Exploring the meaning of traumatic life events for adults with learning disabilities

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Anna Mitchell

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ADDENDUM

Transcripts from the focus groups and individual interviews

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by Anna Mitchell

Background: There has been a lack of research investigating the concept of post traumatic stress disorder (PTSD) with adults with learning disabilities. Previous research investigating the concept of PTSD assumed that adults with learning disabilities would react to traumatic events in a similar way to adults without learning disabilities. A review of current literature investigating children's reactions to trauma challenged this assumption.

Methodology: A two-stage study was chosen using a qualitative methodology. In the pilot study two focus groups were held for staff members working with adults with learning disabilities to talk about their experiences of working with people who had experienced traumatic events. The findings from the pilot study informed the remainder of the study. In the main study semi-structured interviews were used to interview six adults with mild learning disabilities about their experiences of trauma. The transcripts were analysed using an Interpretative Phenomenological Analysis (IPA) methodology. A quantitative measure, the Posttraumatic Diagnostic Scale, was used in conjunction with the individual interviews.

Results: An organising conceptual principle, whether individuals perceived the world to be a dangerous or a safe place organised the themes into a coherent framework. Five main themes emerged from the data which were labelled: The impact of the trauma, I avoid things that remind me of the trauma, I am prepared for danger in the future, the tension of talking or not talking and the struggle of who to blame.

Discussion: The results were related to previous theoretical frameworks and the methodological limitations of the research acknowledged. The clinical implications of the findings for disclosure, assessment and therapeutic intervention were discussed.

Introduction

Over the past decade there has been a growing interest in the effect of traumatic events upon the lives of adults with learning disabilities. Research has begun to investigate the effects of bereavement (Bonell-Pascual et al., 1999; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997) and sexual abuse (Fenwick, 1994; Mansell, Sobsey & Moskal, 1998; Strickler, 2001) upon the lives of adults with learning disabilities. There has been a limited amount of research that has explored the concept of PTSD in relation to people with learning disabilities (see reviews by McCarthy, 2001; Newman, Christopher & Berry, 2000). McCarthy (2001) stated that one of the reasons for this was that PTSD had only been recognised as a concept in the last 25 years. At present it has been assumed that adults with learning disabilities show post-traumatic stress reactions to traumatic events that are similar to adults without learning disabilities e.g. Royal College of Psychiatrists (as cited in McCarthy, 2001).

This literature review begins by providing a brief overview of the current state of knowledge in relation to the presentation of the phenomenon of PTSD in adults. The main focus of this section is a review of the literature about the reaction of children to traumatic events and the reaction of individuals with learning disabilities to traumatic events. The implications of the research undertaken with children for future research with individuals with learning disabilities are then discussed and the methodological limitations of previous research outlined.

Previous research suggests that it is likely that there are many adults with learning disabilities living in the community who have mental health problems that have not been recognised (Prosser, 1999). There are a number of reasons for this including reliance on information from third parties, difficulties in differentiating challenging behaviour from underlying mental health problems and assumptions about a person's difficulties being

related to their learning disability (see review by Prosser, 1999). One further explanation is that people have not wanted to acknowledge that adults with learning disabilities might be suffering as the result of trauma (McCarthy, 2001).

This literature review focuses on children's responses to traumatic events rather than those of adults to provide evidence to challenge the assumption that adults with learning disabilities show post-traumatic stress reactions to trauma that are similar to adults in the non-disabled population. It will be argued that there is a need for further research into how individuals with learning disabilities respond to traumatic life events. This review does not seek to present adults with learning disabilities and children as the same, inferring that they will present in similar ways following traumatic life events. There is an acknowledgement that there are many differences between adults with learning disabilities and children including biological, cognitive, psychological and emotional differences depending on each individual's genetic makeup and their life experience. However, there may be important insights and analogies that can be learned about how individuals communicate distress, if they have difficulties in verbally communicating and expressing themselves. Since this has also been a relatively recent area of research in relation to children, it was also considered that important lessons could be learned from the methodology that was used to assess for the presentation of the concept of PTSD in children.

The presentation of the concept of PTSD in adults

The concept of post traumatic stress disorder (PTSD) arises from an understanding that people will respond in a similar way to a variety of traumatic experiences. It was recognised that after a particularly stressful event some people developed symptoms of intrusive re-experiencing of the trauma, avoidance behaviours associated with reminders of

the trauma and increased physiological arousal as a result of the trauma (Yule, Williams & Joseph, 1999). Kudler (2000) gave the definition that PTSD "begins with an external event that is psychologically perceived and transduced into psychological, biological and social manifestations" (p 9). For the current criteria for the concept of PTSD in adults according to DSM-IV (American Psychiatric Association, 1994) see Appendix no. 1.

The prevalence of the diagnosis of PTSD from surveys of the general adult population ranges from 1% to 12% and can be as high as 30% in at risk groups e.g. Vietnam veterans (see review by Fairbank, Schlenger, Saigh & Davidson, 1995). Co-morbidity with other psychiatric illnesses such as depression, substance abuse and anxiety disorders is common. Identified risk factors for developing PTSD include: psychiatric illness in the family; parental poverty; childhood trauma and adverse life events before and after the trauma (see review by Fairbank et al.,1995).

Joseph, Williams & Yule (1997) stated in their review of normal and abnormal reactions to trauma that "the subject of what constitutes a traumatic event has proved to be a definitional quagmire" (p14). See appendix no. 1 for the current definition used by DSM-IV. There has been a recent debate about whether events that may not be outside the range of usual human experience e.g. the death of a spouse through cancer also fulfil the criteria for PTSD (see review by Joseph, Williams & Yule, 1997).

