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Mevissen-Renckens, E.H.M.; de Jongh, A.

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

**L. Mevissen<sup>1</sup> & A. de Jongh<sup>2</sup>**

<sup>1</sup> Accare, Centre for Child and Adolescent Psychiatry, Drenthe, the Netherlands

<sup>2</sup> Department of Behavioural Sciences, Academic Centre for Dentistry Amsterdam (ACTA),  
Universiteit van Amsterdam and Vrije Universiteit, Amsterdam, the Netherlands

Corresponding author: L. Mevissen

Accare, divisie KJP, Fazantenlaan 1, 9422 EZ Smilde, Netherlands

Tel.: +31 (0)570 503363

E-mail address: l.mevissen@accare.nl

## **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 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 reliable and valid instruments for assessing PTSD in this population are completely lacking, there are no prevalence data on PTSD among people with ID. Nine articles involve 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 assessment of PTSD symptomatology in this population is required, as it could facilitate further research on its prevalence and treatment.

**Keywords:** Intellectual disability (ID); Mental retardation (MR); Learning disabilities (LD) ; Post-Traumatic Stress Disorder (PTSD); Assessment; Prevalence; Psychological trauma; Trauma treatment

## **1. 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, Borthwick-Duffy, Buntinx, Coulter, Craig, Reeve, Schalock, Snell, Spitalnik, Spreat, & Tasse, 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 (Rutter, Graham & Yule, 1970; Eaton & Menolescino, 1982; Reiss, Levitan & Szyszko, 1982; Linna, Moilanen, Ebeling, Piha, Kumpulainen, Tamminen, & Almqvist, 1999; Dekker, Koot, van der Ende, & Verhulst, 2002; Emerson, 2003; Einfeld, Piccinin, Mackinnon, Hofer, Taffe, Gray, Bontempo, Hoffman, Parmenter, & Tonge, 2006; Cooper, Smiley, Morrison, Williamson, & Allan, 2007).

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; Rush & Francis, 2000; Fletcher, Loschen, Stavrakaki, & First, 2007).

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 (Rayn 1994, Mansell, Sobsey, & Moskal 2003, Focht-New, Clements, Barol, Faulkner, & Pekala, 2008). 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 (Turk & Brown, 1993; Beail & Warden, 1995; Sequeira & Hollins, 2003; Mansell et.al, 2003). 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 (McGillivray & McCabe, 2007; Tsanikos, Bouras,

Costello, & Holt, 2007; Hastings, Hatton, Taylor, & Maddison, 2004; Owen et al., 2004; Hamilton et al., 2005; Levitas & Gilson 2001). More importantly, in a prospective study by Esbenson and 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 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 (van der Kolk & McFarlane, 1996; Brady, 1997). 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 disorganized 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, 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 institutionalization 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.

## **2. 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.

### **3. Results**

A total of 18 studies was 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.

#### *3.1. 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 (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 et al., 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 and the



recommended adaptations for children and those recommended for people with ID by Tomasculo 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). 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, Tomasculo et al., 2007; Martorell et al., 2008).

### *3.2. 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 (Mitchell, Clegg, & Furniss, 2006; Ryan, 1994; Firth, Balogh, Berney, Bretherton, Graham, & Whibley, 2001; Balogh, Bretherton, Whibley, Berney, Graham, Richold, Worsley, & Firth, 2001). 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 incidence of a feature in large heterogeneous populations. Unfortunately, such studies are completely lacking.

