

## Is Post-Traumatic Stress Disorder a helpful concept for adults with intellectual disability?

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### Abstract

**Background** Research using the concept of Post-Traumatic Stress Disorder (PTSD) with adults with intellectual disability (ID) assumes they perceive and react to traumatic events in a similar way to non-disabled adults. Reactions to trauma displayed by children may be relevant to adults with ID as well.

**Methods** Two focus groups were held with professionals and practitioners to explore the relevance of criteria from child as well as adult literature to adults with ID who experience trauma. Descriptive thematic analysis was carried out.

**Results** Abuse, parental bereavement, and having children removed were considered common sources of trauma. Similarities identified between disabled and non-disabled adults were flashbacks and nightmares; distressed by reminders; avoidance; hypervigilance and increased arousal. Differences were the frequent occurrence of multiple rather than single events, which were considered significant in generating chronic problems similar to those described as PTSD; also the occurrence of physical health problems and behavioural re-enactments.

**Discussion and conclusions** Experienced professionals and practitioners considered most of the ideas from PTSD research with non-disabled adults to be relevant to adults with ID who experience trauma, but that some behaviour reported in research with children was also relevant. Topics and questions for use in clinical and research practice with individuals who have experienced trauma were proposed.

**Keywords** focus groups, Post-Traumatic Stress Disorder, thematic analysis, trauma

Investigations into the way traumatic events affect the lives of adults with intellectual disability (ID) have grown in the past decade. This review summarizes literature accessed by searching Psychinfo, BIDS, Medline, Cochrane Library, and EMBASE from 1985 to 2002. Search words were post-traumatic stress, PTSD, trauma, life events/experiences, abuse (exploded), bereavement, learning disability\*, intellectual disability\*, developmental disability\*, mental retardation, mental handicap, children, adults, assessment, measurement.

Although research has begun to investigate the effects of bereavement (Bonell-Pascual *et al.* 1999), sexual abuse (Sequeira & Hollins 2003) and Post-Traumatic Stress Disorder (PTSD; McCarthy 2001), Hollins & Sinason (2000) argue that symptoms of trauma continue to be under-recognized in practice.

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Harper & Wadsworth (1993) interviewed people with ID and staff concerning bereavement. Intense reactions to bereavement were reported concerning 10–15% respondents. They exhibited breathing difficulties, disorientation, hyperactivity, increased sexual behaviour, suicidal statements, loss of body function and pretending to be dead. McCarthy (2001) and Newman *et al.* (2000) argued for further research to provide a better clinical description of different groups of adults with ID who have experienced traumatic events.

Single case studies described people with ID who demonstrated symptoms of PTSD according to criteria of the third edition of Diagnostic and Statistical Manual of Mental Disorders – Revised (DSM-III-R; APA 1987). These followed physical abuse, sexual assault or road traffic accidents (Hudson & Pilek 1990; Davison *et al.* 1994; McCreary & Thompson 1999): individuals reported flashbacks, intrusive thoughts, nightmares and insomnia. They also avoided reminders, felt more irritable and showed exaggerated startle responses; two were depressed and suicidal. Other cases (Johnson 2001) suggest that some people with ID dissociate. Of a sample of 310 adults with ID seen consecutively in a psychiatric service (Ryan 1994), 17% met DSM-III-R criteria for PTSD.

Are the experiences of adults with ID following trauma adequately represented by research concerning non-disabled adults? While clear biological, cognitive, psychological and emotional differences exist between adults with ID and children, child research may illuminate the way people with communication difficulties experience and express distress.

