). Protective factors (Bonnano, Galea, Bucciareli, & Vlahov, 2007) apparently fall short in case children are overwhelmed by a great burden of (combinations of) traumatic and life events.

An important limitation of this study is the small sample size. Nevertheless, the findings of this study are of particular value considering the difficulty to include suitable participants due to the common concern that exposing children to such an interview may be too overwhelming and could re-traumatize participants, although independently performed evaluation of participants have pointed to the reported benefits and personal satisfaction with participation (Scotti, Stevens, Jacoby, Bracken, Freed, & Schmidt, 2012).

In conclusion, given the impact of PTSD on daily life functioning on the one hand, and the widespread hesitation to discuss traumatic experiences with potentially vulnerable individuals on the other, it is of importance that the present findings suggest that an adapted interview is applicable, useful and even child-friendly. Furthermore, these pre-

liminary findings suggest that the interview is meaningful in terms of enhancing timely and accurate assessment, and is congruent with the introduction of DSM-5 in which research-based attention is given to the (mental) age-related manifestation of PTSD, making it of particular relevance for people with intellectual and developmental disabilities. Due to the inclusion of a timeline, it offers the opportunity to establish an overview of exposure to potentially traumatic events, in relation to the client's complaints and by means of this be helpful in the preparation for treatment of PTSD in children with mild and borderline ID. The results also showed that for both the DSM-5 and DSM-5 for pre-school children greater level of exposure to potentially traumatic events were associated with greater PTSD symptom report. Another important finding was that the manifestations of PTSD in children with ID did not appear to differ from those in children without ID. Overall, these preliminary results provide no reason to conclude that the criterion A1 for children with mild to borderline ID should be broadened.

DECLARATION OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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4.2

**Validation of the *adapted ADIS-C section PTSD* in children
with mild to borderline intellectual disabilities**

**Assessing posttraumatic stress disorder in children with
mild to borderline intellectual disabilities**

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ABSTRACT

Background Evidence suggests that children with mild to borderline intellectual disabilities (MBID; IQ 50-85) have an elevated risk for both being exposed to potentially traumatic events and developing a posttraumatic stress disorder (PTSD). In this target group PTSD often remains undiscovered due to a lack of diagnostic instruments. Valid instruments for the assessment of PTSD in children with MBID are therefore needed.

Objective The aim of the current study was to validate the adapted PTSD section of the Anxiety Disorders Interview Schedule for Children (ADIS-C) for the assessment of PTSD in children with MBID according to DSM-IV-TR and DSM-5 criteria.

Method Eighty children (6-18 years) with MBID who were referred to an outpatient psychiatric service and their primary caregivers were interviewed using the adapted ADIS-C.

Results The adapted ADIS-C PTSD section has excellent interrater reliability and good convergent validity. PTSD symptoms described spontaneously by children with MBID and their caregivers closely matched those included in the DSM-IV-TR and DSM-5. Many of the children who met Criterion A did not meet PTSD symptom criteria. Conversely, children meeting the full PTSD criteria were more likely than other children with MBID to have been exposed to at least one traumatic event meeting Criterion A and to a higher total number of potentially traumatic events.

Conclusions The results support the reliability and validity of the adapted ADIS-C PTSD section for assessing PTSD in children with MBID. The use of this clinical interview helps to improve detection of PTSD and subsequent access to trauma-focused interventions for this at risk target group.

INTRODUCTION

Exposure to severe adverse events such as interpersonal violence, sexual abuse, a severe accident, or the sudden loss of a loved one can have a far-reaching impact on someone's life. Up to 80% of people encounter such potentially traumatic events and a significant proportion of about 7% develops post-traumatic stress disorder (PTSD) (Kessler, Berglund, Demler, Jin, Merikangas, & Walters, 2005). PTSD is associated with clinically significant distress or impairment in social, occupational and other important areas of daily functioning in both adults and children (Yule, 2001). The events may also lead to other symptoms and conditions, for example, major depression, anxiety disorders, substance use disorder, and physical health problems (Olf, 2015). Especially the experience of severe, prolonged, or repeated stressors, such as child abuse or interpersonal violence, is associated with chronic mental and physical health problems involving high costs to society, thereby assigning great importance to timely trauma detection and subsequent trauma treatment (Olf, 2015).

Intellectual disability a risk factor for PTSD

Children with intellectual disabilities (ID) have been found to experience a greater number and range of adverse life events than children without ID (Hatton & Emerson, 2004). Furthermore, they have an elevated risk of developing any psychiatric, emotional, or conduct disorder (Hatton & Emerson, 2004). Also, evidence suggests that children with ID suffer from more severe forms of psychopathology than children without ID (Hatton & Emerson, 2004). Although cognitive and adaptive impairments are supposed to be a risk factor for the development of PTSD (DiGangi, Gomez, Mendoza, Jason, Keys, & Koenen, 2013) very few studies have been conducted on the manifestations of PTSD, and the development and psychometric evaluation of instruments for the assessment of PTSD in children with ID (Mevissen & De Jongh, 2010).

Assessment of PTSD in ID

To facilitate assessment of PTSD in children with mild to borderline ID (MBID), the present study replicates and extends the study by Mevissen, Barnhoorn, Didden, Korzilius, and De Jongh (2014) that examined the feasibility of an adapted version of the PTSD clinical interview (Anxiety Disorders Interview Schedule for Children [ADIS-C] PTSD section) in a sample of children with MBID (IQ 50 – 85). The latter study explored to what extent manifestations of PTSD corresponded with four PTSD algorithms; that is, DSM-IV-TR, DSM-5 proposed revision, PTSD-Alternative Algorithm, and the proposed DSM-5 for pre-school children. The ADIS-C PTSD appeared applicable for children with MBID and the study's findings suggested that manifestations of PTSD correspond with the four PTSD algorithms

that were developed based on research in people without ID (Mevisen, Barnhoorn, Didden, Korzilius, & De Jongh, 2014).

The current study

The aim of the current study was to validate the adapted ADIS-C PTSD using a sample of children with MBID including the children's caregivers. To this end, its reliability as well as its convergent validity were determined. It was hypothesized that: (1) PTSD symptoms in children with MBID would correspond with those included in the DSM-IV-TR (American Psychiatric Association, 1994) and DSM-5 (American Psychiatric Association, 2013) PTSD algorithms, (2) fulfilling the A criterion for trauma would be associated with the presence of PTSD, (3) children meeting PTSD symptom criteria would report higher subjective levels of daily life impairments than children not meeting criteria for PTSD, (4) children meeting PTSD symptom criteria would report a higher level of exposure to potentially traumatic events than those not meeting PTSD symptom criteria and, finally, given that children exposed to trauma have high rates of psychiatric disorders (Copeland, Keeler, Angold, & Costello, 2007), (5) positive correlations would be found between rates of PTSD symptoms and Child Behavior Checklist (CBCL) internalizing, externalizing and total scale scores.

METHOD

Participants

Participants were 80 children (46% [$n = 37$] female) with MBID who were referred to an outpatient center for child and adolescent psychiatry in the eastern part of the Netherlands. Their mean age was 11.6 years (min = 6, max = 18, SD = 3.25). Of this sample, 41% ($n = 33$) had mild ID (IQ 50-70), and 59% ($n = 47$) had borderline ID (IQ 70-85). Mean IQ was 72 (min = 51, max = 84, SD = 8.00).

Their primary caregivers also participated. For 53 children, the primary caregiver was the mother, for 5 children, it was the father, and for 17 children, it was both parents, whereas in the remaining cases, adoptive parents ($n = 1$), a legal guardian ($n = 2$) or a professional caregiver ($n = 2$) participated. Ninety percent ($n = 72$) of the children lived at home, 10% ($n = 8$) lived in a residential facility.

Measures

The Adapted ADIS-C PTSD section (Mevisen et al., 2014) uses simplified language and visual cues. The interview consists of an event and a symptom section with answer categories "yes", "no" or "other". The event section (26 items) includes type A trauma events as well as life events and has one open ended question. 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 (37 items) includes 30 symptoms originating from PTSD measures that are used in children without ID, and five potentially atypical symptoms that were found in the literature on clinical experiences regarding PTSD and its treatment in people with ID. Also, two open ended questions are part of the symptom section (question 37 child/caregiver): “If something reminds you/your child of the event(s), have you noticed anything that’s different about yourself/your child?” and the last symptom question: “Have you noticed anything else that’s different about yourself/your child since the event(s)?” If the answer is “yes”, the interviewer asks “What do you notice?”. Finally, a thermometer card is used to support the child to indicate the interference score (0 = totally not, 8 = very much) representing his or her subjective level of daily life impairment. In a pilot study, the adapted ADIS-C PTSD section appeared both feasible and child friendly and had excellent interrater reliability with kappa (κ) varying between 0.87 to 0.95 (Mevisen et al., 2014).

CBCL – Dutch version

The Dutch version of the CBCL (Achenbach, 1991; Verhulst, Van der Ende, & Koot, 1996) was used to determine convergent validity. The CBCL is a widely used 113-item behavior rating scale for children aged 6 to 18 years to measure emotional and behavioral problems. Caregivers rate their child’s behavioral and emotional problems on a 3-point Likert-type scale (0 = absent, 1 = occurs sometimes, 2 = occurs often). For the Dutch version of the CBCL, good reliability and validity have been demonstrated, also for children with ID (Douma, Dekker, Verhulst, & Koot, 2006; Verhulst et al., 1996).

In the present study, Cronbach’s alpha’s of the CBCL internalizing as well as the externalizing scale was 0.91 (excellent) (Bakeman & Gottman, 1986).

Procedure

Between April 2012 and June 2014, children with their primary caregivers who were referred to an outpatient center of a psychiatric service in the eastern part of the Netherlands received an information brochure and were asked to participate in the study. Eighty caregivers and their children (aged 12 or older) gave their written informed consent, permission to record the interview on video, and to process the data anonymously. This study was performed in accordance with the precepts and regulations for research as stated in the Declaration of Helsinki, and the Dutch Medical Research on Humans Act (WMO) concerning scientific research. The WMO was not applicable to the present study because (1) the surveys contained only a small number of items, (2) history taking by a psychologist, including potentially traumatic events, is considered common practice in an outpatient center for child and adolescent psychiatry, (3) the study lacked random

allocation and (4) no 'physical infringement of the physical and/or psychological integrity of the individual' was to be expected.

Trained psychologists administered the interviews for the child and the primary caregiver(s).

While the children were being interviewed, the primary caregiver(s) filled out the CBCL. All interviews were recorded on video.

Three children did not complete the interview. Two of them did not understand the questions and one child became upset when asked the first question of the event section. This child was not able to concentrate on the questions that followed.

PTSD criteria were applied to child ($n = 77$) as well as caregiver interviews ($n = 80$) using DSM-IV-TR and DSM-5. The first author and two psychologists independently coded the symptom questions according to DSM-IV-TR and DSM-5 diagnostic criteria, and in case of disagreement, the last author made the final decision. The same procedure was followed with regard to the decision whether or not an event met the A criterion.

For DSM-5 two different analyses were performed. First, data of all participants were scored according to DSM-5 criteria and according to DSM-5 criteria for children aged 6 years and younger. Second, DSM-5 criteria were applied for child and caregiver data taking into account the child's estimated mental age (eMA) $[(IQ/100) * \text{chronological age} - \text{max } 16 \text{ years}]$. Fifty-six children had an eMA of ≥ 7 years and 24 had an eMA < 7 years.

Statistical analyses

T-tests for independent samples, Mann-Whitney tests, Chi-square and Fisher's exact tests, Cohen's Kappa, and Pearson's correlations were performed. All tests were two-tailed and the level of significance was set at 0.05.

RESULTS

Interrater reliability

Three secondary observers independently scored 25% of the interviews (20 child and 20 caregiver interviews) on a question-by-question basis (63 questions) with results corrected for chance. Interrater agreement was 90%. Mean Cohen's kappa of both the child interviews and the caregiver interviews was excellent (Bakeman & Gottman, 1986) (child: $\kappa = 0.81$, range: 0.38 - 1, $M = 0.81$, $SD = 0.16$; caregiver: $\kappa = 0.79$, range: 0.34 - 1, $M = 0.79$, $SD = 0.15$).

Correspondence of PTSD symptoms in children with MBID with those included in the DSM-IV-TR and DSM-5 PTSD algorithms (also see Table 1)

Eighty-nine times one of both open ended symptom questions of the child and caregiver interview was answered in the affirmative. Some answers to the subsequent question “What do you notice” were vague, for example: “She has changed”. Clear answers were compared with the PTSD symptoms already included in the interview. All of these appeared to match with symptoms already included in the interview. For example, the answer “Jitters in my stomach” matched with the symptom question “If something reminds you of the event(s), do you get awful feelings in your body? “ Next, it was checked whether the participant had really answered “yes” to that corresponding interview question. If not, it was checked whether the child may have been unfairly diagnosed as not having a PTSD diagnosis (i.e., false negative). In one out of the 157 scored interviews this might have been the case.

Furthermore, it was examined whether the five interview questions that are not included in DSM-IV-TR, DSM-5 and DSM-5 for children 6 years and younger (eating problems, decreased self-care, difficulties when things go differently than expected, obsessive-compulsive behaviors and pretending to be happy) might be distinctive for children with MBID, so-called atypical PTSD symptoms. It was found that, except for caregiver reports of children with an eMA < 7 years, the mean number of those five symptoms was significantly higher in children who met the full PTSD symptom criteria than in children who did not meet the full PTSD symptom criteria, irrespective of the PTSD algorithm and whether child or caregiver data were used (subsequent statistical outcomes are available upon request).

Table 1. ADIS-C PTSD MBID symptom section¹

Symptom questions (answer categories: yes, no, other ²)	DSM-IV-TR	DSM-5	DSM-5Y ⁴	atypical kappa
28 Do you still often think of the event(s) even though you really don't want to? If eMA ³ <7: Do you sometimes play or draw what happened?	x	x	x	.90
29 Do you hear voices in your head about the event (s)?	x			.88
30 Do you frequently have nightmares or horrible dreams about what has happened?	x	x	x	.71
31 Do you have nightmares or horrible dreams about other things?	x	x	x	.82
32 Do you sometimes feel as if it could happen again right now?	x	x	x	.90
33 Do you get totally upset if something reminds you of those event(s)		x	x	.68
34 Do you start to act in a very happy way if you have to think about the event(s)?				x .73

Table 1. ADIS-C PTSD MBID symptom section¹ (continued)

Symptom questions (answer categories: yes, no, other ²)	DSM-IV-TR	DSM-5	DSM-5Y ⁴	atypical kappa
35 If something reminds you of the event(s), do you get awful feelings in your body? For example does your heart start to beat much faster, do you start to sweat or shake?	x	x	x	.80
36 If something reminds you of the event(s) do you get stomach ache or headache?	x	x	x	.90
37 If something reminds you of the event(s) do you notice anything different about yourself?				1.00
38 Do you try as hard as you can, not to think of those event(s)?	x	x		.90
39 Do you try to stay away from things that remind you of the event(s)? For example situations, places, noises, smells?	x	x	x	1.00
40 Are there some parts of the event(s) you no longer remember?	x	x		.79
41 Since those event(s) happened, did you stop doing things you really liked to do before, for example playing games or going out, hobbies? Or do you no longer like to do those things?	x	x	x	.63
42 Do you no longer feel like seeing your friends or girlfriends since the event(s)?	x	x	x	.78
43 Do you feel lonely or isolated more often since those event(s)?	x	x	x	.85
44 Since the event(s), has it become more difficult for you to show other people how you feel? For example, do you avoid showing someone else how you are feeling and do you keep your feelings to yourself?	x	x		.92
45 Has it become more difficult to trust other people since the event(s)?		x		1.00
46 Do you think that if you are grown up, you are able to do anything you would like to do for example receive training, get married, find a job, raise children or any of these types of things?	x	x		.90
47 Do you often feel bad? Do you for example often have feelings of anxiety, blame or shame or do you often think things are very awful?		x	x	.89
48 Do you always blame yourself or others about what has happened while in fact this is not with good reason?		x	x	.88
49 Can't you feel happy anymore since those event(s)?	x	x	x	.73
50 Is it as if you can't feel anything anymore since those event(s)?		x		.38

Table 1. ADIS-C PTSD MBID symptom section¹ (continued)

Symptom questions (answer categories: yes, no, other ²)	DSM-IV-TR	DSM-5	DSM-5Y ⁴	atypical kappa
51 Did you start doing things again you didn't do since you were a little child, for example wetting your pants again, sucking your thumb or always trying to stay close to your father and mother or caregivers?				.74
52 Are you unable to sleep well, for example; is it difficult to fall asleep, do you often wake up during the night or do you wake up too early in the morning?	x	x		.62
53 Do you get angry more often since those event(s) happened?	x	x	x	.67
54 Do you sometimes hurt yourself or others or do you break things?		x	x	.83
55 Do you have serious outbursts of anger?	x	x	x	.90
56 Is it difficult to keep your mind on things, do you have difficulties concentrating?	x	x	x	1.00
57 Do you always watch out very carefully because you think something bad might happen again?	x	x	x	1.00
58 Are you seriously frightened when something happens unexpectedly or suddenly, for example if all of a sudden you hear a loud noise or if someone touches you unexpectedly?	x	x	x	.92
59 Do you no longer watch out for what you're doing; do you act dangerously?		x		.73
60 Since the event(s), did you change eating behaviour for example eating too much or too little?				x .69
61 Do you no longer take care of yourself as well as you did before, for example has it become more difficult to wash yourself and dress and do you no longer succeed in brushing your teeth well?				x 1.00
62 Since those events, is it harder to accept when things go different than expected, for example if an appointment has been cancelled or if you suddenly have to do something unexpected?				x .73
63 Do you have to do some things again and again or always in the same order?				x .60
64 Have you noticed anything else that's different about yourself since the event(s)?				.85

¹ Caregivers were asked the question for the child, e.g.: "Does (child's name) still often think of the event(s) even though he/she really does not want to?"

