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# Post-traumatic stress disorder in people with learning disability

Jane McCarthy

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It is well recognised that traumatic events can cause psychological disorders in those who experience them. The most common disorders suffered are depression and substance misuse; others include acute stress reactions, anxiety states and personality changes. One disorder following trauma that has received considerable attention over the past 20 years is post-traumatic stress disorder (PTSD). PTSD occurs in 20–30% of people exposed to traumatic events and the prevalence in the general population is 1% (Helzer *et al*, 1987), with life-time prevalence of 9.2%.

PTSD was introduced as a separate diagnosis in DSM–III. The defining criteria for PTSD in DSM–IV (American Psychiatric Association, 1994) is the experiencing of a traumatic stressor as opposed to an ordinarily unpleasant stressor, which is a threat to life or severe injury to self or others. In ICD–10 (World Health Organization, 1992) there is the broad category of neurotic, stress-related and somatoform disorders (F40 to F48). Within this category PTSD is listed with acute stress reaction and adjustment disorder. Recently, diagnostic criteria for learning disability have been developed, but with no change to those currently used within ICD–10 and DSM–IV for PTSD (Royal College of Psychiatrists, 2001).

There is very limited literature on the subject of PTSD in people with learning disability. This begs the question of why PTSDs occurring in people with learning disability have been understudied to date. In part this is because PTSD was recognised as a separate concept only in the past 20 years. It is only in this time-scale that there has been a full acknowledgement that people with learning disability suffer from serious mental illness. It was as recently as 1983 that the seminal paper by Sovner & Hurley (1983), entitled “Do the mentally retarded

suffer from affective disorders?”, asked such a fundamental question about mental health needs of those with learning disability.

Disorders that are more recently described in the general population will take time, therefore, to be delineated and explained in those with learning disability. Also, it may be that accepting that people with learning disability do suffer trauma has been a difficult concept to comprehend. Certainly it is only in the past decade that universal experiences such as bereavement have come to be recognised and studied in those with learning disability (Hollins & Esterhuyzen, 1997).

This article outlines the theoretical understanding of PTSD, which may be relevant to the field of learning disability, and discusses the nature of these disorders within this group. It then considers clinical assessment and treatment, finally commenting on the need for further research of these disorders.

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## Pathophysiology and risk factors

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Post-traumatic stress disorder is considered to be a neurophysiological disorder with effects on the hypothalamic–pituitary axis, hippocampal volume and endogenous opioid function.

The psychological understanding of PTSD is that it represents a failure to process the experience of fear, reflecting either a previous vulnerability to fear or exposure to extremes of fear (Foa & Kozak, 1986). Others suffer sadness, guilt and shame (Andrews, 1998), that is, fear shatters their inner, rather than

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their external, sense of security. Resilient individuals see themselves as neither omnipotent nor helpless in the face of stress, and they are not ashamed to seek help and use what is offered. In contrast, vulnerable individuals tend to see care-seeking as shameful and anxiety inducing. How these emotions and coping strategies are understood in those with learning disability is largely unknown. Hollins & Sinason (2000) present a review on the development of individuals with learning disability from a psychological/emotional perspective that considers the three areas of trauma for this group: disability, sexuality and death. These will be critical issues in the vulnerability or resilience to traumatic events of people with learning disability.

The risk of developing PTSD is related to a number of factors, including duration of exposure to trauma, personality and early childhood adversity. The occurrence of depression during the months that follow a traumatic event is an important predictor in chronic PTSD (Freedman *et al.*, 1999). Some have suggested that the adult sequelae of childhood trauma may be conceptualised as chronic and 'complex' PTSD (Herman, 1992). Complex PTSD particularly affects the patient's concept of self and is associated with prolonged exposure to trauma (i.e. days, months or years) and interpersonal victimisation, such as prisoner of war experiences and early-life abuse. As will be discussed later, early abuse is a significant factor in the development of PTSD in those with learning disability.