### *3.3 Treatment of PTSD in people with ID*

Three articles were found recommending an interdisciplinary treatment approach for PTSD in people with ID (Ryan, 2000; McCarthy, 2001; Focht-New et al., 2008; see Table 3). From the biological point of view pharmacological interventions are described targeting the deregulation that occurs in various neurotransmitter systems (Ryan, 2000; McCarthy, 2001; Focht-New et al., 2008). 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 are recommended to increase understanding of the symptoms and teach appropriate responses (Ryan, 2000). A series of practical guidelines for carers is offered to help the traumatized person with ID (Ryan, 2000; Focht-New et al., 2008). 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 (Ryan, 2000; McCarthy, 2001; Focht-New et al., 2008). The same holds true for methods that have proved to be successful in the psychotherapeutic treatment of PTSD in the general population (Ryan, 2000; McCarthy,

2001; Focht-New et al., 2008). Five articles were found on psychotherapeutic treatment of PTSD in people with ID (see Table 4). Two of these reports pertain to 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 et al. (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. Symptom 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 her colleagues (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 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 program offered to the clients. In the first case initial supportive counseling, practical problem solving and basic coping strategies had been used in order to treat symptoms of anxiety and depression. After treating the nightmares, psychological treatment was continued 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 Desensitization 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 as to 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 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 (Greenwald, 1994; Seubert, 2005; Benjamin, 2007) psychodynamic psychotherapy is a rather frequently used approach for trauma treatment including all levels of ID. Case reports suggest positive treatment effects (Sinason, 1992, Beail, 1998; Peeters-Thijssen; Hoekman, Mous, Arends, & Broesterhuizen-Janssen, 1998; Carlsson, 2000; De Belie, Ivens, Lesseliers, & Van Hove, 2000; Cottis, 2008). 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 et al., 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 (1992) 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.

#### **4. 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 institutionalization and hospital admissions due to comorbid medical impairments (Tomasulo et al., 2007). Further, it has been argued that understanding oneself as disabled can be traumatizing in itself (Hollins et al., 2000; Levitas, 2001). Thus, the findings of this study support the importance of the potential predisposition of people with ID to 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. First, although it is conceivable that with regards to the MH-ID criteria, the range of potentially traumatizing 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, 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 findings of Prout and 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 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 (Cloitre, 2009; Bisson, Ehlers, Matthews, Pilling, Richards, & Turner, 2007; 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, in press). In contrast, although widely used, there is as yet no empirical evidence for a clinically important effect of psychodynamic therapy on PTSD (Schottenbauer, Glass, Arnkoff, & Gray, 2008; National Collaborating Centre for Mental Health, 2005).

In his article on efficacy of CBT in people with ID Sturme (2006) argues that claims on the efficacy of CBT in this population often are not well-founded. Techniques, labeled as cognitive, are more likely to be based on the principles of applied behavior 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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**Table 1 Posttraumatic Stress Disorder**

| <b>DSM-IV-TR Criteria</b>  | <b>Adapted Criteria in children</b>  | <b>Adapted Criteria for individuals with ID (DM-ID)</b>   |
|--|--|---|
| <p><b>A (1+2)</b><br/>           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<br/>           2. response involved intense fear, helplessness, or horror</p>  | <p>1. no adaptation<br/><br/>           2. response might have involved disorganized or agitated behavior</p>  | <p>1. no adaptation<br/>           note: the range of potentially traumatizing events is greater for individuals with ID<br/><br/>           2. increased likelihood of disorganized or agitated behavior when developmental age is lower (quite common with severe to profound ID)</p>   |
| <p><b>B (one or more)</b><br/>           1. recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions<br/><br/>           2. recurrent distressing dreams of event<br/><br/>           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)<br/>           4. intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event<br/>           5. physiological reactivity on exposure to internal cues that symbolize or resemble as 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<br/><br/>           2. frightening dreams without recognizable content may occur<br/>           3. in young children trauma-specific re-enactment may occur<br/><br/>           4. no adaptation<br/><br/>           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)<br/><br/>           2. frightening dreams without recognizable content appear to be more common when developmental age is lower<br/>           3. trauma-specific enactments have been observed in adults with moderate to severe ID; they can appear to be symptoms of psychosis in adults<br/><br/>           4. no adaptation<br/><br/>           5. no adaptation</p> |
| <p><b>C (three or more)</b><br/>           1. efforts to avoid thoughts, feelings, or conversation associated with the trauma<br/><br/>           2. efforts to avoid activities, places, or people that arouse recollections of the trauma</p>  | <p>1. no adaptation<br/><br/>           2. no adaptation</p>   | <p>1. no adaptation<br/>           note: assessment may be difficult in individuals with severe verbal limitations<br/><br/>           2. no adaptation<br/>           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</p>  |