² The child answers e.g.: "I don't know", "sometimes" or any other unclear answer

³ eMA = estimated Mental Age [(IQ/100) * chronological age -max 16 years-]

⁴ DSM-5Y = DSM-5 6 Years and Younger

Association between level of exposure to potentially traumatic events and fulfilling PTSD symptom criteria

Table 2 presents the differences in mean number of potentially traumatic events between children who did and those who did not meet full PTSD symptom criteria according to the different PTSD algorithms for child as well as caregiver reports.

Children who met the full PTSD symptom criteria had been exposed to a significantly greater number of potentially traumatic events than those not meeting PTSD criteria, except when DSM-IV-TR was applied to caregiver reports and DSM-5 for children 6 years and younger was applied to child reports of children with an eMA < 7 years.

Table 2. Mean number of potentially traumatic events between children who fulfilled and those who did not fulfill PTSD symptom criteria, according to the different diagnostic algorithms and child and caregiver reports.

Diagnostic algorithm	PTSD symptom criteria	Reported by the child						Reported by the caregiver					
		<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>
DSM-IV-TR	yes	20	14.55	3.82	5.40	75	0.000***	21	11.33	3.60	1.26	78	0.211
	no	57	9.09	3.92				59	10.24	3.36			
DSM-5	yes	18	13.56	5.20	3.47	75	0.001**	26	12.42	3.09	3.69	78	0.000***
	no	59	9.58	3.94				54	9.61	3.24			
DSM-5 for children 6 years and younger	yes	26	12.92	4.68	3.57	75	0.001**	35	12.29	2.87	4.51	78	0.000***
	no	51	9.27	4.01				45	9.16	3.23			
DSM-5 children eMA ^a ≥7 Years	yes	11	15.18	4.64	3.58	54	0.001**	16	12.94	2.67	3.59	54	0.001**
	no	45	10.16	4.06				40	9.93	2.90			
DSM-5 children eMA ^a < 7 Years	yes	10	10.50	4.58	1.93	19	0.069	13	12.15	2.88	3.61	22	0.002**
	no	11	7.27	3.00				11	7.27	3.74			

Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

^a eMA= estimated mental age: $(IQ/100) \times \text{age}$ (age max = 16 x 12 months)

Applicability of the A criterion for trauma

Table 3 presents results of Chi-square tests on the association between meeting criterion A and fulfilling PTSD symptom criteria for each of the PTSD algorithms.

Children who had been exposed to a criterion A1 event were more likely to meet PTSD symptom criteria than those not exposed to a criterion A1 event. This outcome held true

Table 3. PTSD Criterion A and PTSD symptom criteria for DSM-IV-TR, DSM-5 and DSM-5 for children 6 years and younger, according to child and caregiver reports.

PTSD Criterion A		PTSD symptom criteria			PTSD symptom criteria		
		Reported by the child			Reported by the caregiver		
				<i>p</i>			<i>p</i>
		Yes	No		Yes	No	
DSM-IV-TR	Yes	20	42	0.018*	19	49	0.502
	No	0	15		2	10	
DSM-5	Yes	15	35	0.090	23	33	0.023*
	No	3	24		3	21	
DSM-5 for children 6 years and younger	Yes	20	26	0.048*	30	24	0.003**
	No	6	25		5	21	
DSM-5 children eMA ^a ≥7 Years	Yes	10	30	0.150	15	27	0.084 ^b
	No	1	15		1	13	
DSM-5 children eMA ^a <7 Years	Yes	6	3	0.198	10	4	0.095
	No	4	8		3	7	

Note. * $p < 0.05$, ** $p < 0.01$

^a eMA= estimated mental age: $(IQ/100) \times \text{age}$ (age max = 16 x 12 months)

^bFisher's exact test indicated significance ($p = 0.047$) and thus did not corroborate the finding of the Chi-square test.

for child reports of DSM-IV-TR and DSM-5 for Children 6 years and younger, and for the caregiver reports of DSM-5 and DSM-5 for Children 6 years and younger.

Children who met full PTSD symptom criteria, but who did not meet the Criterion A for the specific PTSD algorithm, had a history of event(s) fitting DSM-IV-TR A criterion and/or event(s) that were potentially A events but reports contained insufficient information to score the event(s). The only child who met PTSD DSM-5 and DSM-5 6 years and younger symptom criteria without reporting a type A event had an eMA of 5.3 years and was referred to the outpatient centre with suspicion of autism. According to the caregiver report, a PTSD diagnosis was not applicable. Twice a caregiver reported no type A event while symptoms met DSM-5 PTSD criteria. In one case the father, with whom the relationship was close, left the family when the child was 3 years old. Moreover the child had a history of being bullied. In the second case parents divorced when the child was 2 years

old, with subsequent foster placement of the child. The caregiver reported “suspected” abuse, so the answer could not be coded as a type A event

Association between subjective level of impairment and fulfilling PTSD symptom criteria

Table 4 presents the differences in mean thermometer scores of children fulfilling the PTSD criteria according to the different PTSD algorithms and children not fulfilling these symptom criteria, according to child and caregiver reports.

Except for reports from children with an eMA < 7 years, children who met the PTSD symptom criteria of DSM-IV-TR, DSM-5 and DSM-5 for children 6 years and younger reported a significantly higher mean thermometer score than those who did not meet the PTSD symptom criteria.

Table 4. Mean thermometer scores in children who fulfilled and those who did not fulfill PTSD symptom criteria, according to the different diagnostic algorithms and child and caregiver reports.

Diagnostic algorithm	PTSD symptom criteria	Reported by the child						Reported by the caregiver					
		n	M	SD	t	df	p	n	M	SD	t	df	p
DSM-IV-TR	yes	20	6.35	1.70	6.12	55.88	0.000***	17	6.71	1.11	5.29	59.02	0.000***
	no	56	3.09	2.80				63	4.56	2.43			
DSM-5	yes	16	6.94	1.57	7.23	59.02	0.000***	23	6.43	1.16	4.86	76.41	0.000***
	no	60	3.15	2.69				57	4.44	2.51			
DSM-5 for children 6 years and younger	yes	19	6.58	1.68	6.64	51.06	0.000***	30	6.37	1.19	5.15	74.45	0.000***
	no	57	3.07	2.73				50	4.20	2.55			
DSM-5 children eMA ^b ≥7 Years	yes	11	6.91	1.58	5.72	54	0.000***	15	6.33	1.23	3.75	49.66	0.000***
	no	45	2.58	2.38				41	4.41	2.56			
DSM-5 children eMA ^b <7 Years	yes	5	7.00	1.73	1.98	11.98	0.071	10	6.60	0.97	3.26	17.92	0.004**
	no	15	4.87	2.90				14	4.21	2.49			

Note. As the assumption of equal variances was not met (tested with Levene’s test) results of *t*-tests for unequal variances are reported.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

^a One thermometer score was missing

^b eMA= estimated mental age: $(IQ/100) \times \text{age}$ (age max = 16 x 12 months)

Association between PTSD symptom scores and CBCL scores

A significant positive correlation was found between total number of PTSD symptoms and CBCL internalizing subscale score (DSM-IV-TR: $r = 0.53$, $p < 0.01$; DSM-5: $r = 0.58$, $p < 0.01$;

DSM-5 6 years and younger: $r = 0.57, p < 0.01$), as well as CBCL externalizing subscale score (DSM-IV-TR: $r = 0.23, p < 0.05$); DSM-5: $r = 0.29, p < 0.01$; DSM-5 6 years and younger: $r = 0.26, p < 0.05$). Also for children with an eMA < 7 years a significant positive correlation (DSM-5 6 years and younger: $r = 0.65, p < 0.01$) was found between the total number of PTSD symptoms and the CBCL internalizing subscale score. For the CBCL externalizing subscale score, the correlation with the total number of PTSD symptoms was positive though not significant ($r = 0.25, p = 0.24$) for children with an eMA < 7 years.

DISCUSSION

The present study is the first study to validate a PTSD clinical interview for assessing PTSD in children with MBID. Both the child and caregiver version of the interview yielded excellent interrater reliability, and proved to have good convergent validity for assessing PTSD.

It was found that PTSD does not manifest itself atypically in children with MBID. PTSD symptoms reported by children with MBID and their caregivers were in accordance with the PTSD symptoms in the DSM-IV-TR and DSM-5. This finding not only is in line with the results of the pilot study by Mevissen et al. (2014), it also underpins the expert guidelines for the assessment of PTSD in people with mild ID as recommended in the Diagnostic Manual-Intellectual Disability (DM-ID) (Fletcher, Loschen, Stavrakaki, & First, 2007). The five atypical symptoms that were included in the interview were more likely to be recognized by children and caregivers whose reports were meeting PTSD criteria than by participants whose reports did not fulfill all PTSD criteria. Most of these atypical symptoms may be similar to symptoms of depression and anxiety, seen in children with severe or 'complex' forms of PTSD (e.g., Suliman, Mkabile, Fincham, Ahmed, Stein, & Seedat, 2009).

According to DSM-IV-TR analyses of the child reports, children who had been exposed to a criterion A event would be more likely to meet PTSD symptom criteria than children who had not been exposed to a criterion A event. However, the caregiver data did not correspond with those of the children. This is conceivable given that caregivers are only partially able to assess the inner world and perceptions of their trauma-exposed child (criterion A2). The DSM-IV-TR differed from the DSM-5 in that children reported symptoms fulfilling the DSM-5 PTSD symptom criteria in the absence of a DSM-5 type A event. This finding might be explained by the sharpened formulation of the criterion of what constitutes a type A event as introduced in DSM-5 in comparison to former DSM A1 definitions. That many of the children who met the Criterion A did not meet PTSD symptom criteria corresponds well with other child trauma samples (Alisic, Jongmans, Van Wezel, & Kleber, 2011).

Children meeting PTSD symptom criteria were found to report a higher level of exposure to potentially traumatic events than those not meeting PTSD symptom criteria. This held true for all PTSD algorithms, and for caregiver as well as child reports. This finding is in line with the general literature about PTSD, and with studies showing that the likelihood of developing PTSD is linearly associated with the level of exposure to traumatic events (Perkonig, Kessler, Storz, & Wittchen, 2000; Wilker, Pfeiffer, Kolassa, Koslowski, Elbert, & Kolassa, 2015).

Meeting PTSD symptom criteria appeared to be associated with higher subjective levels of daily life impairment, regardless of the algorithm that was used and held true for child as well as caregiver reports. Apparently, elevated distress and impairments in daily life functioning are characteristic of PTSD, irrespective whether a child has ID or not.

Positive correlations were found between rates of PTSD symptoms and CBCL scores. The correlations were higher for internalizing problems than for externalizing problems. This seems logical because PTSD largely consists of symptoms representing thoughts and feelings included in the PTSD clusters re-experiencing, avoidance, and negative alterations in mood and cognition. In clinical practice the CBCL is used to assess psychopathology in children with MBID. An internal CBCL score in the deviant range should be a sign for psychologists to further investigate potential psychological trauma.

Strengths and limitations

The study has several strengths and limitations. Obvious strengths were that it was the first study to validate a PTSD clinical interview for children with MBID in which three PTSD algorithms were compared, taking ID into account. Considering the latter, recently Gigengack, van Meijel, Alisic, & Lindauer (2015) demonstrated the importance of the developmentally sensitive PTSD criteria for young children, as incorporated in the DSM-5 subtype for children aged six years and younger. In the present study, these DSM-5 6 years and younger criteria were used for children having a mental age corresponding with that of nondisabled children aged six years and younger. This PTSD subtype does not include symptoms that require skills which young children have not yet developed, such as verbal expression, memory or abstract thought, thereby improving the identification of PTSD relative to DSM-IV-TR for this (mental) age category. Taking into account the limited skills of children with a mental age of six years and younger, it is also a strength of this study that both child and caregiver data were collected. Furthermore, the thorough event section of the interview seems to be valuable considering that there is evidence indicating that the number of traumatic event types experienced leads to the best prediction of lifetime PTSD (Wilker et al., 2015). A feature of the study which is difficult to qualify in terms of strength or limitation is the use of a timeline which incorporates all negative events the participant has been exposed to considering it is common practice to take

into account only one event when asking for trauma related symptoms. Research findings suggest that traumatic events, experienced during developmental sensitive periods have a significant impact upon the development of childhood and adult psychopathology (Wilker et al., 2015). From this point of view assessment of trauma exposure with use of a timeline seems to be valuable. Limitations of this study were that IQ data were based on information from case files and that children with IQ 70-85 (i.e., borderline ID) were over-represented. Additional analyses revealed that the pattern of results found for children with IQ 70-85 was comparable for the sub sample of children with IQ 50-70 with regard to symptom severity, level of exposure to potentially traumatic events, as well as subjective level of daily life impairment (Supplementary Tables). It could be argued that the sample is not fully representative of the overall population of children with MBID because of self-selection, meaning that replication is needed with additional samples of children with MBID. It is worth noting that the participants of the current study were referred to the outpatient psychiatric service under suspicion of a wide variety of psychiatric disorders by a wide variety of notifying parties.

Concluding comments and future directions

The adapted ADIS-C as a valid and reliable PTSD clinical interview could be of great relevance in mental health care for children and adolescents with MBID. Timely detection and diagnosis in this population, which is at higher risk for exposure to potentially traumatic events and developing PTSD, is the first step in preventing serious long term psychological and somatic disorders which have been found to require costly professional care (Olf, 2015). This could be enhanced by the development of a less time-consuming screening tool to identify children with MBID who need further clinical assessment by trained professionals. The present study focussed on children. An important future direction of research is the development and validation of a PTSD clinical interview for adults with MBID, an even larger and likewise at high risk target population.

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5

EMDR therapy for PTSD in children and adolescents with mild to borderline intellectual disability: A multiple baseline across subjects study

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ABSTRACT

Objective This study explored the effectiveness of EMDR for PTSD in persons with mild to borderline intellectual disability (MBID) using a multiple baseline across subjects design.

Method One child and one adolescent with MBID, who met diagnostic criteria for PTSD according to a PTSD clinical interview (i.e., ADIS-C PTSD section), adapted and validated for this target group, were offered four sessions of EMDR. PTSD symptoms were measured before, during and after EMDR, and at six weeks follow-up.

Results For both participants, number of PTSD symptoms decreased in response to treatment and both had lost their PTSD diagnosis at post-treatment. This result was maintained at 6 weeks follow-up.

Conclusions The results of the present study add further support to the notion that EMDR can be an effective treatment for PTSD in children and adolescents with MBID. Replication of this study in larger samples and using a randomized controlled design is warranted.

INTRODUCTION

On average 16% of children exposed to trauma develop PTSD (Alisic, Zalta, Van Wesel, Larsen, Hafstad, Hassanpour, & Smid, 2014) which may negatively affect their emotional, social, academic and physical development (Alisic, Jongmans, Van Wesel, & Kleber, 2011). Not only the child, also the parents may be affected through concerns for their child's well-being, for example when their child has been exposed to injury, life-threatening illness or sexual abuse (Scheeringa, Meyers, Putnam, & Zeanah, 2015). Probably siblings will also suffer from the consequences of traumatization in their family. Cumulative exposure to traumatic events in children is related to many forms of psychopathology, with the strongest links being with anxiety and depressive disorders (Copeland, Keeler, Angold, & Costello, 2007). Moreover, cumulative childhood trauma predicts symptom complexity in adults (Cloitre, Stolbach, Herman, van der Kolk, Pynoos, Wang, & Petkovka, 2009). Timely PTSD treatment is of importance considering the personal suffering and the significant costs to society (Priebe, Mtanov, Gavrilović, Crone, Ljubotina, Knežević, Kučukalić, Frančičković, & Schützwohl, 2009).

Children with intellectual disabilities (ID) experience a greater number and range of adverse life events than children without ID (Hatton & Emerson, 2004). Processing adverse events is supposed to be more difficult due to impairments in their cognitive and adaptive skills (Mevissen & De Jongh, 2010). Also early separation from parents through institutionalisation or hospital admissions, fewer experiences in managing negative life events successfully, and limited availability of a supportive network as well as capacity for gathering social support may make individuals with ID particularly vulnerable for the development of PTSD (Mevissen, Didden, & De Jongh, in press).