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## Psychopathology

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Post-traumatic stress disorder is similar to but different from other anxiety disorders, particularly in the re-experiencing of traumatic incidents. It is still not clear whether there is a spectrum of post-traumatic reactions nor whether there is a distinct type that follows from repeated traumatisation.

In studies of PTSD in the adult general population, the symptoms most commonly reported were nightmares, a feeling of jumpiness and trouble sleeping (Helzer *et al.*, 1987). In half of those with symptoms, the symptoms lasted less than 6 months, but for one-third the symptoms persisted for over a year. About half of those with any symptoms had experienced only one, and the average was 2.3 for men and 2.5 for women – well below the four required for DSM-IV diagnosis. It is unusual for PTSD to occur in isolation and comorbidity with other psychiatric disorders is the norm.

Chronic PTSD in young people presents with symptoms such as dissociation, self-injurious

behaviours, substance misuse and/or conduct problems that may obscure the post-traumatic origin of the disorder. This indicates the importance of viewing the symptoms of PTSD in the context of the developmental level of the individual and, for those with learning disability, particularly their cognitive and emotional capacity. The presentation of symptoms over a prolonged period may not lead the clinician to consider traumatic events as an aetiological factor.

People with learning disability are at greater risk for psychiatric disorder than the general population (Rutter *et al.*, 1970). Individuals with mild to profound learning disability suffer disorders similar to those affecting the more able population. The main difficulty is diagnosis, as the presentations of disorder may be different in those with severe developmental delay. Therefore, the diagnosis of PTSD in those who do not have the communication skills to describe their thoughts, feelings and mood may be hindered. At times we are reliant on observing changes in behaviour and function, for example, aggression, regressive behaviours and changes in sleep pattern. Owing to the limited recognition of PTSD in people with learning disability these symptoms may be attributed to other psychiatric diagnoses.

In considering the nature of the psychopathology following a traumatic stressor in those with learning disability, it needs to be recognised that neurotic/anxiety disorders and adjustment disorders are still unknown quantities. One study of anxiety disorders (Stavrakaki, 1997) showed the prevailing symptoms to be aggression, agitation, self-injurious behaviour, obsessive fears and insomnia, with specific symptoms of panic attacks, agoraphobia, sexual dysfunction, mood changes, depersonalisation and derealisation. Of 70 patients presenting with these symptoms 63 had experienced one or more of the following events in the past 3–6 months: rape/sexual assault, physical assault, accident, illness, a move, bereavement or change in care. Therefore, it is not unusual for anxiety disorders to be preceded by a traumatic event in those with learning disability. Grief in adults with learning disability is often accompanied by an increase in anxiety symptoms and aberrant behaviours, with an improvement over time, particularly in the anxiety symptoms (Bonell-Pascual *et al.*, 1999).

There has been only one reported major study of adults with learning disability diagnosed to have PTSD (Ryan, 1994). This was of a clinic population of 51 adults and showed that people with learning disability develop PTSD at a rate comparable to the able population when exposed to trauma. Each person had suffered at least two types of trauma. That most frequently experienced was sexual abuse

by multiple perpetrators (commonly starting in childhood), physical abuse or life-threatening neglect committed with some other active abuse or trauma. A few cases did not involve abuse: for example, a sibling dying in a fire, seeing a close friend die during a seizure or an accident or witnessing a parent commit suicide by a gunshot wound to the head. All those cases of trauma involved seeing a carer, friend or close relative die in traumatic circumstances.

Almost all those with PTSD were referred with violent or disruptive behaviour. The most common psychiatric diagnosis prior to the diagnosis of PTSD was no diagnosis or schizophrenia. Other more common diagnoses included autism and intermittent explosive disorder. In about half of the cases someone working with the client knew of the traumatic event. The most common comorbid psychiatric condition diagnosed when PTSD was identified was a major depression.

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## Nature of traumatic events

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In PTSD the stressor must be of an extreme nature, although the clinician has some latitude in determining whether a particular stressor is extreme. Recognised stressors include: war; natural disasters, for example, ferry sinking/road traffic accident; deliberate attack and witness to violence; and physical and sexual abuse. Children and adults with disability are more frequently abused than persons without.