Childhood trauma was defined as ‘the result of one sudden, external blow or a series of blows, rendering the young person temporarily helpless and breaking past ordinary coping and defensive operations’ (Terr 1991, p. 11). Terr argued that children suffer from psychic trauma if the event was extreme enough and experienced directly. She described four common reactions: visualized or otherwise perceived memories, repetitive behaviours, trauma-specific fears and changed attitudes about people, life and the future. Terr (1988) had previously described two different types of trauma reactions. Type I reactions occur in children who experience unanticipated single events; they have full and detailed memories, ‘omens’, tend to misperceive events, struggle to understand why the

event happened to them and how it could have been averted. By contrast, Type II reactions occur when children have been exposed to trauma repeatedly: they remember in fragments rather than as a whole, experiencing an absence of feeling, a general sense of rage and unremitting sadness. Children similar to Terr’s Type II group were found as small sub-group in Normand *et al.* (1996) study of the effects of parental death on the 10–12-year-olds. The disturbed group felt as if they were dealing with a ghost who might be activated at any time. They disliked visiting the grave, reported never having cried in the year after their death, and generally avoided talking about the deceased. Their main emotions were fear and anger.

Shah & Mudholkar (2000) describe a traumatic event as involving ‘actual or threatened death or serious physical injury to self and others, or loss of self-esteem. The person may have experienced the traumatic event or simply witnessed it and felt intense fear, helplessness or horror’ (p. 99). It is a crucial component of the diagnosis. They use three clusters to describe its clinical presentation in children. Persistent re-experiencing occurs through distressing dreams, repetitively re-enacting the event in play, and feelings of helplessness and guilt. This re-experiencing cluster challenges the common belief that flashbacks are required for PTSD: vivid dissociative flashbacks are uncommon in children (Yule *et al.* 1999). Second, children persistently avoid stimuli associated with the trauma. They may experience a foreshortened sense of the future; a numbing of general responsiveness; and believe they can predict untoward future events (‘omens’). Third, they experience increased arousal: difficulty falling or staying asleep, problems concentrating, hypervigilance and exaggerated startle response. Children with these experiences may lose interest in school work, and withdraw from social activities.

Children experience PTSD symptoms following combat, natural disasters, accidents (Di Gallo *et al.* 1997), domestic violence (Black & Newman 2000), rape and incest (Boney-McCoy & Finkelhor 1995) and sexual abuse (Kiser *et al.* 1988). Children also experience high levels of co-morbidity with other psychiatric disorders including depression, anxiety, and drug and alcohol dependence: the child’s response depends on proximity, gender, age, family support and cultural factors (Pfefferbaum 1997). Children

under three exhibit PTSD-like symptoms (Drell *et al.* 1993). Younger children may develop enuresis or encopresis and separation anxiety; and appear to manifest distress through somatic complaints such as headaches, breathlessness and vertigo. Partial symptomatology for PTSD is common. Pynoos *et al.*'s (1995) model of the aetiology of post-traumatic distress in children combines the experience with subsequent reminders and secondary stresses, in a context of parental and societal expectations, interacting with the child's maturation and emerging personality.

Children's presentation differs to adults mainly through their behaviour, particularly the re-enactment of the event through play. Adults with ID often respond to difficult life events through behaviour such as aggressive outbursts, which suggests hyperarousal (Ghaziuddin 1988). Behavioural reactions shown by children such as somatic complaints (Shah & Mudholkar 2000) also appear relevant to adults with ID (Harper & Wadsworth 1993). Assessment of PTSD in children is through the use of clinical interview and standardized questionnaires. In the clinical interview the child should be asked for a description of what happened to them, and how it affected them: for example what they saw, heard, felt and any thoughts they had (Yule *et al.* 1999). Standardized questionnaires that have been developed to use with children are the Children's Post-Traumatic Stress Reaction Index (Frederick & Pynoos 1988), the Trauma Symptom Checklist for Children (Briere 1996), the Impact of Events Scale – Revised (Dyregrov & Yule 1995) and the Child Report of Post-Traumatic Symptoms (Greenwald & Rubin 1999).

Is traumatic bereavement relevant to PTSD? Around 9% of bereaved individuals without disabilities experience intense and prolonged grief (e.g. Midleton *et al.* 1996). Prigerson *et al.* (1999) distinguish this from PTSD on the grounds that traumatic grief includes loss-related searching and yearning that is not part of PTSD. On the other hand Bonanno & Kaltman (1999, p. 769) describe a continuum of grief reactions that ends with 'the most profound existential concerns about the meaning of life and death'. In similar vein Stoppelbein & Greening (2000) consider parentally bereaved children and adolescents to be at risk of PTSD because their usual sense of invulnerability is shattered. Because PTSD research with adults who have ID is in its infancy, and Clegg &

Lansdall-Welfare (2003) have argued that they are at greater risk of traumatic grief, it seems unwise to exclude bereavement totally from consideration.