Trauma-focused Cognitive Behaviour Therapy (CBT) and Eye Movement Desensitisation and Reprocessing (EMDR) therapy are the psychotherapies recommended by the World Health Organization (2013) for the treatment of PTSD. A meta-analysis by Rodenburg, Benjamin, De Roos, Meijer and Stams (2009) showed that in children (1) application of EMDR therapy resulted in a substantial reduction in PTSD symptoms compared to therapy-as-usual or no-treatment control groups, and (2) although both CBT and EMDR were effective, EMDR added "a small but significant incremental value" (p. 604).

Controlled studies that have assessed the effectiveness of PTSD treatment in people with ID are lacking. Until now, as few as 5 case reports have been published pertaining to the treatment of posttraumatic stress symptoms in children and adolescents with MBID (for an overview, see Mevissen et al (in press); see also Table 1). In one of these case studies (Stenfert Kroese & Thomas, 2006) Imagery Rehearsal Therapy, a CBT approach, was used to reduce trauma-related nightmares, whereas in the remaining four cases a broad range of trauma-related symptoms were addressed using EMDR with promising results.

Table 1. Treatment of PTSD in children and adolescents with MBID: 5 case reports.

Authors/ Year	Treatment method	Number of sessions	Age in years	Male/ Female	Level of ID/ comorbidity	Trauma's/life events	Results
Stenfert Kroese & Thomas (2006)	CBT (Imagery Rehearsal Therapy)	3	18 years	F	Mild	Sexual, physical and emotional abuse	Nightmares ceased, improved self-confidence
Giltaij (2004)	EMDR	12	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)	EMDR	5	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)
Mevissen et al. (2011)	EMDR	5	11 years	M	Mild	Witnessing car fire, being threatened, witnessing domestic violence, parents divorced, and outplacements	Absence of pre-treatment symptoms (fears, compulsive behavior, obsessions, hearing voices, difficulties distinguishing reality from fantasy, avoiding to sleep at parental home). At follow-up medication was faded out.
Mevissen et al. (2011)	EMDR	3	7 years	F	Mild/ autism	Two dear family members died, suicide attempt of father's best friend, and serious illness of school friend	Disturbing thoughts disappeared, more often cheerful, significant decrease of anger outbursts, more relaxed.

Research investigating the efficacy of EMDR in children with MBID has been particularly hindered by the lack of valid and reliable instruments to assess PTSD in this target group. In three of the four aforementioned EMDR case studies (Giltaij, 2004; Mevissen, Lievegoed, & De Jongh, 2011) results were based on only caregiver reports regarding problem behaviours that resembled posttraumatic stress symptoms. The Impact of Event Scale (IES), a screening self-report questionnaire to index subjective stress caused by traumatic events, used by Rodenburg, Benjamin, Meijer, & Jongeneel (2009) to measure PTSD symptoms, was not validated for persons with ID at that time. Therefore, to fill this gap in diagnostic accuracy, the 'Adapted ADIS-C PTSD section' was developed, a PTSD clinical interview that was adapted for use in children and adolescents with MBID aged 6 to 18 years, and which has shown good to excellent psychometric properties Mevissen, Barnhoorn, Didden, Korzilius, & De Jongh, 2014; Mevissen, Didden, Korzilius, & De Jongh, 2016). As a result, research on PTSD and its treatment in children with MBID can be improved because PTSD symptoms, and therefore treatment results, can be measured in a standardized and reliable way. Another problem with the case studies on PTSD treatment in patients with MBID (see Table 1) is that internal validity has been impaired by the lack of control for natural recovery in the course of time given that before the start of treatment the measurements were taken only once. None of the case reports measures to achieve reliability of recording. Finally, there were no follow-up assessments in two of the case studies (Giltaij, 2004; Mevissen et al., 2011).

The present study, therefore, aimed to examine the effectiveness of EMDR regarding symptoms of PTSD in one child, and one adolescent, with MBID. The aforementioned limitations were taken into account by (1) using the Adapted ADIS-C-PTSD section as a valid and reliable PTSD instrument, (2) collecting data using a multiple baseline across subjects design, (3) conducting video-analyses to assess reliability of recording, and (4) assessing maintenance of outcomes at 6 weeks follow-up.

METHODS

The study is part of a broader research project which received ethical approval of the Ethical Committee of the Department of Social Sciences of the Radboud University Nijmegen.

Participants

Participants were William, a 10-year-old boy (mild ID, IQ 66), and Rose, an 18-year-old girl (mild ID, IQ 67), both living in a single-parent family. Emotional and behavioral problems were the reason for referral to an outpatient centre for child and adolescent psychiatry in the eastern part of the Netherlands. William showed aggressive behavior, he was restless

and unable to build relationships with peers. His behavioral problems were supposed to be related to a long period of emotional and physical abuse by a stepparent. Rose had completed CBT treatment for emotional and behavioral problems at the same outpatient centre 2 years earlier after which she functioned well during about 1 year. Then she gave birth to a child after which serious conflicts with youth welfare developed that impeded professional parental support, delivered by workers from a centre specialized in the care for youth with MBID. This service centre advised her to undergo treatment of her emotion regulation problems which were considered to be a risk factor for her baby's development.

Participants met PTSD DSM-IV and DSM-5 criteria according to the child version of the adapted ADIS-C PTSD section, a clinical interview for assessing PTSD according to DSM-IV and DSM-5 criteria in children with MBID, aged 6-18 years (Mevissen et al., 2014; Mevis-sen et al., 2016).

Procedure

Both participants were recruited during the final stages of a study aimed to validate the adapted ADIS-C PTSD section, a clinical interview for assessing PTSD according to DSM-IV and DSM-5 criteria in children with MBID, aged 6-18 years (Mevissen et al., 2014; Mevis-sen et al., 2016). Eligible for the current study were children who met PTSD DSM-IV and/or DSM-5 criteria according to the interview. Participants and their parent(s) were informed about PTSD and EMDR therapy and about the aims of the study. They gave their written consent to participate.

Trauma history was taken at the first baseline measurement by administration of the adapted ADIS-C PTSD section (see below). The traumatic events to which the participant had been exposed were visualised on the time line that is an integral part of the interview. It is conceivable that during the course of the study the participant would be exposed to new potentially traumatic events, influencing PTSD symptom outcomes. Therefore, at each measurement point, the participant was asked as to whether new potentially traumatic events had occurred.

All measurements were videotaped for the purpose of assessing interrater reliability of recording (see below).

Treatment

EMDR therapy comprised a maximum of four 60-minute sessions. No subsequent treatment session was offered in case none of the participants' time line events elicited any disturbance when bringing up the corresponding memories, meaning that all traumatic memories had successfully been processed. For William, EMDR was administered by the first author, a licensed clinical psychologist and EMDR Europe accredited consultant. Rose was treated by a psychologist who had been trained in EMDR therapy at an advanced

level, and who was supervised by the first author. Supervision consisted of agreement beforehand on the case conceptualisation, and provision of feedback on applying the EMDR protocol on the first targeted memory.

EMDR therapy is a protocolized, 8-phase psychotherapeutic approach, developed by Shapiro (2001) aimed to resolve symptoms resulting from disturbing and unprocessed life experiences. EMDR Phase I consists of history taking and case formulation, resulting in a treatment plan. In the present study history taking was performed by administering the Adapted ADIS-C PTSD section (see below). In Phase II the participant is prepared for the trauma work. Skill building and resource development were not applied as this was deemed not necessary (Lindauer, 2015). In the first treatment session EMDR was introduced followed by Phase III to VII which pertain to the reprocessing of the traumatic memory. Phase III begins with a focus on the traumatic memory itself by asking the participant to bring up the memory and to concentrate on various aspects of it, specifically the most distressing image and the dysfunctional negative cognition (NC) 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 a working memory demanding task, typically, the therapist moving his fingers back and forth in front of the client, asking him or her to track the movements, 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 or her fingers, while encouraging to 'go with' whatever freely arises in the client's awareness. Repeatedly the client is asked to report about emotional, cognitive, somatic and/or imagistic experiences that arise, until intern disturbances reach a SUDs (Subjective Unit of Disturbances scale) of zero and an adaptive and positive statement about oneself (PC, Positive Cognition) is rated as fully believable 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 re-evaluation and integration.

The underlying adaptive information processing theory of EMDR therapy 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 (De Jongh, Ernst, Marques, & Hornsveld, 2013; Engelhard, van den Hout, Smeets, 2011). 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 & Settle, 2008).

In the present study the Dutch protocol for children and adolescents (De Roos, Beer, De Jongh, & ten Broeke, 2013) was applied in that instructions as how to activate the trauma memory, and how to support the participant during the desensitization and reprocessing phase, were adjusted to the participant's estimated mental age (in the two patients: 7 and 10 years, respectively). For William, rating the VOC had to be omitted because he did not understand the instruction. Both participants were able to follow the therapist's finger with their eyes.

Adapted ADIS-C PTSD section

The Adapted ADIS-C PTSD section (Mevisen et al., 2014; Mevisen et al., 2016) is a PTSD interview for diagnosing PTSD according to DSM-IV and DSM-5 criteria. The interview was adapted for the use in children with MBID and uses simplified language and visual cues. It consists of an event and a symptom section with answer categories "yes", "no" or "other". The event section (26 items) includes type A trauma events as well as life events and has one open ended question. 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. Once the timeline is completed the child will be prompted to point out which event actually is the worst to think of. The symptom section (37 items) includes symptoms originating from PTSD measures that are used in children without ID, and five potentially atypical symptoms that were found in the literature on clinical experiences regarding PTSD, and its treatment in people with ID. Also two open-ended questions are part of the symptom section. The interviewer inquires whether the child has any other complaint(s) related to the experienced adverse events and, if so, asks for an explanation. Finally, a thermometer card is used to support the child to indicate the interference score (0 = totally not, 8 = very much) representing the subjective level of daily life impairment. The Adapted ADIS-C PTSD Section appeared feasible and child friendly (Mevisen et al., 2014). Convergent validity was good (Mevisen et al., 2016): a significant positive correlation was found between total number of PTSD symptoms and CBCL internalizing subscale score (DSM-IV-TR: $r = 0.53, p < 0.01$; DSM-5: $r = 0.58, p < 0.01$; as well as CBCL externalizing subscale score (DSM-IV-TR: $r = 0.23, p < 0.05$; DSM-5: $r = 0.29, p < 0.01$). Interrater reliability of both the child interviews and the caregiver interviews was excellent (Bakeman & Gottman, 1986; Mevisen et al., 2016) with mean Cohen's kappa: child: $\kappa = 0.81$, range: 0.38 - 1, $M = 0.81$, $SD = 0.16$; and caregiver: $\kappa = 0.79$, range: 0.34 - 1, $M = 0.79$, $SD = 0.15$.

The Adapted ADIS-C PTSD section is administered by a trained psychologist.

Based upon the results of the validation study of the *Adapted ADIS-C PTSD section* (Mevisen et al., 2016) in the present study the five "additional symptom questions" and the two open-ended symptom questions were removed from the symptom section. Thus, the maximum total number of PTSD symptoms was thirty.

Interrater reliability

Five of nineteen (26%) randomly chosen PTSD symptom interviews consisting of 30 questions per interview were independently scored by a second observer on a question-by-question basis. Mean percentage of agreement was 95.3 ($SD = 21.2$; range 0-100), indicating excellent interrater reliability of recording (Cicchetti, 1994).

Evaluation

Total number of PTSD symptoms were plotted on a graphical display. Data were interpreted by visual inspection, following the guidelines of Lane and Gast (2014) for assessing trend, level and stability of data within and between conditions. Results with regard to the information as to whether or not PTSD criteria were met at post-treatment and at follow-up are presented in a table.

Design

Data were collected within a (nonconcurrent) multiple baseline across subjects design (Kazdin, 2011). The two participants were randomly assigned to different numbers of baseline and post-treatment measurements. Six weeks after the last post-treatment measurement a follow-up was conducted. During treatment PTSD symptoms were measured immediately prior to each session. Baseline measurements started at different time points. The time between the first and second baseline measurement was one week for William and five weeks for Rose. EMDR was introduced after three and four baseline measurements, respectively. From the second baseline until the last post-treatment session, measurements were carried out weekly. William was assessed on PTSD symptoms nine times instead of ten times because EMDR was completed after 3 instead of 4 sessions as all unprocessed memories had been treated at that time (also see Table 2).

By randomizing participants across different baseline lengths, the effect of time and the start of therapy were separated (Kazdin, 2011). The effect of the therapy was expected to become visible shortly after the start of treatment, and to hold on at post-treatment and at follow-up.

Table 2. Multiple baseline design.

Patient	Measurements
William	t1/B B B B/T T T T P P FU
Rose	t1/B B B/T T T T P P P FU

Note. t1/B=first baseline measurement (PTSD is diagnosed); B = baseline; B/T = last baseline measurement prior to the first treatment session; P = post-treatment; FU = 6 weeks follow-up

RESULTS

William

(First) Baseline outcomes (Adapted ADIS-C PTSD Section)

Trauma exposure. William’s time-line displayed the following potentially traumatic events: parents divorced (age 2), got lost (age 5), stepparent did not allow him to play outside the home/no food (from age 6), pushed by a peer resulting in a wounded leg (age 7), grabbed by the throat, kicked and beaten in the face by stepparent (age 8), witnessed (parental) domestic violence (age 9), placement at a special school (age 9), death of his cat (age 9), building in fire nearby (age 10), bullied at school (age 10), and watching war on television (from age 4 until present). The actually worst event was the physical abuse by his stepparent at age 8.

PTSD symptoms. William reported symptoms of re-experiencing (often thinking of the events unintentionally, having nightmares, awful physical feelings when thinking of the events), avoidance (trying not to think of the events, avoiding certain people and situations), hyperarousal (sleeping problems, outbursts of anger, difficulties concentrating, hypervigilant, easily startled), and negative thoughts and feelings (feeling lonely, more difficult to trust other people, often bad feelings). The interference score was 8.

PTSD diagnosis. The outcomes of the adapted ADIS-C section PTSD, resulted in a PTSD diagnosis according to both DSM-IV-TR and DSM-5.

EMDR therapy

For each time-line event William rated his actual subjective level of disturbance that was elicited by thinking of the event, on a scale reaching from zero (no disturbance) to ten (highest). The memories of the events in which his stepparent was involved (not allowed to play outside, physical abuse and parental domestic violence) bothered him most (10) and were treated first. The consecutive target images were: “Stepparent hits me, it hurts”, “Me, alone in my bedroom, my friends playing football outside”, and “Stepparent grasps me by my throat”. Within two sessions these memories were processed and a future template was installed successfully (meeting his stepparent: “Me and my mother at the

pay desk, stepparent behind us, I feel calm”). At the start of the third EMDR session William was asked to carefully check all time-line events one by one. He reported that he was unable to recall a memory that elicited any distress. Considering that no unprocessed memories were present, EMDR therapy was terminated.

Course of PTSD symptoms

Figure 1 shows the course of the total number of PTSD symptoms from the first baseline measurement to the 6-weeks follow-up. At first glance, the baseline measurements seem to show a slightly decreasing trend in the data. However, when applying the guidelines of Lane and Gast (2014) for assessing within-condition stability of data (criterion stability envelope $\geq 80\%$ within $\pm 25\%$ of median), the baseline (B1 = 17, B2 = 18, B3 = 14, B4 = 13) can be considered as ‘stable’ (100% within $15.5 + 3.9 = 19.4$ and $15.5 - 3.9 = 11.6$).

Mean number of PTSD symptoms in the different phases were: 15.5 [range 13 - 18] (baseline), 3 [range 2 - 4] (treatment), and 2 [range 2 - 2] (post-treatment and follow-up). After the first treatment session a substantial decrease in total number of PTSD symptoms had occurred. Results remained stable at post-treatment and were maintained at 6-weeks follow-up.

PTSD diagnosis

At post-treatment, William had lost his PTSD diagnosis on the basis of the criteria of DSM-IV and DSM-5. This result was maintained at 6-weeks follow-up (also see Table 3).

ROSE

(First) Baseline outcomes (Adapted ADIS-C PTSD Section)

Trauma exposure. Rose’s time-line displayed the following potentially traumatic events: her father was repeatedly imprisoned for addiction-related crimes (from birth until present), for the first time her father left the house (age 2.5), was bullied by peers (age 8 - 12), left the country to live abroad temporarily (age 12), witnessed domestic violence (age 12), her father took all the money and disappeared (age 12), serious illness of sibling (age 12), taken by police and questioned (age 14), witnessed a big fire nearby (age 14), a close family member died (age 16), she met father in court (age 17), youth welfare took her child from her and forced her to accept help (age 17), and a dear friend was threatened with death (age 18). The actually worst event was youth welfare taking her child from her at age 17.