People with learning disability are likely to be found in situations of natural disasters, but none of the studies have identified them as a separate group. As regards war, in developing countries children with disability are usually the ones left behind during the conflict, thus suffering a double trauma.

The other area that needs consideration is the experience of poor and abusive care, which many people with learning disability may have experienced over the years. This is detailed in the Longhirst Inquiry (Buckinghamshire County Council, 1998) and the events that took place on the Greek island of Leros and in the orphanages of Romania (Gath, 1992).

Findings from adult studies suggest that natural disasters produce fewer emotional problems than technological disasters, and that accidents caused by human error have less serious sequelae than those where deliberate actions cause harm. Acts of deliberate violence, particularly physical and sexual abuse, may have the worst outcome. This suggests that those with learning disability may be at risk of

worse outcome if they are diagnosed to have PTSD, as abuse is the commonest aetiological factor in the onset of the disorder.

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## Developmental perspective

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Children and adolescents surviving life-threatening disasters show a wide range of symptoms that tend to cluster around signs of re-experiencing the traumatic event, trying to avoid dealing with the emotions that this gives rise to and a range of signs of increased physiological arousal (Yule, 1992). There is considerable comorbidity with depression, generalised anxiety or pathological grief reactions. The incidence of PTSD in children is around 33% to 50% following a traumatic event. There are very few longitudinal studies that indicate the natural history of PTSD in children and adolescents, but a significant number, 15%, will have symptoms 7 years after a civilian disaster (Yule *et al*, 2000).

Children's level of cognition and language development is absolutely crucial in determining how they will react to a particular traumatic experience. From a developmental aspect, pre-school children show much more regressive behaviour as well as more antisocial, aggressive and destructive behaviour. Young children are able to give graphic accounts of their experiences and to report how distressing the re-experiencing was, in thoughts and images. Practice guidelines of assessment and treatment of children with PTSD are given in a paper by Cohen (1998).

In a clinical population study of 233 children and adolescents with learning disability in the USA, presenting to a clinic over a 1-year period, four (1.5%) were diagnosed to have PTSD; three of these had borderline learning disability and one had mild learning disability (Hardan & Sahl, 1997). That is, the diagnosis was more common in the more able group. Suicidal behaviours, depressive and oppositional disorders were more frequently encountered in those young people with learning disability diagnosed with PTSD than in those found to have other disorders (Hardan & Sahl, 1999).

As can be seen from studies of children without learning disability, the nature of the symptoms presenting in those children with, will be determined by their level of development. People with learning disability will experience traumatic events in keeping with their developmental disability. There is an ongoing debate about the criteria for PTSD in children and adolescents who have suffered traumatic events. There has been an argument for developmental-state-specific diagnostic criteria for

PTSD, since there is some evidence that children of different developmental stages display different PTSD symptom clusters. Field trials are thus needed to evaluate the validity of current PTSD criteria for persons with learning disability at different levels of functioning.

## Assessment

The important point to emphasis is for the clinician to be aware that PTSD should be considered in the diagnosis of a person with learning disability presenting with a wide array of symptoms (Box 1).

If a person is presenting soon after a traumatic event then it may be apparent to the clinician that symptoms of PTSD may be present. However, in the case of those with chronic PTSD related to abuse earlier in life, this may be less obvious and the trauma may not be known to the patient's wider network of contacts. A person with learning disability and good communication skills may be able to talk about 'flashbacks', vivid memories or recurring dreams. Those with mild learning disability may have the autonomy and ability to show avoidance of circumstances resembling or associated with the trauma. This may not be so for those with severe to profound learning disability.

It is clear from what we know that behavioural problems, particularly aggression, are the most common presenting symptoms in those with learning disability, whereas sleep problems, including nightmares and jumpiness are the most common symptoms reported in the able population. If a mood disorder (anxiety or depression) is diagnosed, it needs to be ascertained whether this is comorbid with post-traumatic symptoms.