|   |   |  |
|---|---|--|
| <p>3. inability to recall an important aspect of the trauma</p> <p>4. markedly diminished interest or participation in significant activities</p> <p>5. feeling of detachment or estrangement from others</p> <p>6. restricted range of affect (e.g., unable to have loving feelings)</p> <p>7. sense of a foreshortened future (e.g. does not expect to have a career, marriage, children, or a normal life span).</p> | <p>3. no adaptation</p> <p>4. no adaptation</p> <p>5. no adaptation</p> <p>6. no adaptation</p> <p>7. no adaptation</p> | <p>recollections of the trauma</p> <p>3. no adaptation<br/>note: problems with recall may appear to be solely a function of the individual's developmental age. Assessment may be difficult</p> <p>4. no adaptation<br/>note: caregivers may report the symptom as <input type="checkbox"/> non-compliance <input type="checkbox"/> especially for individuals with lower developmental age who cannot verbalize their feelings</p> <p>5. for individuals with severe to profound ID caregivers may report that the individual isolates him or herself</p> <p>6. no adaptation</p> <p>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 realize that they are different from peers and siblings and therefore don't expect a normative future</p> |
| <p>D (two or more, not present before the trauma)</p> <p>1. difficulty falling or staying asleep</p> <p>2. irritability or outbursts of anger</p> <p>3. difficulty concentrating</p> <p>4. hypervigilance</p> <p>5. exaggerated startle response</p>  | <p>1. no adaptation</p> <p>2. no adaptation</p> <p>3. no adaptation</p> <p>4. no adaptation</p> <p>5. no adaptation</p> | <p>1. no adaptation</p> <p>2. no adaptation</p> <p>3. no adaptation</p> <p>4. no adaptation</p> <p>5. no adaptation</p>  |
| <p>E</p> <p>Duration of the disturbance (symptoms B,C and D) is more than 1 month</p>   | <p>no adaptation</p>  | <p>no adaptation</p> <p>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</p>  |
| <p>F</p> <p>The disturbance causes clinically significant distress or impairment in social, occupational or other important area's of functioning</p>   | <p>no adaptation</p>  | <p>no adaptation</p> <p>note: clinically significant impairment in functioning may appear to be solely a function of the cognitive limitations so careful assessment is necessary</p>  |
| <p>Specify if: <b>Acute:</b> if duration of symptoms is less than 3 months months or more      <b>Chronic:</b> if duration of symptoms is 3 months or more</p> <p>Specify if: <b>With Delayed Onset:</b> if onset of symptoms is at least 6 months after the stressor</p>   |   |  |



**Table 2. Prevalence of PTSD in people with ID**

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

**Table 3. Multidisciplinary treatment of PTSD in people with ID**

| Authors/<br>Year          | Type   | Interventions   |
|---------------------------|--|---|
| Focht-New et al.,<br>2008 | <p>Descriptive study, based on the literature of PTSD in the general population with clinical and anecdotal reports of PTSD in people with ID</p> <p>Interventions for victims of interpersonal violence or crime</p>                        | <p>Interventions that should be carried out by support persons (carers, family members , friends) are described</p> <p>Psychotherapeutic methods are listed</p> <p>Pharmacological treatment possibilities are described</p>  |
| McCarthy, 2001            | <p>Descriptive study, based on the literature of PTSD in the general population and clinical and anecdotal reports of PTSD in people with ID</p> <p>Some limited attention for psychological treatment approaches and psychopharmacology</p> | <p>Psychotherapeutic methods used in the general population are recommended</p> <p>Inclusion of support persons is recommended</p> <p>Some pharmacological interventions with proven efficacy in the general population are recommended</p>   |
| Pitonyak, 2005            | <p>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</p> <p>Interventions with the focus on support persons of institutional clients</p>      | <p>Comprehensive guidelines/tips for caregivers and illustrated with examples from the lives of institutionalized clients</p>   |
| Ryan, 2000                | <p>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</p> <p>Interdisciplinary treatment guidelines</p>  | <p>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</p> <p>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</p> <p>Various interventions focussed on the person's environment are illustrated as well as staff training and support</p> |