PTSD symptoms. Rose reported symptoms of re-experiencing (feeling as if it could happen again right now, awful physical feelings when thinking of the events), avoidance (trying not to think of the events, doesn’t remember some parts of the events, keeps feelings to

herself), hyperarousal (outbursts of anger, destroys things, hypervigilant), and negative thoughts and feelings (more difficult to trust other people). The interference score was 6.

PTSD diagnosis. The outcomes of the adapted ADIS-C section PTSD resulted in a PTSD diagnosis according to criteria of both DSM-IV-TR and DSM-5.

EMDR therapy

Between the first and second baseline measurement, Rose had been exposed to a new (DSM-IV-TR) type A trauma event. She was told that her beloved grandma was terminally ill. This event was added to her time-line. At the start of EMDR therapy Rose was still upset and preoccupied by her grandma's nearing death. This time-line event actually elicited the highest subjective level of disturbance (i.e., 10). The distress, linked with memories related to her child, her father, and the death of a beloved family member was very high as well (i.e., 9). A central theme of these events is the experience of loss or threatened loss by death, serious illness or being abandoned. The consecutive target images which were brought up in the first session were "Grandma putting a farewell letter in a drawer", "X (= close family member) in a coffin, I close the lid", and "Y (= close family member) in a hospital bed, screaming in pain". The target images, belonging to the memories that were treated in the second EMDR session, were "Me in the courtroom, sitting alone, it's black around me" (the judge assigned the custody of her child to youth welfare), "I'm sitting in the living room, he drives away" (father leaves the family), and "The policeman is questioning me". In session 3 a memory of witnessing a parental row was treated as well as a memory of being bullied by peers for giving birth to a child at such a young age. The fourth session was terminated early. The only unprocessed memory that could be detected and subsequently treated was about a violent row between her and her mother in relationship with the care of her child.

Course of PTSD symptoms

Figure 1 shows the course of the PTSD symptoms from the first baseline measurement to the 6-weeks follow-up. During the baseline phase the total number of PTSD symptoms substantially increased after Rose had been exposed to a new type A traumatic event. Mean number of PTSD symptoms in the different phases were: 14.7 [range 10 – 19] (baseline), 14.5 [range 11 - 19] (treatment), and 4.8 [range 1 - 8] (post-treatment and follow-up).

According to the guidelines of Lane and Gast (2014) the split-middle method of trend estimation was used. First half, second half and mid rate for each condition were 10, 15 and 12.5 (baseline), 19, 11 and 14.5 (treatment), and 7.5, 2 and 4.75 (post-treatment and follow-up), respectively. The results indicate a deteriorating trend in participant's functioning during baseline (explained by the occurrence of a new type A traumatic event), a strong improving trend during treatment, and a less stronger improving trend during post-treatment and follow-up. Figure 2 shows the trend lines within the different phases.

PTSD Diagnosis

At post-treatment, Rose had lost her PTSD diagnosis on the basis of the criteria of DSM-IV and DSM-5. This result was maintained at 6-weeks follow-up (also see Table 3).

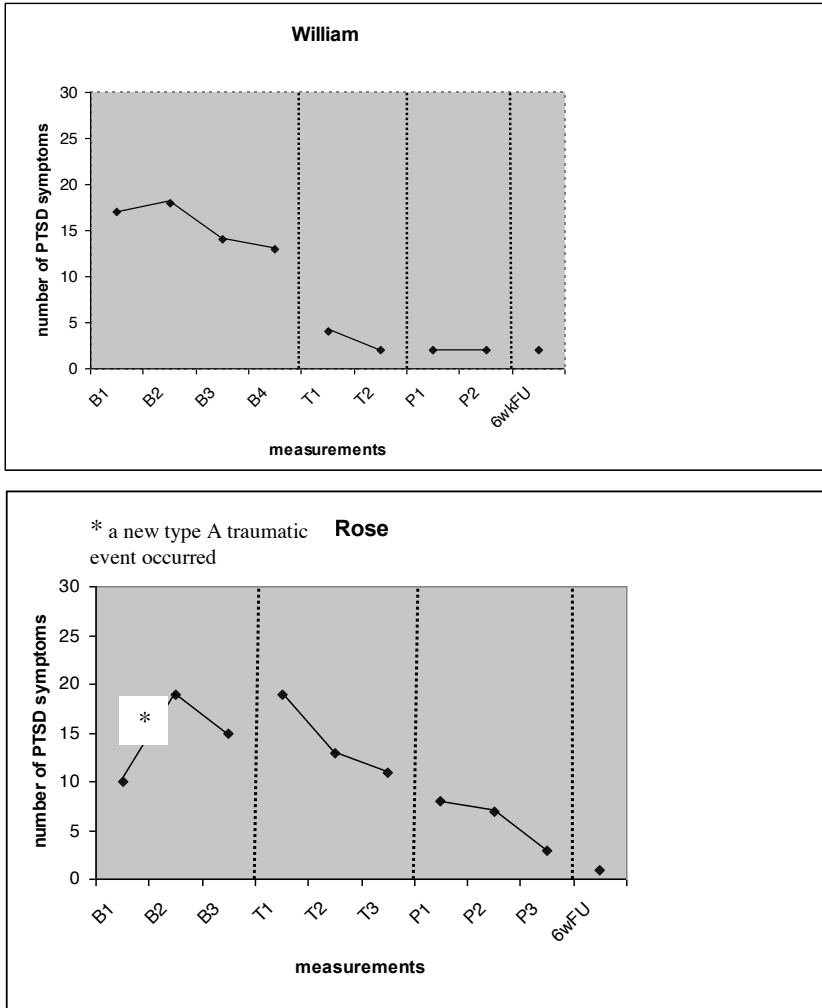


Figure 1. Total number of PTSD symptoms (max = 30) for participants. Scores across baseline, treatment, post-treatment and follow-up [phases divided by vertical lines]

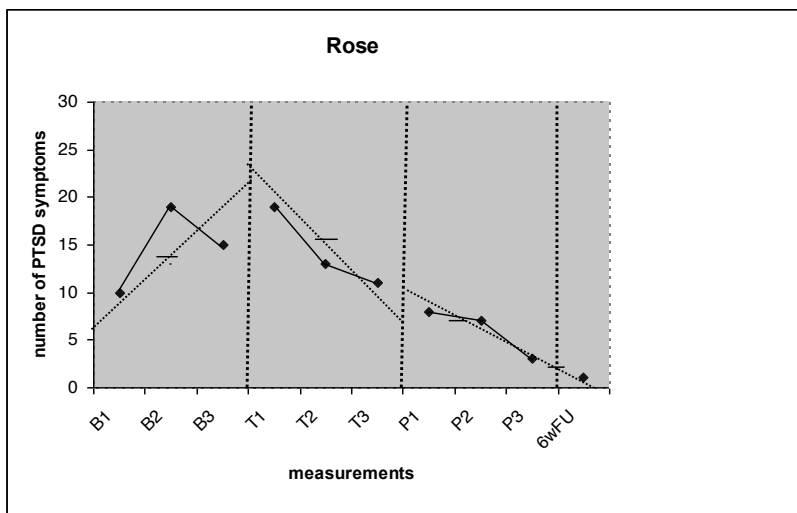


Figure 2. Trend estimation within baseline, treatment, and post-treatment & follow-up [phases divided by vertical lines]

Table 3. PTSD diagnoses before treatment, after treatment and at follow-up

Participant	PTSD algorithm	Baseline1	P1	Follow-up
William	DSM-IV-TR	yes	no	no
	DSM-5	yes	no	no
Rose	DSM-IV-TR	yes	no	no
	DSM-5	yes	no	no

DISCUSSION

As far as we know, this study is the first to examine the effectiveness of EMDR therapy in patients with MBID and PTSD using a multiple baseline design. The results suggest that EMDR therapy is effective for PTSD treatment in this target group. This study extends the literature on the effectiveness of EMDR therapy in patients with MBID and PTSD in that a design was used that controlled for natural recovery in the course of time, and in which the PTSD diagnoses and the course of PTSD symptoms were measured with a valid and reliable PTSD clinical interview adapted for this target group (i.e., Adapted ADIS-C PTSD Section, (Meivissen et al., 2014; Meivissen et al., 2016). Other improvements were that inter-rater reliability and follow-up measurements were taken.

In both participants, the number of PTSD symptoms decreased as a result of EMDR therapy. Both had lost their PTSD diagnoses at post-treatment, a result which was maintained at 6-weeks follow-up. EMDR therapy was adapted to the participant's mental age by following the mental age-related instructions of the Dutch standard EMDR protocol for children and adolescents without intellectual disability (De Roos et al., 2013) with no more than a single minor adaptation (i.e., omitting the VOC in William's treatment). The findings of the present study underpin the outcomes of the previously published case studies on EMDR and on the feasibility and effectiveness of this therapy in children and adolescents with PTSD and MBID (Giltaij, 2004; Mevissen et al., 2011; Rodenburg et al., 2009). EMDR therapy may be especially applicable in individuals with ID as it does not involve (1) detailed descriptions of the events, (2) direct challenging of beliefs, (3) prolonged exposure, and (4) daily homework, as opposed to trauma-focused CBT. The results of the current study also are in line with the WHO guidelines (WHO, 2013) recommending EMDR, besides trauma-focused CBT, as evidence-based practice in the treatment of PTSD in children and adolescents.

With regard to the course of PTSD symptoms (see Figure 1) it is remarkable that during the baseline period Rose showed a substantial increase in number of PTSD symptoms. Unlike William, she had been exposed to a new DSM-IV type A trauma event during baseline. This deterioration in functioning is in line with the literature on the cumulative effect of trauma, indicating that a higher number of traumatic event types as well as repeated exposure to similar traumatic experiences is related to an increase of PTSD symptom severity (Wilker, Pfeiffer, Kolassa, Koslowski, Elberts, & Kolassa, 2015). It is assumed that repeated exposure to disturbing memories of an event might strengthen people's fear memories of that event (Wilker et al., 2015). As Rose had a history of other serious illness and death related events, we may assume that the experience of a similar new potentially traumatic event might have caused the increase of the total number of PTSD symptoms that was observed during baseline.

Strengths and limitations

The current study has several strengths. First, data were collected using a multiple baseline across subjects design, which has the advantage of controlling for natural recovery in the course of time. Secondly, we used a valid and reliable PTSD interview adapted for children and adolescents with MBID for the use of history taking, establishing a PTSD diagnosis, and the evaluation of the intervention (Mevissen et al., 2014; Mevissen et al., 2016). Child measurements were used to diagnose PTSD which can be viewed as a strength given that caregivers are only partially able to assess the inner world and perceptions of their trauma-exposed child. A final extension of the literature is that in the current study an excellent inter-rater reliability was assessed. Considering the PTSD interview,

an advantage compared to the PTSD clinical interviews for people without intellectual disability is that persons' whole trauma-history is visualised on a time line. Moreover, the time line not only plays a role in assessing PTSD, but also serves as an instrument to decide about the sequence of targeting memories in EMDR therapy, and thereby enhancing standardisation of EMDR's history taking. Finally, in the present study at each measurement (i.e., immediately prior to a session) the participant was asked for the occurrence of new potentially traumatic events leading to an update of the treatment plan if required. The present study also has several limitations. Although two baselines are considered minimum for a multiple baseline design (Kazdin, 2011) a design consisting of three or more baselines would have offered opportunities to calculate effect sizes developed for N=1 studies (Parker, Vannest, & Davis, 2011). Another limitation is the lack of measurements concerning treatment fidelity of EMDR therapy.

Concluding comments and future directions

Besides other types of trauma, both participants in the present study had been exposed to domestic violence, one of the most common forms of child maltreatment putting children at risk for the development of other mental health problems besides PTSD, such as anxiety disorders, mood disorders, reactive attachment disorder and conduct disorder (Lindauer, 2015). Child maltreatment also predicts adult delinquent behavior (Van der Put & De Ruiter, 2016). This emphasizes the importance of timely PTSD treatment and the need of further research to establish a firm evidence-base for EMDR therapy as an effective treatment method for PTSD in children and adolescents with MBID. Replication of the present study in larger samples and implementation of randomized controlled trials is certainly warranted.

Conflicts of interest statement

No conflicts declared

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6

Summary and General discussion

INTRODUCTION

Posttraumatic Stress Disorder is a mental disorder with an estimated lifetime prevalence rate of 5 to 10% in adults (Kessler et al., 2005) and a mean prevalence rate of 16% in children (Alisic, 2014). Without timely and effective treatment, PTSD goes along with severe and long-term impairments, high costs of care and low levels of subjective quality of life (Alisic, 2011; Priebe et al., 2009).

The present research project as described in this dissertation focused on PTSD in individuals with intellectual disability (ID), a group of individuals with a high level of exposure to potentially traumatic events (Focht-New et al., 2008; Hatton & Emerson, 2004) and limited capacities to process overwhelming experiences in a natural way (Bomyea et al., 2012). Although prevalence rates of PTSD in individuals with ID are supposed to be high, PTSD is a largely underdiagnosed, undertreated and understudied mental disorder in this population. This is a serious problem, especially given that in clinical practice Eye Movement Desensitisation and Reprocessing (EMDR) therapy, an evidence-based first-line therapy recommended by the World Health Organization (WHO, 2013) appears to be safe and applicable for individuals with various levels of ID and often results in rapid and impressive positive effects on clients' PTSD symptoms and well-being.

The purpose of this dissertation was to review the international literature on PTSD in individuals with ID and to stimulate bridging the gap between the comprehensive knowledge on PTSD in individuals without ID, and what is known about PTSD in individuals with ID. In this respect (1) manifestations of PTSD in adults and children with various levels of ID were studied and presented in 10 case descriptions, (2) a reliable and valid assessment instrument (*Adapted ADIS-C PTSD section*) was developed, and (3) the effects of EMDR therapy on symptoms of PTSD in individuals with ID were explored in a controlled case study in preparation for future more extensively controlled studies to establish its effectiveness for PTSD.

SUMMARY OF THE MAIN FINDINGS

Nearly ten years ago a review of the international literature from 1992-2008 was conducted on (1) prevalence, (2) assessment, and (3) treatment of PTSD in persons with ID. A total of 18 studies were identified. The outcomes, listed in **Chapter 2**, gave rise to the studies described in the other chapters of this dissertation. The main findings were that:

(1) prevalence rates of PTSD in large heterogeneous samples of individuals with ID appeared to be lacking. Only four articles reported on rates of PTSD, and these pertained to small samples of individuals with ID who were referred for treatment, and who presented

a history of exposure to one or more traumatic events. The PTSD rates varied substantially; that is, from 2.5 to 60%.

(2) at that time, using the PTSD section of the Diagnostic Manual-Intellectual Disability (DM-ID, Fletcher et al., 2007) was the only way to assess PTSD in individuals with ID. Due to the lack of empirical studies on assessment of PTSD in individuals with ID, PTSD symptoms as described in the DM-ID, were based on literature and clinical expertise only. According to the DM-ID it was assumed that in patients with more severe levels of ID, PTSD symptoms can present atypically and can be similar to those seen in children without ID, with behavioural equivalents like self-injurious behaviour as common symptoms (Tomasulo & Razza, 2007).

(3) empirical studies on the efficacy of PTSD treatment in people with ID were lacking. Four articles were found recommending an interdisciplinary treatment approach for PTSD in people with ID (Focht-New et al., 2008; McCarthy, 2001; Pitonyak, 2005; Ryan, 2000). The recommended treatment components were (a) pharmacological treatment, (b) changing environments aimed to eliminate frightening cues, and (c) psychotherapeutic interventions. No more than five articles were found that reported about the psychotherapeutic treatment of PTSD (Giltaij, 2004; Lemmon et al., 2002; Razza, 1997; Stenfert Kroese et al., 2006; Tharner, 2006). Only five case reports pertained to the evidence-based first-line PTSD treatments recommended by the World Health Organization (WHO, 2013): Trauma Focussed Cognitive Behavioural Therapy (TF-CBT, 3 cases) or Eye Movement Desensitisation and Reprocessing (EMDR, 2 cases). These case descriptions were limited to participants with mild level of ID.

Chapter 3 presents the results of a study aimed to extend on previous literature regarding manifestations of PTSD and PTSD treatment in people with ID. Ten systematic case reports were conducted on EMDR treatment of posttraumatic stress in children as well as adults with mild ID (**Chapter 3.1**, four cases), moderate ID (**Chapter 3.2**, two cases) or severe ID (**Chapter 3.3**, four cases). Prior to treatment, participants displayed behavioural and emotional problems, most of them for several years. They also had been exposed to various types of overwhelming events such as domestic violence, traffic accidents, sexual abuse, intrusive medical treatments or the death of a beloved person. The Dutch version of the EMDR Standard protocol for children was administered using instructions suited to the individual's mental age. The main findings were that EMDR therapy was applicable and achievable for individuals with various levels of ID. In all cases trauma-related complaints had disappeared and in all but one case (a women with severe ID and symptoms of autism spectrum disorder) results were maintained at 6 weeks to 32 months follow-up. Irrespective of age and level of ID, the overwhelming events participants had been exposed to, as well as most of the symptoms that had disappeared in the course of EMDR treatment, were consistent with the DSM-IV-TR criteria which were current at that time.