One of the diagnostic criteria for PTSD is an inability to recall the trauma. This may not be useful in people with learning disability who have less experience of talking about events in their lives and may not necessarily have the communication skills

### Box 1 Assessment of post-traumatic stress disorder

- When did the trauma occur?**
- What is the nature of the trauma?**
- What symptoms has the patient suffered?**
- What support and treatment have been received?**
- Is there a previous history of trauma?**

### Box 2 Presenting symptoms of post-traumatic stress disorder in people with learning disability

- Aggression**
- Disruptive/defiant behaviour**
- Self-harm**
- Agitation/jumpiness**
- Distractability**
- Sleep problems**
- Depressed mood**

to talk about traumatic events. Therefore, what may seem an inability to recall events or details may not in fact be a symptom of PTSD.

The symptoms of increased psychological sensitivity and arousal need to be assessed with knowledge of the individual prior to the trauma. Problems with sleep are common in those with severe learning disability. The symptoms of irritability or outbursts of anger, which can be shown as physical aggression, do seem to be common symptoms in those with learning disability suffering from PTSD. Difficulty in concentrating would probably be recognised by a loss of ability to stay at tasks that had previously been carried out by the individual. Hypervigilance of environment and exaggerated startle response may be difficult to detect, although with close observation of the person one may detect a jumpiness and increased sensitivity to the environment. There may also be a sense of detachment from the environment, which may be evident in relating to carers, and loss of interest in activities previously enjoyed (Box 2).

Even for those with significant social and communication disability, such as people with pervasive developmental disorders, it is possible to assess the impact of abuse (Howlin & Clements, 1995). This was shown in a group of children in a special school for autism who had been subjected to physical and emotional mistreatment, and was achieved by assessing changes in skills, communication and behaviours. The core symptoms of pervasive developmental disorder, i.e. obsessional/stereotyped behaviours, were not affected, but other behavioural difficulties were evident, such as refusal to go to school, self-injurious behaviour, aggressive behaviour, changes in mood, changes in activity level and sleep disturbance. There was no change in their compliance with or enjoyment of activities. Development of relationship problems was assessed as behaviours not previously observed, for example, becoming either overclinging or withdrawn from a social situation.

The following case vignettes illustrate common presentations of PTSD in those with learning disability.

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## Clinical vignettes

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### *Case one*

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A 15-year-old girl with learning disability has suffered early abuse of a physical and sexual nature, including neglect. She presented in early childhood with behavioural problems of aggression. She settled in a residential school from age 12–13 before an act of arson. She later revealed that she had experienced inappropriate sexual behaviours with peers at school. She complained of intrusive thoughts and images, along with depressive symptoms. At times she shows sexually inappropriate behaviour and self-harm.

### *Case two*

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A 40-year-old man with moderate learning disability who had been sexually assaulted by a carer presented in acute state with disturbance of appetite, sleep, loss of skills and emotional numbness, but the abuse was revealed only months later. On being exposed to the perpetrator at a later date he showed a deterioration in mental state with acute symptoms of anxiety, and later developed a depressive disorder requiring medication. His level of functioning never returned to that prior to the traumatic event.

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## Treatment of PTSD

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It is common for people with learning disability not to receive treatment for psychiatric disorders, particularly anxiety disorders, or receive appropriate support during major life events such as bereavement (Bonell-Pascual *et al*, 1999). For people with learning disability treatment interventions are used as in the general population. The approach to the treatment of PTSD historically has been psychological, but more recently consideration has been given to pharmacological interventions.

### *Psychological approaches*

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The common approach with PTSD has been prevention, in the form of psychological debriefing. This is a set of procedures including counselling and the giving of information aimed at preventing

psychological morbidity and aiding recovery after a traumatic event. A recent review (Kenardy, 2000) suggests that there is little evidence to support current debriefing practices and little is known about why debriefing might adversely affect recovery. There is no evidence to support such approaches in those with learning disability. It would seem that a therapeutic approach that is brief, such as debriefing, which may cause harm in the general population, is unlikely to be of benefit in those who need more care and consideration in therapeutic interventions. However, an effective early intervention after a trauma would be most helpful.