**Table 4. Psychotherapeutic treatment of PTSD in people with ID**

| Authors/<br>Year                     | N  | Treatment<br>method                     | age                    | M/F         | Level of ID &<br>comorbidity                                | Complaints  | Trauma's/<br>life events  | Number<br>of<br>sessions | Results   | Follow-up    |
|--------------------------------------|----|---|------------------------|-------------|---|---|---|--------------------------|---|--------------|
| Giltaij,<br>2004                     | 2  | EMDR                                    | ?                      | F           | Mild<br>Blind   | Fears/avoidance<br>Being dependant on<br>caregivers<br>Often crying<br>Uncertain  | Single sexual abuse   | 4                        | Complaints resolved   | 3 months     |
|                                      |    |   | 16y                    | F           | Mild<br>Nearly blind<br>Epilepsy<br>Brain damage            | Fears/avoidance<br>Sleep problems<br>Demanding behavior   | Witnessed mother being<br>threatened with knives  | 12                       | Significant decrease<br>problem score on self-<br>report scale (9→1)  | None         |
| Lemmon,<br>et al., 2002              | 1  | CBT<br>(exposure)                       | 32y                    | F           | Mild  | Crying and fearful when<br>questioned about perpetrator<br>and when driving to<br>where the event took place<br><br>Refusing to discuss traumatic<br>experiences and not looking<br>at the place where the<br>traumatic event happened<br><br>Outbursts of anger, and<br>hypervigilance | Sexual abuse by former<br>work supervisor<br><br>Suspected sexual abuse<br>by former foster father<br><br>Recent frightening<br>incidents | 25                       | No longer distressed when<br>exposed to trauma-related<br>stimuli<br><br>No avoidance in speaking<br>about the traumatic events<br><br>Anger outbursts and<br>hypervigilance<br>significantly decreased | None         |
| Razza,<br>1997                       | 1  | Psycho<br>dynamic                       | 27y                    | F           | Mild<br><br>Cerebral palsy                                  | Insomnia<br>Tearfulness<br>Lack of self-care skills<br>Suicidal ideation<br>Agitation<br>Hostility  | Chronic childhood<br>sexual abuse   | ?                        | Reduction of symptoms<br>after 5 years of individual<br>and group treatment   | None         |
| Stenfert,<br>Kroese, et<br>al., 2006 | 2  | CBT/<br>Imagery<br>Rehearsal<br>Therapy | 18y                    | F           | Mild<br><br>Basic verbal<br>capacities                      | Frequent nightmares   | Sexual, physical and<br>emotional abuse from<br>the ages of 5yrs.-15 yrs.   | 3, and daily<br>homework | Nightmares ceased<br><br>Improved self-confidence   | 4 & 6 months |
|                                      |    |   | 24                     | F           | Mild<br><br>Basic verbal<br>capacities<br><br>Down syndrome | Frequent nightmares<br>Sleep disturbance<br>Flashbacks<br>General anxiety<br>Fear of the dark and being left<br>on own  | Rape  | 3, and daily<br>homework | Nightmares ceased   | 3 & 6 months |
| Tharner,<br>2006                     | 19 | EMDR                                    | Children<br>and adults | M<br>&<br>F | Mild  | Not specified   | Not specified   | ?                        | 16 successful treatments<br>i.e.: patient thinks of<br>trauma without much<br>distress and with positive<br>self cognition  | None         |