Chapter 4. 1 describes the results of a pilot study among 15 children with mild to borderline ID (MBID) who visited a special needs school. Participants were interviewed using the *Adapted ADIS-C PTSD section*, a clinical interview for the assessment of PTSD in children without ID that was adapted for children with MBID. This interview takes into account a broader range of potentially traumatic events (including type A trauma events as well as life events) and a broader range of symptoms compared to typical PTSD clinical interviews. A time-line and a thermometer are used as visual cues. The symptoms were derived from four existing PTSD algorithms, complemented with symptoms based on the hypothesis that PTSD might manifest atypically in people with ID. Moreover, the adapted interview that was constructed in anticipation of the upcoming release of the DSM-5 allows for (mental) age related manifestations of PTSD. The clinical interview appeared to be applicable and was completed by all participants. None of the children showed any signs of adverse reactions to being interviewed about potentially traumatic events and related complaints. The results did not support (1) broadening the A criterion for a traumatic event for children with MBID, nor the notion that (2) PTSD symptoms would manifest atypically in children with MBID.

The pilot study was replicated and extended to validate the *Adapted ADIS-C PTSD section* in a sample of 80 children and adolescents with MBID and their caregivers. Meanwhile, the DSM-5, which includes a PTSD subtype for children aged 6 years and younger, had been released and was taken into account. The results of this study, presented in **Chapter 4.2**, showed that both the child and caregiver version of the interview yielded excellent interrater reliability and that convergent validity for the assessment of PTSD in children and adolescents with MBID was good. The hypothesis that PTSD does not manifest atypically in this target group, could further be supported. Manifestations of PTSD were in accordance with the DSM-IV-TR and DSM-5 criteria. Children and adolescents who had been exposed to a type A event were found to be more likely to meet PTSD symptom criteria than those who had not been confronted with a type A event. Also, participants who met PTSD criteria had been exposed to a higher number of potentially traumatic events, thereby supporting the notion of the cumulative effects of trauma. Meeting PTSD symptom criteria was found to be associated with higher subjective levels of daily life impairment. The pattern of results found for children with IQ 70-85 was similar to that of the sample of children with IQ 50-70 with regard to impact of type A trauma, level of exposure to potentially traumatic events as well as subjective level of daily life impairment. Finally, positive correlations were found between rates of PTSD symptoms and CBCL scores with higher correlations for internalizing than for externalizing problems.

Chapter 5 presents the results of a study aimed at examining the effectiveness of EMDR therapy in a child and an adolescent with MBID who were diagnosed with PTSD according to DSM-IV-TR as well as DSM-5 criteria as determined with the *Adapted ADIS-C*

PTSD section. Data were collected using a multiple baseline across subjects design thereby controlling for natural discovery in the course of time. Interrater reliability of scores was excellent. In both participants the number of PTSD symptoms decreased as a result of EMDR therapy. Both had lost their PTSD diagnosis at post-treatment, a result which was maintained at 6-weeks follow-up. The results suggest that EMDR therapy, adapted to the participant's mental age, is effective for PTSD treatment in children and adolescents with MBID.

General discussion and recommendations for further research

The discussion concerning the results of the studies that are part of the current thesis will focus on the following topics: (1) manifestations of PTSD, (2) assessment of PTSD, and (3) EMDR therapy for PTSD and other trauma- and stressor-related disorders in individuals with ID.

Manifestations of PTSD in individuals with ID

At the start of the present research project it was hypothesized that PTSD might manifest atypically in individuals with ID, especially in individuals with severe levels of ID. However, the results were not supportive of this contention. For example, as outlined above, it was found that PTSD in children and adolescents with MBID did not present atypically (see Chapter 4). No evidence was found for broadening the A criterion for a traumatic event, nor for the addition, omission or adaptation of PTSD symptoms on account of the ID. Similar to children without ID, PTSD symptoms appeared to cause severe impairment and distress in children with mild to borderline ID. Further, the results suggest that a higher level of exposure to potentially traumatic events enhances the risk of developing PTSD. The pattern of results found for children with IQ 70-85 (borderline ID) was similar to that of children with IQ 50-70 (mild ID).

Within the framework of this thesis the investigation of manifestations of PTSD, and the development of a PTSD clinical interview, were directed at children and adolescents with MBID. Regarding the assessment of PTSD in adults, and in people with more severe levels of ID, several remarks can be made.

It is supposed that, as in children and adolescents with MBID, PTSD in adults with ID will not present atypically because, rather than the persons's chronological age, it is more likely that it is the adult's mental age that influences how PTSD symptoms are manifested (Scheeringa et al., 2012).

To estimate whether PTSD might present atypically in individuals with more severe levels of ID (IQ < 50), the release of the DSM-5 (APA, 2013) in the course of the current study has been of importance because it introduced several differences in PTSD criteria when comparing the DSM-IV-TR PTSD criteria with the DSM-5 criteria. To this end, at

first the removal of the A2 criterion for trauma can be considered beneficial, because in particular for people with severe levels of ID, it is difficult for them to reliably report initial responses of fear, helplessness or horror (McClure et al., 2009). Moreover, parents or caregivers are not always present to observe the person's reaction when trauma occurs. Secondly, the addition of a fourth symptom cluster 'negative alterations in cognitions and mood' fits with the case studies presented in Chapter 3.2 and 3.3, reporting positive mood changes after EMDR therapy in clients with moderate as well as severe ID. Thirdly, the behavioural features 'reckless or self-destructive behaviour' and 'angry outbursts with little or no provocation typically expressed as verbal or physical aggression toward people or objects' are added to the symptom cluster 'markedly alterations in arousal and reactivity'. This change is also in line with the findings in the case studies presented in Chapter 3.2 and 3.3, reporting a decrease or absence of aggressive outbursts after EMDR therapy. An equally important change is the introduction of the developmentally sensitive DSM-5 subtype for children aged six years and younger. This PTSD subtype does not include symptoms that require skills which young children have not yet developed, such as verbal expression, memory or abstract thought. Moreover, fewer symptoms are required to meet the PTSD criterion. Considering the aforementioned clinical findings and DSM-5 features, it is likely that the DSM-5 definition of PTSD fits well to the manifestations of PTSD in individuals with more severe levels of ID, meaning that PTSD does not manifest atypically, but in accordance with the individual's mental age.

Assessment of PTSD using the Adapted ADIS-C PTSD section: clinical applications and future research

The availability of the *Adapted ADIS-C PTSD section* is of great relevance in mental health care for children and adolescents with MBID, because it offers the opportunity to establish a timely valid and reliable PTSD diagnosis, which is a crucial step to effective treatment. Considering that, according to the normal IQ distribution ($mean = 100$, $SD = 15$), about 15% of the population fall into the range of mild to borderline ID, in principle, a sizable group of children and adolescents is at risk for the development of PTSD. Thus, in samples of children and adolescents with emotional and behavioural problems who are referred to mental health care centres, the percentage of those with a PTSD diagnoses is supposed to be high. For example, in a study sample of the current thesis participants were not selected on trauma-history at intake, but they were referred to the outpatient psychiatric service under suspicion of a wide range of mental health disorders by a wide variety of notifying parties. Nevertheless, in 20% to 38% (depending on the PTSD algorithm, and whether the child or caregiver interview was used) of all 80 children and adolescents a PTSD diagnosis could be established. To prevent unnecessary long-term personal suffering and high (mental) health costs by an incorrect attribution of PTSD symptoms to other

disorders followed by ineffective treatments, it is important to routinely screen for PTSD at the initial assessment. Therefore, it is strongly recommended to develop a screening instrument such as a short version of the *Adapted ADIS-C PTSD section* for use in mental health care for children and adolescents with MBID.

After publication of the review of the literature (see Chapter 2) the results of a Dutch study (Wieland, 2012) became available which pointed to similar high rates of PTSD in adults with MBID who were referred for specialized outpatient psychiatric care compared to children and adolescents with MBID. DSM-IV-TR diagnoses were formulated using the DM-ID criteria, and patients were assessed multidisciplinary by at least a certified and experienced psychiatrist, a certified and experienced mental health psychologist, and an experienced psychiatric community worker. Psychiatric morbidity of patients with borderline intellectual functioning (BIF, IQ 70-85; $n = 235$) were compared with outpatients from “regular” mental health care (RMHC; $n = 1,026$) and outpatients with mild ID (IQ 50-70; $n = 152$). In the BIF and mild ID groups PTSD appeared to be the most prevalent Axis I diagnosis. Moreover, the rate of PTSD that was found in the BIF (19.6%) and mild ID (19.7%) groups was significantly higher compared to the RMHC (10.4%) group.

During the course of the present research project two instruments were developed to index the effects of traumatic events on adults with mild to moderate ID. The *Lancaster and Northgate Trauma Scales (LANTS)* (Wigham et al., 2011) comprises a 29-item self-report and an 43-item informant measure which showed good internal consistency, test-retest reliability and validity. Hall et al. (2014) developed the *Impact of Event Scale - Intellectual Disabilities (IES-IDs)* as a screening self-report questionnaire that is used as a semistructured interview, indexing subjective stress caused by traumatic events corresponding with the DSM-IV-TR PTSD symptom categories. Unfortunately, none of these instruments is in line with DSM-5 PTSD. Considering that the *Adapted ADIS-C PTSD section* is in accordance with DSM-5, the development and validation of an adult version of this clinical interview is recommended. A subsequent research project might be the development of short version of the adapted version, as a screening instrument for PTSD in adults with MBID. This might enhance timely detection of PTSD in adult mental health care, making clinical assessment and subsequent treatment by trained professionals more likely.

To establish a valid and reliable PTSD diagnosis in individuals with more severe levels of ID future research is required. Based on clinical experiences of manifestations of PTSD in these individuals (also see Chapter 3.3) PTSD is supposed to not manifest atypically but instead fits the developmentally sensitive DSM-5 subtype for children aged six years and younger. Therefore, it is suggested to use the caregiver version of the *Adapted ADIS-C PTSD section* in the interim for the assessment of PTSD in individuals with a developmental age of six years and younger.

Given the importance of timely detection and treatment of PTSD in people with ID, professionals should be willing and able to communicate with clients about potentially traumatic events they may have experienced. However, in the course of the present research project it appeared to be a common concern, even among professionals in specialized mental health care, that exposing individuals with ID and their caregivers to a clinical PTSD interview would be too overwhelming, and therefore considered as potentially hazardous in that it may 're-traumatize' participants. Neither the experiences of the interviewers in our validation study, nor the findings of a study by Scoty et al. (2012), support this widespread hesitation to discuss traumatic experiences with vulnerable individuals and their caregivers. Participants, who were asked about the experience of trauma, had pointed out the benefits and personal satisfaction with participation.

Using EMDR therapy in individuals with ID: clinical applications and future research

Since the publication of the review of the literature on PTSD in people with ID 6 years ago, the number of EMDR case descriptions (2) in the international literature has been extended by 19 (Mevisen et al., in press). Ten of the case studies were part of the current research project. Our case studies showed that EMDR therapy, adapted to the person's mental age, appeared to be applicable and achievable for individuals with ID, resulting in a significant decrease of trauma related symptoms with maintenance of results, irrespective of age or level of ID. These findings are supportive of the hypothesis that also individuals with more severe intellectual disabilities store emotionally charged memories, and that it is possible to reproduce these memories; that is, to consciously bring up such a memory in mind (i.e., to place the memory in the 'working memory'), to activate, and to process this memory. In the current study, the EMDR procedure has been applied in a manner that is consistent with the client's estimated developmental age. The cognitive level associated with the individuals developmental age generally functioned as a starting point to determine the way as to how the dysfunctionally stored memories should be activated. The developmental or mental age concept was chosen because it indicates the level at which the therapist needs to instruct the client to reproduce a memory, and activate it to allow resolution of the traumatic material. In this regard the instructions correspond to the Dutch version of the EMDR protocol adapted for children and adolescents up to 18 years. This protocol includes instruction levels for the following age categories: 1-3 years, 4-5 years, 6-8 years and 9-18 years. In children aged 1-3 years, a trauma memory can be activated using the so called Storytelling Method. In addition to the use of simple language, when applying Story Telling, the therapist also introduces specific trauma related triggers by, for example, showing objects or touching the child's body parts in order to activate the memories that need to be processed. In the present study, this method was used in clients with severe intellectual disabilities because it was assumed that this would fit best

to their developmental age. It should be noted that studies regarding the effectiveness of EMDR treatment on PTSD symptoms in typically developing children younger than 4 years old have not been conducted as yet. Neither have studies been found that focus on the mechanisms that might explain the treatment effects which were identified in clinical practice, nor in typically developing children nor in individuals with intellectual disabilities. Hopefully, future research will address these issues.

Apparently, the substantial increase in the number of EMDR case reports resulted in two published case study reviews on EMDR treatment in people with ID (Gilderthorp, 2015; Jowett et al., 2016). These authors conclude that EMDR is a safe and acceptable intervention for people with ID. To this end, Jowett and colleagues recommend to conduct randomized controlled studies to establish EMDR's effectiveness for DSM-5 PTSD in people with ID. They thereby address the need for a DSM-5 PTSD measure with tailored language, a standardized accurate assessment of traumatic history, and controlled adherence to an adapted standardized EMDR protocol. In the multiple baseline study for children and adolescents with MBID which was the closure of the current research project, almost all these needs were met. This study utilized the Adapted ADIS-C PTSD section as a valid and reliable measurement instrument. Moreover, the study controlled for natural recovery in the course of time. Findings of this first controlled study on the effects of EMDR therapy were in line with the clinical experiences in that the number of PTSD symptoms decreased as a result of EMDR therapy and participants had lost their PTSD diagnosis at post-treatment with results maintained at 6-weeks follow-up. Both aforementioned reviews on the feasibility and effectiveness of EMDR treatment for PTSD in individuals with ID emphasize the need of future randomized controlled trials. However, at present the extend of specialized mental health care for patients with ID is very small compared to specialized mental health care for patients without ID. Moreover, the number of experienced and well-trained psychotherapists, specializing in treating people with ID, is even smaller. Replication of the multiple baseline study in larger samples of children, as well as in adults with various levels of ID, seems to be more attainable than conducting RCT's, and may therefore be preferable.

In the past six years, for trauma-focused cognitive behavioural therapy (TF-CBT), the other evidence-based first-line treatment for PTSD, recommended by the World Health Organization (WHO, 2013), the total number of case descriptions has been extended only by three (Carrogan & Allez, in press; Mevissen et al., in press), reporting positive outcomes for PTSD symptoms as well. There are several possible explanations for this lagging number pertaining to TF-CBT. At first, EMDR's lack of need to do homework and practice outside the sessions offloads the person and his or her caregivers. Secondly, EMDR is supposed to be less burdensome for the patient, because it does not rely on frequent and lengthy exposures to trauma-related stimuli which is considered pivotal in CBT-based exposure

therapy. Finally, when applying EMDR, different from TF-CBT, a task is offered which taxes working memory while the patient concentrates on an aversive memory. This usually results in a decrease of the emotionality and vividness of the corresponding memory (Engelhard et al., 2011). In clinical practice with patients with ID, similar to children without ID, EMDR therapy often leads to a rapid decrease of PTSD symptoms, making treatment of PTSD generally less time consuming. In conclusion, compared to TF-CBT, EMDR seems more suitable for patients with ID.

EMDR therapy is a psychotherapeutic treatment aimed to treat not only PTSD, but a variety of mental health disorders stemming from a wide range of traumatic and other adverse life events (Shapiro, 2001, 2014). Based upon the results of a series of randomized controlled trials in children, EMDR therapy has been demonstrated, for example, to result in significant improvement of self-esteem and behavioural problems (Wanders et al., 2008), and a significant decrease in symptoms in patients with conduct disorder (Soberman et al., 2002). Preliminary studies have also shown EMDR therapy to create positive effects on parent-child attachment (Wesselmann et al., 2012). In adult studies its efficacy has been shown for specific phobias (e.g., Doering et al., 2013), general symptoms of anxiety and distress (Abbasnejad, Mahani & Zamyad, 2007; Arabia, Manca, & Solomon, 2011), obsessive compulsive disorder (Nazari et al., 2011; Marsden, 2016), depression (Gauhar, 2016), and adjustment disorder (Cvetek, 2008). Given that EMDR is applicable and feasible in individuals with various levels of ID, EMDR therapy might be an appropriate and effective psychotherapeutic treatment method for other mental health problems than PTSD *per se*. From this perspective it is relevant to emphasize that within DSM-5, PTSD is part of the new chapter entitled “trauma- and stressor-related disorders”¹. A common feature of these conditions is that exposure to a traumatic or stressful event is listed as an indispensable diagnostic criterion. Furthermore, in DSM-5 it is mentioned that there is a close relationship between these trauma- and stressor-related disorders and anxiety disorders, obsessive-compulsive and related disorders, and dissociative disorders. When mental health problems stem from adverse life experiences, EMDR therapy is likely to be an effective treatment alternative. Prior to EMDR treatment of such trauma- and stressor related complaints the *Adapted ADIS-C PTSD section* might be of use. The *Adapted ADIS-C* includes a broad event section with not only type A events, but also other negative life events. Moreover, it consists of an extended section of event-related symptoms. Thus, using the *Adapted ADIS-C PTSD section* might facilitate the detection of other event- and symptom combinations than PTSD alone. Future research on EMDR treatment for other conditions than PTSD is particularly important, because effective psychotherapeutic treatment methods for individuals with ID suffering from not only PTSD but other mental health disorders are lacking, and greatly needed.