Most studies of PTSD in ID have had small samples and represent a wide range of disabilities. There is a need for better clinical description of the way adults with ID react to traumatic life events; establishing what material to gather is necessary for such research. Professionals and practitioners with experience of adults with intellectual disabilities could contribute to such a study through focus groups. Morgan (1997) defined focus group research as a 'technique that collects data through group interaction on a topic determined by the researcher'; they create consensus and enrich understanding of emerging topics.

An investigation was carried out into the way staff from different backgrounds understood responses to trauma observed in adults who have ID.

## Aims

- 1 To test the hypothesis 'some responses to trauma made by children are relevant to an understanding of PTSD in adults with ID'.
- 2 To identify appropriate topics and questions to use when interviewing adults with ID about their experiences of trauma.

## Procedure

### Participants

Presentations about PTSD recruited some participants, others responded to direct invitation. Ten people contributed to 90-min discussions, three in Focus Group 1 (FG1), seven in FG2. A consultant psychiatrist, two clinical psychologists, a trainee clinical psychologist, social worker, community nurse, student nurse, day care officer and two community care officers took part. Participants without professional qualifications had worked with people who have ID for over 10 years; quotations use pseudonyms.

## Methods and materials

Diagnostic criteria of PTSD were sent to participants in advance (APA 1994). Morgan (1998a,b) and Krueger (1998a) guidelines shaped the format of discus-

sion, which was piloted first. Discussions were facilitated by the first author. An assistant managed the audio-recording, took notes, and held a recorded debriefing with the facilitator. Discussions were transcribed verbatim: descriptive thematic analysis was undertaken using guidelines from Krueger (1998b) and Morgan (1997).

## Results

### Traumatic events for adults with intellectual disability

At least one participant reported people who had been distressed by a car accident, a house fire, and burglary. The following events were described by several participants.

#### *Abuse*

Participants from both groups reported the apparent consequences of physical and sexual abuse.

I'm working with a woman who is 42 and she was sexually abused as a child . . . she didn't know what was happening to her until a long time afterwards. (Joyce, FG1)

#### *Death of parents*

Several participants from both groups mentioned particularly distressing bereavements, the person having witnessed the parent dying or found them dead.

His parents died within the space of a few months about 25 years ago. He found one of them dead in the garden . . . it's central to unresolved things. (David, FG1)

#### *Children removed*

Another client's wife had three children taken into care. She was distraught, she's been hospitalised for stress, she's never really come to terms with her loss. (Joyce, FG1)

Elaine and James (FG2) gave similar examples.

### Single vs. multiple life events

There were reports about people who had experienced a single traumatic event, but the majority

described people who had experienced multiple events.

After her mother died . . . her father made her pregnant, the baby was taken away and she had umm, she had a breakdown. (Vicky, FG2)

Participants often found it difficult to determine which event had caused the most distress.

### Similarities to adult Post-Traumatic Stress Disorder

Groups were asked about similarities between the DSM-IV criteria and the way people with intellectual disabilities presented following traumatic events.

#### *Re-experiencing the event*

Both groups gave examples.

Now one was sort of regular continual physical abuse by his father and that has left him with these sort of flashbacks. (Chris, FG2)

She had kind of dreams . . . they were pretty kind of bizarre sort of stuff but there was a sort of theme really of threat and helplessness. (James, FG2)

#### *Avoidance*

Avoiding reminders was commonly reported by both groups:

I've got a couple of people who . . . come up to you and say (whispers) 'stop saying that word' . . . Where there are these kind of key words that then suddenly, if, you know they'll suddenly people will get very distressed at hearing that word. (James, FG2)

#### *Increased arousal*

Both groups described some hyper-vigilant people.