Adshead (2000) has recently been reviewed psychological therapies for PTSD. Although some patients with complex or chronic PTSD may require specialist interventions such as in-patient care or highly skilled therapist interviews, most patients can be treated effectively by a specialist mental health service that can offer both pharmacological and psychological interventions. For those with learning disability, cognitive and psychotherapeutic approaches have been established for other disorders and there is no reason for these not to be used in those suffering from PTSD (Esterhuyzen & Hollins, 1997).

Inclusion of parents/supportive others is important for resolution of PTSD symptoms in children. Parental emotional reaction to the traumatic events and parental support of the child are powerful mediators of the children's PTSD symptoms. As people with learning disability are invariably dependent on others for care, then practical education for carers about PTSD would be useful. Also, people with learning disability may have less opportunity to avoid traumatic stressors such as perpetrators or places, so support and guidance on how they may achieve this would be invaluable. Consideration needs to be given to people with learning disability who are witnesses to traumatic events. The Youth Justice and Criminal Evidence Act is more supportive vulnerable witnesses giving evidence in court.

### *Psychopharmacology*

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A systematic review of mainly small randomised controlled trials has found that antidepressants and anxiolytics reduce symptoms more than placebo in those suffering from PTSD. There is insufficient evidence on the effects of antipsychotic drugs or carbamazepine. For those with learning disability with clear evidence of depressive illness the use of an antidepressant from the selective serotonin reuptake inhibitors group, such as fluoxetine, would be indicated, as its efficacy has been proven in the general population (Connor *et al*, 1999).

## Further research

The starting point is good clinical descriptive community studies of people with learning disability, identifying groups who have suffered specific types of traumatic experience, for example, abuse and crime. This will aid clinicians in understanding the nature of psychological symptoms in this group. Second, longitudinal studies are required to clarify the natural history of PTSD in this group, in both child and adult populations. Third, outcome studies of treatment interventions are needed to establish whether people with learning disability respond to treatments as does the general population, and what modifications may be required.

One of the factors that may hinder good research is ways of assessing the impact of traumatic events and symptoms of PTSD in people with learning disability. An interviewer-based assessment, conducted with the person with learning disability and an informant, has become the accepted approach in determining psychopathology in this population. A common example is the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Moss *et al*, 1993). A module of questions about a wide range of life events, a screen for key PTSD symptoms and a detailed interview about all PTSD symptoms are required. This would be the most useful approach for people with learning disability, both young and old.

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## Multiple choice questions

1. People with learning disability:
  - a do not suffer traumatic events
  - b rarely suffer traumatic events
  - c are overdiagnosed as having PTSD
  - d diagnosed with PTSD have commonly experienced sexual assault, which is the precipitating trauma
  - e commonly also have depression.

2. The following are common symptoms of PTSD in those with learning disability:
- aggression
  - self-injurious behaviour
  - agitation
  - sleep disturbance
  - auditory hallucinations.
3. Diagnosis of PTSD in people with learning disability:
- never needs a history of trauma
  - should involve eliciting of mood and cognitive symptoms
  - should observe behaviour
  - should involve carers, who may provide valuable information
  - may be very difficult in those with profound learning disability.
4. Management of PTSD in people with learning disability:
- cannot use psychological treatments
  - always indicates use of antidepressant medication
  - usually involves critical debriefing
  - does not require support to carers
  - should discourage them from being a witness in court.
5. PTSD:
- only occurs in adults with learning disability
  - is more commonly diagnosed in children with mild to borderline learning disability
  - commonly involves suicidal ideas and behaviours
  - cannot be assessed in those with autism/pervasive developmental disorders
  - does not occur comorbidly (e.g. with oppositional defiant disorder).

## MCQ answers

1	2	3	4	5
a F	a T	a F	a F	a F
b F	b T	b T	b F	b T
c F	c T	c T	c F	c T
d T	d T	d T	d F	d F
e T	e F	e T	e F	e F



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**21 June 2001**

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