CONCLUSIONS

Individuals with ID, including those with borderline intellectual functioning, form a large minority in mental health care services. PTSD appears to be underdiagnosed and undertreated in this target group. Given their high risk for developing PTSD, a mental health condition leading to severe and long-term impairments, high costs of care and low levels of subjective quality of life, the findings of the current research project are of great importance. The development of the *Adapted ADIS-C PTSD section* as a PTSD clinical interview, as well as the finding that EMDR proved applicable and feasible for children and adults of various levels of ID and showed positive results using a controlled case study, offer opportunities for timely detection and effective treatment of PTSD in this target group. Mental health services should adjust their policies to transform the widespread hesitation to discuss traumatic experiences with this potentially vulnerable population and make the assessment of trauma a usual standard in psychotherapy. To meet the needs of people with ID and PTSD, professionals have to be facilitated to learn how to timely detect and effectively support as well as treat clients with ID and PTSD, irrespective of their age or level of ID. An important future challenge is to extend further scientific support for accurate assessment of PTSD in individuals with ID, and to enhance the number of controlled studies to demonstrate the effectiveness of EMDR in the treatment of PTSD and a wide variety of other mental health disorders resulting from disturbing and unprocessed life experiences in this at risk target group.

- ¹ The DSM-5 chapter of “trauma-and stressor-related disorders” consists of: reactive attachment disorder, disinhibited social engagement disorder, posttraumatic stress disorder (including post-traumatic stress disorder for children 6 years and younger), acute stress disorder, adjustment disorders (specified whether with depressed mood, anxiety, mixed anxiety and depressed mood, disturbance of conduct, mixed disturbance of emotions and conduct, or unspecified), and other specified or unspecified trauma- and stressor-related disorders.

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7

Samenvatting en algemene discussie

INTRODUCTIE

Uit onderzoek blijkt dat naar schatting 5% tot 10% van de volwassenen ooit in zijn of haar leven een posttraumatische stress stoornis (PTSS) ontwikkelt (Kessler e.a., 2005). Onder kinderen wordt de gemiddelde prevalentie van PTSS geschat op 16% (Alisic, 2014). Zonder tijdige en passende behandeling gaat PTSS gepaard met ernstige en langdurige beperkingen, een als slecht ervaren kwaliteit van leven, en hoge zorgkosten voor de samenleving (Alisic, 2011; Priebe e.a., 2009).

Het onderzoek dat in dit proefschrift beschreven is, richtte zich op PTSS bij mensen met een verstandelijke beperking (VB). Deze personen worden relatief vaak aan potentieel traumatische gebeurtenissen blootgesteld. (Focht-New e.a., 2008; Hatton & Emerson, 2004) terwijl ze beperkte mogelijkheden hebben om schokkende gebeurtenissen op een natuurlijke wijze te verwerken (Bomyea e.a., 2012). Ondanks dat de prevalentie van PTSS bij mensen met een VB hoog zal zijn, wordt PTSS bij deze doelgroep dikwijls niet herkend en gediagnostiseerd, en dientengevolge ook niet behandeld en nauwelijks wetenschappelijk onderzocht. Dit is een groot probleem, zeker gezien het feit dat behandeling goed mogelijk is. Eye Movement Desensitisation and Reprocessing (EMDR) therapie, een *evidence-based* eerste keus behandeling voor PTSS, aanbevolen door de World Health Organization (WHO, 2013), blijkt in de klinische praktijk veilig en uitvoerbaar bij mensen met uiteenlopende niveau's van VB, en laat vaak snelle en indrukwekkende positieve effecten zien op symptomen van PTSS en het persoonlijk welbevinden van cliënten.

Het doel van dit proefschrift was om een overzicht te krijgen van de internationale literatuur over PTSS bij mensen met een VB en van daaruit bij te dragen aan het overbruggen van de kloof tussen de enorme hoeveelheid kennis over PTSS bij mensen zonder VB, en wat erover bekend is bij mensen met een VB. Vanuit die gedachte werden (1) verschijningsvormen van PTSS bij zowel volwassenen als kinderen met uiteenlopende niveau's van VB bestudeerd en weergegeven in de vorm van tien casusbeschrijvingen, werd (2) een betrouwbaar en valide onderzoeksinstrument ontwikkeld (de *ADIS-C-LVB-sectie PTSS*), en werden (3) de effecten van behandeling met EMDR onderzocht in de vorm van een gecontroleerde gevalsstudie ter voorbereiding op omvangrijkere gecontroleerde studies om voor mensen met een VB de effectiviteit van EMDR therapie bij PTSS vast te stellen.

Samenvatting van de belangrijkste resultaten

Bijna tien jaar geleden werd een overzicht gemaakt van de internationale literatuur die in de periode 1992-2008 verschenen was met betrekking tot (1) prevalentie, (2) diagnostiek en (3) behandeling van PTSS bij mensen met een VB. Er werden in totaal 18 studies gevonden. De bevindingen, weergegeven in **hoofdstuk 2**, vormden de basis voor de onderzoe-

ken die in de andere hoofdstukken van dit proefschrift beschreven zijn. De belangrijkste resultaten waren dat:

(1) prevalentiecijfers met betrekking tot PTSS in grote, heterogene, groepen van mensen met een VB bleken te ontbreken. In slechts 4 artikelen werden PTSS aantallen genoemd en die betroffen alleen kleine onderzoeksgroepen van mensen met een VB die voor behandeling waren doorverwezen en die een voorgeschiedenis hadden met een of meer traumatische ervaringen. De PTSS aantallen varieerden aanzienlijk, namelijk van 2.5% tot 60%.

(2) in die tijd was de *Diagnostic Manual-Intellectual Disability* (DM-ID, Fletcher et al., 2007) verschenen, met een hoofdstuk waarin (aangepaste) criteria beschreven stonden aan de hand waarvan PTSS gediagnostiseerd kon worden bij mensen met een VB. Vanwege het ontbreken van empirisch onderzoek op het gebied van diagnostiek van PTSS bij mensen met een VB, waren de PTSS symptomen, zoals in de DM-ID beschreven, enkel gebaseerd op literatuur en klinische ervaringen. Volgens de DM-ID was het aannemelijk dat PTSS symptomen zich bij ernstiger niveau's van VB op een ongebruikelijke en atypische wijze zouden presenteren en zouden lijken op wat wordt gezien bij kinderen zonder VB (Tomasulo & Razza, 2007). Zij vertonen vaak symptomen op gedragsniveau, bijvoorbeeld in de vorm van zelfverwondend gedrag (Tomasulo & Razza, 2007).

(3) empirische studies ten aanzien van de effectiviteit van PTSS behandeling bij mensen met een VB ontbraken. Er werden vier artikelen gevonden, die voor mensen met een VB een interdisciplinaire behandelplan adviseerden (Focht-New et al., 2008; McCarthy, 2001; Pitonyak, 2005; Ryan, 2000). De aanbevolen behandelcomponenten waren (a) farmacologische behandeling, (b) omgevingsaanpassingen met als doel het elimineren van angstopwekkende triggers, en (c) psychotherapeutische interventies. Niet meer dan vijf artikelen werden gevonden over de psychotherapeutische behandeling van PTSS (Giltaij, 2004; Lemmon et al., 2002; Razza, 1997; Stenfert Kroese, et al., 2006; Tharner, 2006). Slechts vijf casusbeschrijvingen hadden betrekking op de evidence-based, 'eerste keuze' behandelingen voor PTSS die door de WHO (2013) worden aanbevolen: Trauma Focused Cognitive Behavioural Therapy (TF-CBT, drie gevalsbeschrijvingen) of Eye Movement Desensitisation and Reprocessing therapie (EMDR, twee gevalsbeschrijvingen). Deze casusbeschrijvingen bleven beperkt tot mensen met een lichte VB.

Hoofdstuk 3 toont de resultaten van een onderzoek dat bedoeld was als aanvulling op de reeds bestaande literatuur over manifestaties van PTSS en de behandeling van PTSS bij mensen met een VB. Het omvat tien systematische gevalsbeschrijvingen over de behandeling van posttraumatische stress bij zowel kinderen als volwassenen met respectievelijk een lichte VB (**Hoofdstuk 3.1**, vier gevalsbeschrijvingen), een matige VB (**Hoofdstuk 3.2**, twee gevalsbeschrijvingen), of een ernstige VB (**Hoofdstuk 3.3**, vier gevalsbeschrijvingen). Voorafgaand aan de behandeling lieten de participanten gedragsproblemen en

emotionele problemen zien, de meesten van hen sinds jaren. Eveneens waren ze geconfronteerd met verschillende typen schokkende gebeurtenissen zoals huiselijk geweld, verkeersongelukken, seksueel misbruik, akelige medische behandelingen of de dood van een geliefd persoon. Bij de behandeling werd gebruik gemaakt van de Nederlandse versie van het EMDR standaardprotocol voor kinderen, waarbij de instructies werden gebruikt die aansloten bij de ontwikkelingsleeftijd van de persoon. De belangrijkste bevindingen waren dat EMDR therapie toepasbaar was voor personen met uiteenlopende niveau's van VB. In alle gevallen waren de traumagerelateerde klachten na behandeling verdwenen en in op één na alle gevallen (een vrouw met een ernstige VB en kenmerken van een autisme spectrum stoornis) bleven de resultaten behouden tijdens follow-up na 6 weken tot 32 maanden. Ongeacht de leeftijd en het niveau van VB kwamen het type schokkende gebeurtenissen die de participanten hadden meegemaakt, en de meeste symptomen die in de loop van de EMDR therapie verdwenen waren, overeen met de destijds geldende DSM-IV criteria voor PTSS.

Hoofdstuk 4. 1 beschrijft de resultaten van een pilot studie onder 15 kinderen met een lichte VB of zwakbegaafdheid (LVB) die een school voor speciaal onderwijs bezochten. De deelnemers werden geïnterviewd met de *ADIS-C-LVB-sectie PTSS*, die is gebaseerd op een klinisch interview voor de diagnostiek van PTSS bij kinderen zonder VB en aangepast voor kinderen met een LVB. Dit interview brengt een bredere range van potentieel traumatische gebeurtenissen in beeld (zowel type A trauma als life events) en een bredere range van symptomen vergeleken met de standaard klinische interviews voor PTSS. Een tijdlijn en een thermometer worden gebruikt als visuele ondersteuning. De symptomen werden afgeleid van vier PTSS algoritmen en aangevuld met andere symptomen vanuit de hypothese dat PTSS zich bij mensen met een VB anders dan typisch zou kunnen manifesteren. Bovendien werd bij de ontwikkeling van dit aangepaste interview vooruitgelopen op de op handen zijnde publicatie van de DSM-5 die rekening houdt met bij de (mentale) leeftijd passende uitingsvormen van PTSS. Het klinisch interview bleek geschikt en kon bij alle participanten in zijn geheel worden afgenomen. Geen enkel kind ontregelde als gevolg van de vragen over potentieel traumatische gebeurtenissen en klachten die daarmee zouden kunnen samenhangen. Uit de resultaten kon niet worden afgeleid dat (1) het A criterium voor trauma voor kinderen met een LVB zou moeten worden opgerekt, noch dat (2) PTSS symptomen zich bij kinderen met een LVB op een ongebruikelijke atypische wijze manifesteren.

Om de *ADIS-C-LVB-sectie PTSS* te valideren werd de pilot studie herhaald in een onderzoeksgroep van 80 kinderen met een LVB. Ook hun opvoeders werden geïnterviewd. Verder werd het interview afgestemd op de inmiddels verschenen DSM-5, waarin een PTSS-subtype is opgenomen voor kinderen van 6 jaar of jonger. De resultaten van dit onderzoek, die zijn weergegeven in **Hoofdstuk 4.2**, lieten een uitstekende interbeoorde-

laarsbetrouwbaarheid zien voor zowel de kindversie als de ouderversie van interview. De convergente validiteit voor de diagnostiek van PTSS bij kinderen en adolescenten met een LVB bleek goed. Het vermoeden dat PTSS zich bij deze doelgroep niet anders manifesteert dan bij kinderen zonder een LVB werd ondersteund. De uitingsvormen van PTSS stemden overeen met de DSM-IV-TR en de DSM-5. Kinderen en adolescenten die waren blootgesteld aan een type A traumatische gebeurtenis bleken een grotere kans te hebben om een PTSS te ontwikkelen dan degenen die geen type A trauma hadden meegemaakt. Bovendien hadden deelnemers die aan de PTSS criteria voldeden meer potentieel traumatische gebeurtenissen meegemaakt dan degenen die niet aan de criteria voldeden. Dat past bij de kennis over het cumulatief effect van trauma. Bij kinderen en jongeren die aan de PTSS symptoomcriteria voldeden bleek de ervaren lijdensdruk in het dagelijks leven groter dan bij degenen die niet aan de criteria voldeden. De onderzoeksresultaten voor deelnemers met een IQ 50-70 kwamen overeen met die van deelnemers met een IQ 70-85, zowel wat betreft de betekenis van het A-criterium voor trauma als de mate van blootstelling aan potentieel traumatische gebeurtenissen en de ervaren last in het dagelijks leven. Tenslotte werden positieve correlaties gevonden tussen het aantal PTSS symptomen en de scores op de CBCL waarbij de correlaties voor internaliserende problemen hoger waren dan die voor externaliserende problemen.

Hoofdstuk 5 toont de resultaten van een onderzoek waarbij de effectiviteit van EMDR therapie bestudeerd werd bij een kind en een adolescent met een LVB, die beiden een PTSS diagnose hadden, zowel op basis van de DSM-IV als de DSM-5, gemeten met de *ADIS-C-LVB- sectie PTSS*. Gegevens werden verzameld met gebruikmaking van een *multiple baseline across subjects design*, waarbij werd gecontroleerd voor natuurlijk herstel in de loop van de tijd. De interbeoordelaarsbetrouwbaarheid van de scores was uitstekend. Bij beide deelnemers nam het aantal PTSS symptomen af als gevolg van de EMDR therapie. Beiden hadden geen PTSS diagnose meer na de behandeling en dit effect was nog steeds aanwezig bij de follow-up na 6 weken. De resultaten suggereren dat EMDR therapie, aangepast aan de mentale leeftijd van de participant, effectief is voor de behandeling van PTSS bij kinderen en adolescenten met een LVB.

Algemene discussie en aanbevelingen voor verder onderzoek.

De discussie over de resultaten van de onderzoeken die deel uit maken van dit proefschrift spitsen zich toe op de volgende thema's: (1) verschijningsvormen van PTSS, (2) diagnostiek van PTSS, en (3) EMDR therapie voor PTSS en andere trauma- en stressorgerelateerde stoornissen bij mensen met een VB.

Hoe PTSS zich manifesteert bij mensen met een VB

Bij de start van dit onderzoek werd verondersteld dat PTSS zich bij mensen met een VB anders zou kunnen presenteren dan bij mensen zonder een VB, zeker naarmate de verstandelijke beperking ernstiger is. De resultaten ondersteunden dit echter niet. Zo bleek PTSS zich bij kinderen en adolescenten met een LVB niet anders te manifesteren (zie Hoofdstuk 4). Er werd geen bewijs gevonden voor de noodzaak om het A criterium voor een traumatische gebeurtenis te verbreden, noch voor het toevoegen, weglaten of aanpassen van PTSS symptomen. Net als bij kinderen zonder een LVB bleken bij kinderen met een LVB PTSS symptomen in het dagelijks leven ernstige beperkingen en stressklachten met zich mee te brengen. De resultaten suggereren daarnaast dat meer blootstelling aan potentieel traumatische gebeurtenissen het risico verhoogt op het ontwikkelen van een PTSS. Het patroon van de onderzoeksresultaten dat gevonden werd bij kinderen met een IQ 70-85 (zwakbegaafdheid) was vergelijkbaar met dat van kinderen met een IQ 50-70 (lichte VB).

Binnen het kader van dit proefschrift werden zowel het onderzoek naar de verschijningsvorm van PTSS, als het onderzoek naar de ontwikkeling van een klinisch interview voor PTSS, gericht op kinderen en adolescenten met een LVB. Wat betreft de diagnostiek van PTSS bij volwassenen met een LVB, en bij mensen met een ernstigere verstandelijke beperking, kan het hiernavolgende worden opgemerkt.

Het is aannemelijk dat PTSS zich bij volwassenen met een LVB, evenals bij kinderen en adolescenten met een LVB, niet anders dan gebruikelijk presenteert. Het ligt immers voor de hand dat niet de chronologische leeftijd, maar veeleer de ontwikkelingsleeftijd van de volwassene met een LVB bepalend is voor de manier waarop de PTSS symptomen zich manifesteren (Scheeringa et al., 2012).