A lady who was raped at knifepoint and she was very, very careful not to look attractive to men in any way and when she'd go on the bus she'd sort of cover her hair and she'd sort of hide . . . So as far as she was concerned everybody was dangerous, so she spent her whole life in terror. (Fiona, FG2)

Some people were reported to search for trauma-related information or experiences.

He scans the news and the teletext for single death related events. (Sheila, FG1)

She had a sort of some kind of behavioural repertoires around children . . . I mean not in a sort of sinister way but trying to kind of gain proximity to children and stuff. (James, FG2)

A few participants from both groups described frequent anger.

Of the people that I have mentioned they're all quite aggressive or assaultative themselves. (Chris, FG2)

#### Differences from DSM-IV criteria for adult Post-Traumatic Stress Disorder

##### *Traumatic events and behavioural reactions*

Most participants described strong behavioural reactions following traumatic events: self-harm, disorganized behaviour, agitation, fear of abandonment, withdrawal, outbursts of distress and ambivalence about relationships.

Somebody else who was sexually abused by her brother, as a consequence of that . . . in her early teens she was basically put into an institution to live . . . [she] has extreme self-harming behaviours umm, which weren't apparently were not there prior to the sexual abuse. (Vicky, FG2)

She used to strip off and became you know highly agitated if she saw children, not all the time actually but if she saw babies in pushchairs and things in town. (Elaine, FG2)

One participant described the way people with ID re-enact what has happened.

They snatch at the props and then they can show you exactly what's happened to them. It's quite dramatic. (Ruth, FG1)

##### *Physical reactions*

Focus Group 1 participants described people whose distress was expressed physically.

The lady who lost most of her hair [after abuse] that's a very physical reaction. (Ruth, FG1)

##### *Duration*

Chronic PTSD on DSM-IV involves symptoms that last more than three months. Both groups commented on long-term distress.

A girl who was in her parents' caravan and they had a masked burglar came in . . . now she is in her forties she still has recurrent nightmares and panic attacks and obviously associates it with that happening. (Chris, FG2)

When you spoke to her although this was actually several years ago it was like she was in the moment. She would become extremely tearful very distressed, umm recalled very vividly the point where decisions were made . . . she was a sort of open wound about it. (James, FG2)

Sometimes disclosure came many years later, both groups agreeing it seemed to follow from people feeling secure:

What she has just started to say, this is like five or six years later, is how awful the relationship was and how abused she was within it.' and 'It is only now that she feels safe and secure and she is remembering things . . . I've seen that happen several times it must really be significant. (Ruth, FG1)

#### The usefulness of Post-Traumatic Stress Disorder as a concept

##### *Appraisal of the event*

Focus Group 2 felt that whether or not people had a concept of death or not probably affected their appraisal of an event as life threatening.

I wondered about people with learning disabilities' understanding of death, and whether that would impact on whether you'd get PTSD or not. Because if you didn't understand what death was and you didn't feel that threat of dying then would that mean you would appraise it in a different way? (Fiona, FG2)

Some questioned whether people would react in different ways according to whether they had experienced a prior traumatic event.

*Helplessness*

This PTSD criterion may not be useful for understanding traumatic reactions in people with ID, because they often feel powerless.

Most people . . . that we work with are you know socialised into a helpless sort of state. (Chris, FG2)

*Appropriateness for non-verbal people*

Focus Group 2 agreed that PTSD was a less helpful concept if people could not verbalise flashbacks or nightmares.

**Discussion**

Limitations to the applicability of findings include the presence of only one psychiatrist, inclusion of care staff whose appreciation of DSM-IV criteria may have been limited and relatively small numbers, especially in the first focus group. Nevertheless, the study benefited from focused interactions between staff with a range of professional and practical experience, who discussed how far diagnostic criteria developed with different clients were relevant to reactions they had observed in adults with ID.