Om in te schatten of PTSS bij mensen met een ernstigere verstandelijke beperking (IQ < 50) zich anders manifesteert dan bij mensen zonder een VB, is het verschijnen van de DSM-5 in de loop van het onderhavig onderzoek van belang. Er zijn namelijk enkele verschillen tussen de DSM-5 criteria voor PTSS en de PTSS criteria volgens de DSM-IV-TR. Ten eerste is het achterwege laten van het A2 criterium voor trauma gunstig, omdat het voor mensen met een VB moeilijk is om op betrouwbare wijze verslag te doen van hun allereerste reacties van angst, hulpeloosheid of afschuw (McClure et al., 2009). Bovendien zijn ouders of verzorgers niet altijd ter plekke aanwezig om te kunnen observeren hoe de persoon reageert als de traumatische gebeurtenis zich voordoet. Op de tweede plaats is de toevoeging van het vierde symptoomcluster “negatieve veranderingen ten aanzien van gedachten en gevoelens” in overeenstemming met de bevindingen uit de casusbeschrijvingen van Hoofdstuk 3.2 en 3.3. waarbij participanten met een matige en ernstige verstandelijke beperking na EMDR therapie een opvallende verbetering in stemming lieten zien. Op de derde plaats zijn aan het symptoomcluster “veranderingen

gen in arousal en reactiviteit” gedragskenmerken toegevoegd namelijk “roekeloos of zelfdestructief gedrag” en “prikkelbaar gedrag en woede-uitbarstingen (met weinig of geen aanleiding) gewoonlijk tot uiting komend in verbale of fysieke agressie jegens mensen of voorwerpen”. Deze verandering sluit eveneens aan bij de bevindingen uit de casusbeschrijvingen van Hoofdstuk 3.2 en 3.3, waar na EMDR therapie een afname of het verdwijnen van agressieve uitbarstingen werd gerapporteerd. Een minstens zo belangrijke wijziging is de invoering van het ontwikkelingsgevoelige DSM-5 subtype voor kinderen van 6 jaar of jonger. Dit PTSS subtype bevat geen symptomen die vaardigheden vereisen die jongere kinderen nog niet ontwikkeld hebben, zoals verbale expressie, geheugen of abstract denken. Bovendien zijn er minder symptomen nodig om toch aan het PTSS criterium te kunnen voldoen. Gezien eerdergenoemde klinische bevindingen en de DSM-5 kenmerken is het aannemelijk dat de DSM-5 definitie van PTSS goed aansluit bij hoe PTSS zich presenteert bij personen met een ernstigere verstandelijke beperking, dat wil zeggen niet afwijkend maar op een manier die in overeenstemming is met de mentale leeftijd van de betreffende persoon.

Diagnostiek van PTSS met behulp van de ADIS-C-LVB-sectie PTSS: klinische toepassingen en toekomstig onderzoek

De beschikbaarheid van de *ADIS-C-LVB-sectie PTSS* is van grote betekenis in de geestelijke gezondheidszorg voor kinderen en adolescenten met een LVB, omdat dit de gelegenheid biedt om tijdig een valide en betrouwbare PTSS diagnose te kunnen stellen, een cruciale stap naar effectieve behandeling. Aangezien volgens de normaalverdeling van het IQ (*gemiddeld* = 100, *SD* = 15) ongeveer 15% van de bevolking binnen de LVB range valt, loopt een aanzienlijke groep kinderen en adolescenten een verhoogd risico op het ontwikkelen van een PTSS. Dientengevolge is onder kinderen en adolescenten met een LVB, die vanwege emotionele en gedragsproblemen naar ggz-instellingen worden verwezen, het percentage met een PTSS vermoedelijk hoog. De onderzoeksgroep van de onderhavige studie bijvoorbeeld bestond uit 80 kinderen en adolescenten die bij de intake niet waren geselecteerd op basis van hun traumageschiedenis, maar die vanwege het vermoeden van een breed scala aan psychische stoornissen door verschillende soorten instellingen naar de psychiatrische poli waren doorverwezen. Desondanks kon bij 20% tot 38% van hen (afhankelijk van het PTSS classificatiesysteem en het feit of het de scores van de kindversie dan wel die van de opvoederversie van het interview betrof) een PTSS diagnose worden gesteld. Om langdurig onnodig lijden en hoge (geestelijke) gezondheidszorgkosten te voorkomen door de PTSS symptomen ten onrechte aan andere stoornissen toe te schrijven, en ze dientengevolge met ineffectieve methoden te behandelen, is het belangrijk om bij de intake te screenen op de aanwezigheid van een PTSS. Vanuit dit oogpunt wordt het sterk aanbevolen om een PTSS screeningsinstrument te ontwikkelen, bijvoorbeeld

een verkorte versie van de *ADIS-C-LVB-sectie PTSS*, die gebruikt kan worden binnen de geestelijke gezondheidszorg voor kinderen en adolescenten met een LVB.

Na publicatie van de literatuurstudie (zie Hoofdstuk 2) kwamen de resultaten van een Nederlandse studie (Wieland, 2012) ter beschikking. Deze richtte de aandacht op vergelijkbaar hoge aantallen PTSS diagnoses onder volwassenen met een LVB die naar gespecialiseerde ambulante psychiatrische zorg verwezen waren, als die we gezien hadden bij de onderzoeksgroep van kinderen en adolescenten met een LVB. In de studie van Wieland waren DSM-IV-TR diagnoses geformuleerd met behulp van de DM-ID criteria. De patiënten werden multidisciplinair onderzocht door ten minste een gecertificeerde en ervaren psychiater, een gecertificeerde en ervaren gz-psycholoog en een ervaren sociaal psychiatrisch verpleegkundige. De psychiatrische ziektebeelden van zwakbegaafde patiënten (IQ 70-85; $n = 235$) werden vergeleken met die van ambulante patiënten uit de reguliere geestelijke gezondheidszorg ($n = 1026$) en die van ambulante patiënten met een lichte VB (IQ 50-70; $n = 152$). In de groepen met zwakbegaafde patiënten en patiënten met een lichte VB bleek PTSS de meest voorkomende As I diagnose. Bovendien bleek het aantal PTSS diagnoses in de groepen met zwakbegaafde patiënten (19,6%) en patiënten met een lichte VB (19,7%) significant hoger vergeleken met het aantal in de groep uit de reguliere geestelijke gezondheidszorg (10,4%).

Sinds de start van het onderhavig onderzoeksproject werden twee instrumenten ontwikkeld om de gevolgen van traumatische gebeurtenissen te meten onder volwassenen met een lichte tot matige VB. De *Lancaster and Northgate Trauma Scales (LANTS)* (Wigham et al., 2011) omvat een cliëntversie met 29 items (zelfrapportage) en een versie voor begeleiders met 43 items. De LANTS bleek een goede interne consistentie en test-hertest betrouwbaarheid te bezitten evenals voldoende convergente en inhoudsvaliditeit. Hall et al. (2014) ontwikkelden de *Impact of Event Scale - Intellectual Disabilities (IES-IDs)*, een zelf-rapportage screeningsinstrument dat wordt gebruikt als een semigestructureerd interview. Het meet de subjectief ervaren stress, die wordt veroorzaakt door traumatische gebeurtenissen, overeenkomstig de DSM-IV-TR PTSS symptoom categorieën. Helaas diagnosticeert geen van beide instrumenten PTSS volgens het DSM-5 classificatiesysteem. Aangezien de *ADIS-C-LVB-sectie PTSS* wel is afgestemd op de DSM-5 is het aan te bevelen om van dit klinisch interview een volwassenen versie te ontwikkelen. Een daarop volgend onderzoeksproject zou de ontwikkeling kunnen zijn van een verkorte versie van de *ADIS-C-LVB-sectie PTSS* als screeningsinstrument voor volwassenen met een LVB. Dit zou het tijdig opsporen van PTSS in de geestelijke gezondheidszorg voor volwassenen met een LVB kunnen verbeteren zodat getrainde professionals de klinische diagnose kunnen stellen, en daaropvolgend een effectieve behandeling kunnen bieden.

Toekomstig onderzoek is nodig om ook bij mensen met ernstigere verstandelijke beperkingen een valide en betrouwbare PTSS diagnose te kunnen stellen. Uitgaande van klinische

ervaringen (zie ook Hoofdstuk 3.3) is het aannemelijk dat PTSS zich bij deze personen niet op een abnormale wijze presenteert maar op een manier die aansluit bij het DSM-5 subtype voor kinderen van 6 jaar en jonger, waarvan de criteria rekening houden met de ontwikkelingsleeftijd. Om die reden is het aan te bevelen om voornamelijk de ouderversie van de *ADIS-C-LVB-sectie PTSS* te gebruiken voor de diagnostiek van PTSS bij mensen met een VB en een ontwikkelingsleeftijd van ongeveer 6 jaar of jonger.

Gezien het belang van tijdige opsporing en behandeling van PTSS bij mensen met een VB, zouden professionals bereid en in staat moeten zijn om met hun cliënten te communiceren over potentieel traumatische gebeurtenissen die ze zouden kunnen hebben meegemaakt. Echter, bij de uitvoering van het onderhavige onderzoek bleek er, zelfs onder hulpverleners in de specialistische geestelijke gezondheidszorg, een grote terughoudendheid te zijn om mensen met een VB en hun ouders of verzorgers te onderwerpen aan een PTSS interview uit angst dat dit te overweldigend en mogelijk zelfs gevaarlijk voor hen zou kunnen zijn in die zin dat ze opnieuw 'getraumatiseerd' zouden kunnen worden. Deze wijdverspreide terughoudendheid om traumatische ervaringen met kwetsbare patiënten en hun ouders of verzorgers te bespreken lijkt niet gerechtvaardigd afgaande op de ervaringen van de interviewers die aan de validatiestudie meewerkten. Deze terughoudendheid wordt evenmin ondersteund door de resultaten van een studie van Scotti et al. (2012), die liet zien dat degenen die over traumatische ervaringen waren bevraagd, juist wezen op de voordelen ervan en aangaven dat het hen persoonlijke voldoening had gegeven.

EMDR therapie bij mensen met een VB: klinische toepassingen en toekomstig onderzoek

Sinds onze publicatie van de literatuurstudie over PTSS bij mensen met een VB, 6 jaar geleden (zie Hoofdstuk 2), is het aantal casusbeschrijvingen (twee) in de internationale literatuur met negentien toegenomen (Mevissen et al., in druk). Tien van deze casusbeschrijvingen maakten deel uit van dit proefschrift. Onze casusbeschrijvingen lieten zien dat EMDR therapie, aangepast aan de mentale leeftijd van de persoon, toepasbaar en bruikbaar was voor personen met een VB, en onafhankelijk van leeftijd en ernst van de VB resulteerde in een afname van traumagerelateerde symptomen. Die afname was bij follow-up nog steeds aanwezig. Deze praktijkervaringen geven een voorzichtige steun aan de hypothese dat ook mensen met ernstigere verstandelijke beperkingen emotioneel beladen herinneringen in hun geheugen opslaan en dat het mogelijk is om deze herinneringen te reproduceren, dat wil zeggen in gedachten (lees: 'werkgeheugen') op te halen, deze te activeren en deze vervolgens te desensibiliseren. In het huidige onderzoek is de EMDR procedure toegepast op een manier die aansluit bij de geschatte ontwikkelingsleeftijd van de cliënt. Voor de wijze waarop de dysfunctioneel opgeslagen herinneringen werden geactiveerd is steeds het cognitief ontwikkelingsniveau, oftewel de mentale leeftijd, als uitgangspunt genomen. Er is voor dit concept gekozen, omdat dit richting geeft aan het

niveau waarop de therapeut de cliënt instrueert om een herinnering te reproduceren en de herinnering voldoende te activeren om volledige desensitisatie mogelijk te maken. De instructies corresponderen wat dit betreft met de Nederlandse versie van het EMDR protocol voor kinderen en jongeren tot 18 jaar. Dit bevat instructie niveaus voor de volgende leeftijdscategorieën: 1-3jaar, 4-5 jaar, 6-8 jaar en 9-18 jaar. Bij kinderen van 1-3 jaar worden de herinneringen geactiveerd met behulp van de zogenaamde verhalenmethode ('Story Telling'). Daarbij gebruikt de therapeut naast eenvoudige taal ook concrete triggers zoals aan de traumatische gebeurtenis gerelateerde voorwerpen of worden lichaamsdelen aangeraakt die met de traumatische gebeurtenis geassocieerd zijn. In het onderhavig onderzoek werd deze werkwijze toegepast bij cliënten met een ernstige beperking vanwege de aansluiting bij hun mentale leeftijd. Hierbij moet worden opgemerkt dat tot nu toe, effectstudies naar EMDR bij PTSS onder gemiddeld begaafde kinderen jonger dan 4 jaar ontbreken. Evenmin is, noch bij gemiddeld begaafde kinderen en jongeren, noch bij mensen met een VB, enig onderzoek bekend dat gericht was op de mechanismen die de in de praktijk gesignaleerde behandel-effecten verklaren. De hoop is dat toekomstig onderzoek daar duidelijkheid over verschaft.

Het sterk toegenomen aantal casusbeschrijvingen heeft geleid tot de publicatie van twee artikelen waarin de casusbeschrijvingen betreffende EMDR therapie bij mensen met een VB werden gereviewed. (Gilderthorp, 2015; Jowett et al., 2016). De auteurs concludeerden dat EMDR een veilige en acceptabele interventie is voor mensen met een VB. Daarom deden Jowett en zijn collega's de aanbeveling om middels gerandomiseerde, gecontroleerde studies voor deze doelgroep de effectiviteit van EMDR, bij een volgens de DSM-5 vastgestelde PTSS, te bewijzen. Daarbij wezen ze op het gebruik van een PTSS instrument met aangepast taalgebruik, een gestandaardiseerde afname van de traumageschiedenis en een gecontroleerde, nauwkeurige, uitvoering van een aangepast gestandaardiseerd EMDR protocol. In de *multiple baseline* studie voor kinderen en adolescenten met een LVB, waarmee dit proefschrift werd afgesloten, is aan bijna al deze eisen voldaan. Zo werd in deze studie de *ADIS-C-LVB-sectie PTSS* gebruikt, als valide en betrouwbaar diagnostisch instrument. Verder controleerde het onderzoek voor natuurlijk herstel in de loop van de tijd. De resultaten van deze eerste gecontroleerde studie waren in overeenstemming met de klinische ervaringen, in die zin dat het aantal PTSS symptomen afnam als gevolg van de EMDR therapie en dat de deelnemers geen PTSS meer hadden na behandeling, een effect dat aanhield bij de follow-up na 6 weken. Beide eerdergenoemde *reviews* over de bruikbaarheid en effectiviteit van EMDR behandeling bij mensen met een VB benadrukken de behoefte aan toekomstige *randomized controlled trials* (RCT's). Echter, op dit moment is de omvang van de specialistische geestelijk gezondheidszorg voor personen met een VB erg klein vergeleken met die voor mensen zonder een VB. Het aantal ervaren, goed opgeleide, en in deze doelgroep gespecialiseerde psychotherapeu-

ten is verhoudingsgewijs nog kleiner. Replicatie van de multiple baseline studie in grotere onderzoeksgroepen, van zowel kinderen als volwassenen met uiteenlopende niveau's van VB, lijkt daarom haalbaarder dan het uitvoeren van RCT's en verdient om die reden de voorkeur.

In de afgelopen zes jaar is voor wat betreft *trauma-focused cognitive behavioural therapy* (TF-CBT), de andere door de *World Health Organization* (WHO, 2013) aanbevolen 1e keus behandeling voor PTSS, het aantal gepubliceerde casusbeschrijvingen slechts uitgebreid met drie (Carrogan & Allez, in druk; Mevissen et al., in druk), waarbij eveneens positieve resultaten worden gerapporteerd. Er zijn verschillende verklaringen voor dit achterblijvend aantal. Ten eerste is het in het geval van EMDR in vergelijking met TF-CBT niet nodig om naast de sessies huiswerkopdrachten uit te voeren en te oefenen met exposure in vivo situaties, hetgeen zowel de persoon zelf als diens opvoeders of verzorgers ontlast. Mogelijk zal EMDR therapie voor de persoon met een VB minder belastend zijn, omdat geen frequente en langdurige blootstelling aan traumagerelateerde stimuli is vereist, wat essentieel wordt geacht voor de op CBT gebaseerde exposure therapie. Bij de toepassing van EMDR wordt in de plaats daarvan een afleidende taak aangeboden die het werkgeheugen belast, terwijl de persoon zich concentreert op de akelige herinnering. Dit resulteert in een afname van de emotionaliteit en levendigheid van de betreffende herinnering (Engelhard et al., 2011). In de klinische praktijk zien we dat dit proces bij mensen met een VB vaak opvallend weinig tijd kost, met als gevolg een snelle afname van het aantal PTSS symptomen, hetgeen de behandeling van PTSS minder tijdrovend maakt. Kortom, voor mensen met een VB lijkt EMDR vergeleken met TF-CBT geschikter als behandelmethode voor PTSS.

EMDR therapie voor andere stoornissen dan PTSS: perspectieven voor de toekomst

EMDR therapie is een psychotherapeutische behandeling die niet alleen bedoeld is voor de behandeling van PTSS, maar voor een verscheidenheid aan psychische stoornissen, afkomstig van een breed scala aan traumatische en andere negatieve levensgebeurtenissen (Shapiro, 2001, 2014). Gebaseerd op de resultaten van een aantal RCT's bij kinderen, heeft EMDR bijvoorbeeld ook significante verbeteringen laten zien bij zelfbeeld- en gedragsproblemen. (Wanders et al., 2008), evenals een significante afname van symptomen bij kinderen met een gedragsstoornis (Soberman et al., 2002). Uit pilot onderzoek bleek dat EMDR therapie ook positieve effecten had op de hechtingsrelatie tussen ouder en kind (Wesselmann et al., 2012). In onderzoek onder volwassenen werd de werkzaamheid van EMDR aangetoond bij onder andere specifieke fobieën (o.a. Doering et al., 2013), algemene symptomen van angst en spanning (Abbasnejad, Mahani, & Zamyad, 2007; Arabia, Manca, & Solomon, 2011), obsessief compulsieve stoornis (Nazari et al., 2011; Marsden, 2016), depressie (Gauhar, 2016) en aanpassingsstoornis (Cvetec, 2008). Gegeven het feit

dat EMDR toepasbaar en bruikbaar is bij personen met uiteenlopende niveau's van VB, zou EMDR een geschikte psychotherapeutische behandelmethode moeten kunnen zijn voor andere vormen van psychopathologie dan enkel PTSS. Vanuit dit perspectief is het relevant om te benadrukken dat PTSS in de DSM-5 deel uitmaakt van een nieuw cluster genaamd "Psychotrauma- en stressorgerelateerde stoornissen"¹. Een gemeenschappelijk kenmerk van deze stoornissen is dat blootstelling aan een traumatische of stressvolle gebeurtenis een onvoorwaardelijk diagnostisch criterium is. Bovendien wordt in de DSM-5 opgemerkt dat er een nauw verband bestaat tussen deze stoornissen en angststoornissen, obsessief compulsieve en verwante stoornissen en dissociatieve stoornissen. Indien psychische stoornissen geworteld zijn in negatieve levensgebeurtenissen, lijkt EMDR therapie een passende behandelmethode. Voorafgaand aan de EMDR behandeling van deze categorie trauma- en stressorgerelateerde klachten kan afname van de *ADIS-C-LVB-sectie PTSS* zinvol zijn. De *ADIS-C-LVB-sectie PTSS* bevat een uitgebreide gebeurtenissensectie met niet alleen gebeurtenissen van het type A trauma, maar ook andere negatieve levensgebeurtenissen. Bovendien bevat het interview een uitgebreide sectie met symptomen die het gevolg kunnen zijn van het meemaken van zulke gebeurtenissen. Dit instrument lijkt daarom bijzonder geschikt om ook stoornissen met andere gebeurtenis-symptomencombinaties te kunnen diagnostiseren dan enkel PTSS. Toekomstig onderzoek met betrekking tot EMDR therapie voor andere stoornissen dan PTSS is bijzonder belangrijk omdat voor mensen met een VB, niet alleen voor PTSS maar ook voor andere vormen van psychopathologie, effectieve psychotherapeutische behandelmethoden ontbreken en hard nodig zijn.

CONCLUSIE

Mensen met een VB, met inbegrip van hen die op zwakbegaafd niveau functioneren, vormen een grote minderheid in de geestelijke gezondheidszorg. In deze doelgroep blijkt PTSS op grote schaal ondergediagnostiseerd en onderbehandeld. De resultaten van het onderhavige onderzoeksproject zijn van groot belang gezien het verhoogd risico bij deze doelgroep op het ontwikkelen van een PTSS, een psychische stoornis die gepaard gaat met ernstige en langdurige beperkingen, hoge zorgkosten en een als laag ervaren kwaliteit van leven. De ontwikkeling van de *ADIS-C-LVB-sectie PTSS* als PTSS klinisch interview, in combinatie met de bevinding dat EMDR toepasbaar en bruikbaar is voor kinderen en volwassenen met uiteenlopende niveau's van VB en positieve effecten liet zien in een eerste gecontroleerde case studie, maken het mogelijk om PTSS bij deze doelgroep tijdig vast te stellen en effectief te behandelen. Voorzieningen voor geestelijke gezondheidszorg zouden hun beleid moeten aanpassen om de wijdverbreide terughoudendheid te doorbreken

om traumatische ervaringen te bespreken met mensen die tot deze in potentie kwetsbare doelgroep horen, ongeacht hun leeftijd of het niveau waarop ze functioneren. Om recht te doen aan de behoeften van mensen met een VB en PTSS, zouden professionals moeten worden geschoold in hoe zij PTSS tijdig kunnen vaststellen en hoe zij mensen met een VB en PTSS op effectieve wijze kunnen ondersteunen en behandelen. Een belangrijke uitdaging voor de toekomst is de verdere wetenschappelijke onderbouwing van de diagnostiek van PTSS bij mensen met een VB, en uitbreiding van het aantal gecontroleerde studies om de effectiviteit van EMDR aan te tonen voor de behandeling van PTSS en andere, aan onverwerkte gebeurtenissen gerelateerde vormen van psychopathologie, bij deze risicogroep.

- ¹ Het DSM-5 hoofdstuk "Psychotrauma- en stressorgerelateerde stoornissen" bestaat uit: reactieve hechtingsstoornis, ontremd-sociaalcontactstoornis, posttraumatische-stressstoornis (inclusief de posttraumatische-stressstoornis bij kinderen van 6 jaar en jonger), acute stressstoornis, aanpassingsstoornis (waarbij kan worden gespecificeerd naar de symptomen die op de voorgrond staan in de vorm van sombere stemming, angst, gedrag, of combinaties daarvan) en andere gespecificeerde psychotrauma- of stressorgerelateerde stoornis.

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AWARDS

Winnaar van de Accare prijs 2011 in de categorie "Individuele prijs".

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medical psychotrauma in a child with severe intellectual disabilities and we witnessed the effects of the treatment with EMDR. Our endeavours to obtain empirical support for the effectiveness of EMDR for this client population were unfortunately to no avail. The time was not yet ripe. Thankfully there is now an agenda for the future.

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Following on from this I express my gratitude towards the Foundation Friends of Accare (Stichting Vrienden van Accare), who offered the grant enabling me a number of additional months to process the research data.

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Günther, you have been the one who has stimulated me. Always present as my partner, the most powerful force yet invisible to others.

CURRICULUM VITAE

Liesbeth Mevissen (1956) werd geboren in Heerlen (Nederland) en groeide op in Brunssum. Zij behaalde daar het diploma Atheneum B aan het Rombouts College. Op 7-jarige leeftijd werd in haar nabije omgeving een kindje met het syndroom van Down geboren. Zij genoot ervan om met het jongetje te spelen en hem nieuwe dingen te leren. Een hechte band ontstond. De boodschap van anderen, dat met de komst van dit kindje het gezin iets heel ergs was overkomen, stond in schril contrast met haar eigen ervaringen. Hier moet de oorsprong liggen van de *drive* om zich in te zetten voor mensen met een verstandelijke beperking en hun naaste betrokkenen. Liesbeth begon een studie aan de HBO-V maar brak die na korte tijd af om fulltime aan het werk te kunnen gaan in de zorg voor mensen met een verstandelijke beperking. Zij deed ervaring op in verschillende functies en instellingen met zowel volwassenen als kinderen met een verstandelijke beperking variërend van licht tot zeer ernstig, waarbij haar aandacht steeds meer uitging naar degenen met ernstige emotionele en gedragsproblemen. Het werk in de praktijk heeft zij tot op heden gecombineerd met studies, kennisuitwisseling en kennisoverdracht. Na het behalen van de aktes MO-A en MO-B pedagogiek volgde Liesbeth een individueel programma aan de Universiteit van Amsterdam waar ze in 1989 haar studie orthopedagogiek afsloot bij professor Ad van Gennep, een pleitbezorger voor burgerschap voor mensen met een verstandelijke beperking. In 1998 sloot zij een periode af van postdoctorale specialisaties in diagnostiek en behandeling van kinderen aan de Universiteit Groningen en de Universiteit Leiden.

Als leidinggevende van het Kinder-gezinsvervangend tehuis in Nieuwstadt (1985-1991) en later als beleidsmedewerker bij Sint Anna in Heel, zette zij zich in voor vernieuwingen in het hulpaanbod voor kinderen met een verstandelijke beperking en hun gezinnen. Kernthema's waren zorg op maat voor kind en gezin om uithuisplaatsing te voorkomen, werken aan terugkeer naar het gezin, en als zo'n perspectief niet haalbaar was een andere, zo gewoon mogelijke gezinssituatie voor het kind. Zij deed een haalbaarheidsonderzoek naar pleegzorg dat leidde tot de ontwikkeling van gezinshuizen. In deze periode was Liesbeth docent en supervisor bij het Instituut Trainingen Thuisbegeleiding van de Hogeschool Utrecht en medeauteur van het boek 'Ouders willen veranderen. Een handleiding voor agogisch-pedagogische thuisbegeleiding'. In de functie van orthopedagoog-generalist en later als gz-psycholoog en klinisch psycholoog werkte Liesbeth van 1991 tot 1998 bij Stichting Anna te Heel (tevens als plaatsvervangend hoofd van de behandel- en begeleidingsdienst), van 1998 tot 2002 bij de Severinus te Veldhoven (tevens als coördinator van de psychologisch pedagogische afdeling), van 2002 tot 2003 bij SGLVG-instelling Nieuw-Spraeland te Venraij, van 2003 tot 2004 bij het kenniscentrum OPL van Stichting de Opbouw Utrecht (als hoofd diagnostiek) en van 2004 tot 2007 bij Stichting Prisma

te Waalwijk. De focus van haar werk lag voornamelijk op het ondersteunen van teams die werkten met mensen met een verstandelijke beperking en complexe emotionele en gedragsproblematiek. De vaak hardnekkige problemen rond mensen met een autismespectrumstoornis hadden haar speciale aandacht. In deze periode was Liesbeth hoofddocent van de postdoctorale module 'Behandeling van gedragsproblemen bij mensen met een verstandelijke beperking' bij de PDBO Randstad en schreef zij het boek 'Kwetsbaar en afhankelijk. Diagnostiek en behandeling van gedragsproblemen bij mensen met een verstandelijke beperking'. Het boek biedt handvatten waarmee ouders, begeleiders en leerkrachten de interactie met de persoon met een verstandelijke beperking kunnen vormgeven op een manier die positieve ervaringen genereert en persoonlijke ontwikkeling stimuleert. Het besef dat zich in de levensgeschiedenis van mensen met een verstandelijke beperking en complexe problematiek vaak ingrijpende negatieve gebeurtenissen hadden voorgedaan lag hieraan ten grondslag.

Vlak na de publicatie van haar boek kwam Liesbeth in aanraking met EMDR therapie, een vorm van psychotherapie die zich richt op het verwerken van herinneringen aan beschadigende negatieve levensgebeurtenissen. Vanaf 2006 specialiseerde zij zich in de diagnostiek en (EMDR) behandeling van posttraumatische stressstoornis en andere trauma- en stressorgerelateerde stoornissen bij mensen met een verstandelijke beperking, ook nu weer met bijzondere aandacht voor de rol van ouders en verzorgers met inbegrip van het zo nodig behandelen van psychotrauma bij ouders en andere gezinsleden. In haar klinisch werk verschoof het accent van het begeleiden van teams naar poliklinische diagnostiek en psychotherapeutische behandelingen vanuit instellingen die het onderhavige promotieonderzoek middels een vrijstelling van een halve dag per week faciliteerden: van 2007 tot 2009 Stichting Philadelphia Zorg te Nunspeet (gehandicaptenzorg), van 2009 tot 2015 Accare poli Deventer (kinder- en jeugdpsychiatrie, ook werkzaam voor gemiddeld begaafde kinderen) en sinds 2015 De Swaai (centrum voor verstandelijke beperking en psychiatrie) locatie poli Jeugd te Drachten. Op *free-lance* basis is Liesbeth werkzaam als EMDR supervisor, docent bij GITP-PAO, Rino en Cure & Care en als facilitator bij de EMDR opleidingen van het Nederlands EMDR Instituut. Door middel van publicaties en als spreker op nationale en internationale congressen brengt ze het belang van tijdige diagnostiek en behandeling van psychotrauma bij mensen met een verstandelijke beperking onder de aandacht.

CURRICULUM VITAE

Liesbeth Mevissen (1956) was born in Heerlen (the Netherlands) and spent her childhood in Brunssum. She completed the equivalent of the A levels (Atheneum B) at the Rombouts

College. When she was seven years old a child with Down's Syndrome was born in the neighborhood she was growing up in. She enjoyed playing with this boy and taught him new things. A close bond developed. The overall response from other people was that it was a terrible thing that had happened to the family into which this child was born. This was in sharp contrast to her own experiences with him. So this could very well be the source of Liesbeth's drive to make a difference for people with intellectual disabilities and their caregivers. Liesbeth started her training to become a registered nurse at college but gave this shortly after starting to work fulltime with people with intellectual disabilities. She gained a wide range of experience in various settings with both adults and children with varying degrees of developmental impairments from severe to mild. Her attention was always drawn to those struggling with more severe emotional and behavioural difficulties. She has been able to combine the 'hands on' work with formal course work, exchange of knowledge and teaching. Once she completed her teaching qualifications and Educational Psychology degree, Liesbeth studied Clinical Child and Adolescent Studies with Professor Ad van Gennep at the University of Amsterdam, an advocate for citizenship for people with intellectual disabilities. In 1998 she completed her postdoctoral specialism in the assessment and treatment of children at the University of Groningen and the University of Leiden.

Working as a manager in the children's home in Nieuwstadt (1985-1991) and later as policy officer at Saint Anna in Heel, she was committed to innovating the existing treatments for children with intellectual disabilities. Core issues pertained to creating tailored treatments for both child and family in order to prevent out of home placements, preparing for the return to the family, and if this was not possible to create for the child as much as possible a similar normal family structure. She completed feasibility studies in fostering which lead to the development of family-homes. In this period Liesbeth was teaching and consulting at the Institute Training and Home Guidance of the College of Utrecht and co-author of the book 'Parents want to change' a manual for agogic-pedagogic home guidance. First as an Educational Psychologist, and later on as Primary Care Psychologist and Clinical Psychologist (and also as Acting Head of Treatment and Guidance Services) Liesbeth worked at the Anna Foundation (Stichting Anna) in Heel from 1991 - 1998. From 1998-2002 she worked at the Severinus in Veldhoven as coordinator of the Psychology Department), and from 2002-2003 at the SGLVG Institute Nieuw-Spraeland in Venraij and between 2003-2004 at the Knowledge Institute OPL of Stichting de Opbouw Utrecht (as the head of the assessment unit). From 2004-2007 she worked at Foundation Prisma in Waalwijk. The focus of her work was mainly offering guidance to the teams working with people with intellectual disabilities and complex emotional and behavioural problems. Her specific interest was toward the often persistent problems that people with autism have. During this time Liesbeth was Senior Lecturer of the post doctoral module "Treating

behavioural problems of people with intellectual disabilities at PDBO Randstad and she was the author of the book 'Vulnerable and dependant; assessment and treatment of behavioural problems of people with intellectual disabilities'. The book offers practical guidelines for parents, support workers and teachers to facilitate communications and interactions which in turn can generate positive experiences and personal development. Understanding that many impactful negative experiences occur in the lives of people with intellectual disabilities underpins this approach.

Shortly after the publication of her book Liesbeth came across EMDR therapy, a form of psychotherapy which enables the processing of memories of negative damaging life events. From 2006 she specialized in the assessment and treatment (EMDR) of posttraumatic stress disorder and other trauma related disorders with people with intellectual disabilities, once again paying specific attention to parents and caregivers including treating parental (or other family members) psychotrauma. In her clinical work the emphasis shifted from supporting teams to outpatient assessments and treatments in the departments which also facilitated this PhD study by exempting her for half a day a week to do her research: from 2007-2009 the Philadelphia Foundation in Nunspeet (disability unit), and from 2009-2015 Accare Out Patient Unit in Deventer (child and adolescent psychiatry, also with children with typical development) and since 2015 De Swaai (Centre for Intellectual Disabilities and Psychiatry) at the outpatient Unit for children and adolescents in Drachten. Working on a freelance basis Liesbeth teaches as an EMDR Consultant, but also at GTP-PAO, RINO Cure & Care and frequently facilitates at the EMDR training courses of the Institute EMDR Nederland. By publishing articles, speaking at national and international conferences Liesbeth is able to emphasize the importance of timely assessment and treatment of psychotrauma in people with developmental difficulties