Both the literature review and the focus groups suggest that adults with ID are likely to show reactions to trauma reported for both children and adults with PTSD. Our inclusion of traumatic parental bereavements is debatable, but the argument has been made for its relevance to children. This exploratory study suggests that when some adults with ID see their parent dead or dying it seems to shatter their assumptions about the world, and amplify their sense of vulnerability. Ehlers & Clark (2000) suggested that people who report more overwhelming sensory impressions of an event, and being unable to process it at the time, may suffer from more persistent PTSD. This has clear implications for adults with learning disabilities, whose information processing difficulties probably place them at greater risk of developing PTSD.

The present findings support the contention that it would be premature to exclude distressing bereavements from consideration of trauma in adults with ID. This does have implications for prevalence rates and requires direct research to confirm or disconfirm its relevance. As with children, high rates of co-

morbidity with other psychiatric disorders make differential diagnosis, and comparison between the prevalence rates of disorders in adults with and without learning disabilities, problematic.

Further research would establish empirically whether, and under what circumstances, people with ID experience the overwhelming fear associated with PTSD. Gathering research data from people as they describe their traumatic experiences and reactions requires a format. Recommendations from clinical interviews with children (Yule *et al.* 1999) included asking for a detailed description of what had happened to them, what they saw and how they felt. An interview with adults who have intellectual disabilities could begin with a similar format. The use of prompts has been a successful way of yielding appropriate and extended answers from people with mild to moderate IDs in previous research (Chapman & Oakes 1995; Mattison & Pistrang 2000). Questions in the proposed interview schedule that were similar to items from standardized questionnaires with children (Dyregrov & Yule 1995; Brier 1996; Greenwald & Rubin 1999) included questions about participants' current experiences and how they see the event now. These included: Do you have any pictures in your head about x? What are they? What do you do if thoughts about x pop into your head? Do you have any problems sleeping? Do you have dreams? If yes, what are they about? Do you feel it in your body? Where do you feel it? How do you feel when you think about x? What's it like talking about it now? When x happened what did you think would happen to you?

Proposed interview topics below draw on these topics, using question formats typical to phenomenological research, which investigate both what happened and what meanings the person ascribed to those events. This phenomenological approach provided a frame within which published research could be synthesized with results from focus groups, generating the following questions.

*The event:* Could you tell me about the hardest thing that has ever happened to you? Tell me a bit about what it was like when x happened to you: What do you remember about it? Can you remember what you did? What made you do that? Can you remember what you thought? Can you remember how you felt? What made you feel that way? How many times did it happen to you?

*Getting support or help:* Can you remember who was the first person you told about what had happened to you? What was it like when you told them? What did you want to happen? When did you tell them [Was it the same day it happened, a few days later or a long time later]? If a long time ago – What stopped you from talking about it?

*How they see the event now:* What do you think about x now? What thoughts do you have about it? Have you thought about it in the last week? Where were you? Who were you with? What do you do if thoughts about x pop into your head? Do you have any pictures in your head about x? What are they?

*Current experience:* Do you feel it in your body? Where do you feel it? How is your sleeping? Do you have any problems sleeping? What problems do you have? Do you have any dreams at night? Do you remember any of your dreams? What were they about? How do you feel when you think about x? What do you do when you feel like that? Who notices when you feel that way? How can they tell you are feeling like that? What's it like talking about x now? How do you feel when I ask you these questions?

*Meaning and effects of the event:* When x happened what did you think would happen to you? What made you think that? How has x affected your life? How has your life changed since x happened to you? Have you noticed any changes in yourself? Have you noticed any changes in other people? If your mum or husband/wife were in the room what would they say? Has x stopped you doing anything? What did it stop you doing? Has it changed your relationship with your family? In what ways? Has it changed your relationship with your partner? In what ways?

*Closing the interview:* Out of all the things you have said, what is the most important thing for me to know?

## Conclusions

This exploratory study suggests that PTSD is a helpful concept for adults with ID, if responses to trauma described in children are included. Topics and questions were proposed to support further research, which among other issues may inform debate about the appropriateness of including significant bereavements. The questions may help clinicians to enable

their clients to comprehend traumatic experiences more easily.

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