A number of different theoretical models have been developed recently to explain the different conceptual features of PTSD (e.g. Brewin, 2001; Ehlers & Clark, 2000). Cognitive theories argue that the phenomenon of PTSD arises from individual's attempts to integrate trauma related information into existing beliefs about the world (see review by Dagleish, 1999). The researcher adopted a cognitive framework for this research to investigate the impact and meaning of traumatic life events for adults with learning disabilities.

The presentation of the concept of PTSD in children

In the initial presentation of the concept of PTSD in DSM-III (American Psychiatric Association, 1980) there was no specific mention of the presentation of PTSD in children. This was addressed in the first revision of the criteria in DSM-III-R (American Psychiatric Association, 1987). Since that time following further research there has been another revision of the criteria for PTSD in DSM-IV (American Psychiatric Association, 1994). Recent reviews of the literature by Shah & Mudholkar (2000) and Pfefferbaum (1997) have described the clinical presentation of PTSD in children following a traumatic event. Shah and Mudholkar (2000) used the definition from DSM-IV (American Psychiatric Association, 1994). Pfefferbaum (1997) reviews the literature over the previous ten years, which has used different criteria to define the concept of PTSD.

General clinical presentation

Shah & Mudholkar (2000) and Pfefferbaum (1997) describe the clinical presentation of PTSD in children in three main clusters. Firstly, the persistent re-experiencing of the traumatic event may be observed through distressing dreams relating to the event or generalised nightmares. Vivid dissociative flashbacks are uncommon in children (Yule, Perrin & Smith, 1999). Repetitive play re-enacting the traumatic event is frequently reported, with children describing recurrent images and associated feelings of helplessness and guilt. Secondly, children persistently avoid stimuli associated with the trauma including conversations and thoughts about the traumatic event and experience a numbing of general responsiveness. Children may experience a foreshortened sense of the future and have "omen formation", belief in the ability to see untoward future events. Thirdly, the children persistently experience symptoms of increased arousal including difficulties in falling or staying asleep, problems concentrating, hypervigilance and

exaggerated startle response. Children experiencing these symptoms may lose interest in their work at school, they may withdraw from participating in group activities and games and their peer relationships may be affected. These clinical features can develop immediately or within a short space of time following exposure to an event or may develop years later. Most of these symptoms are similar to Criteria B, C and D for adults described in DSM-IV (American Psychiatric Association, 1994). The criteria for PTSD are met if the duration of the symptoms in criteria B, C, and D is more than one month.

Children's presentation differs from adults mainly through their behaviour and particularly the re-enactment of the traumatic event though play. This seems to suggest that children may not need language skills to be able to express what they have experienced but can verbally comment on the traumatic event through play. Children experience high levels of co-morbidity with other psychiatric disorders including ADHD, conduct disorder, depression and drug and alcohol problems. Children have been shown to experience PTSD symptoms like those described above following a number of different types of events including war (Shalev, Yehuda, & McFarlane, 2000), natural disasters (Galante & Foa, 1986; Pynoos et al.,1993), accidents (Di Gallo, Barton & Parry-Jones, 1997), domestic violence (Black & Newman, 2000), rape and incest (Boney-McCoy & Finkelhor, 1995) and sexual abuse (Kiser et al., 1988). Researchers have found that a child's response to a traumatic event and their coping response to it will depend on a number of factors including proximity to the event, both physically and emotionally, gender, age, family support, and cultural factors (see review by Pfefferbaum, 1997). Partial symptomatology is also common and sometimes symptoms that would fulfil the diagnostic criteria for the concept of PTSD do not develop until years later.

Methodological Problems. A methodological difficulty in the quantitative research described above is how representative the samples were of children who had experienced

similar types of events. Research that has explored the effects of natural disasters has screened large samples of children. However, research screening for PTSD following other traumatic events e.g. accidents or sexual abuse has involved smaller samples. This may be a reflection of the fact that it is easier to access particular populations following specific types of trauma as opposed to others.

The concept of PTSD across the age range

Children and adolescents may show a variety of associated symptoms to those described above. Drell, Siegel & Gaensbauer (1993) have reviewed the effects of traumatic life events upon children who are under the age of three years old. Case study evidence would suggest that children under the age of three exhibit symptoms that are similar to those described by the criteria for PTSD (Drell et al., 1993). Scheeringa, Zeanah, Drell & Larrieu (1995) proposed an alternative set of criteria for diagnosing PTSD in children younger than four years of age, which used more objective behavioural criteria.

Children have presented with associated symptoms to those described earlier. Younger children may develop enuresis or encopresis and can present with symptoms of separation anxiety. Adolescent survivors have reported high rates of depression, suicidal ideation and suicidal attempts (Yule, Perrin, et al., 1999). They may also become irritable, have anger outbursts and destructive behaviour. Children also appear to manifest their distress through somatic complaints including headaches, breathlessness and vertigo. It may be that as children are more physiologically aroused and may have limited verbal communication their distress manifests itself through their physical symptoms. The literature suggests that PTSD is not one phenomenon across the age range and that children will present in different ways depending on their developmental stage. Pynoos, Steinberg & Wraith (1995) have described a developmental model of childhood traumatic stress. It is

a tripartite model of the etiology of post-traumatic distress incorporating the nature of the traumatic experience and subsequent traumatic reminders and secondary stresses. The model recognises the role of the environment including parental and societal expectations and the emerging personality of the child and their own psychological and physiological maturation. This model explains the differences in the presentation of children across the age range from very young children to adolescents.

Methodological problems. In the research conducted by Scheeringa et al. (1995) the percentage of agreement across the items ranged between 50% and 100%, which suggests that the people rating the different items did not show a consistently high level of agreement across all of the items. There is also a need for longitudinal studies to be undertaken that will assess the impact of the traumatic events over time and throughout the development of children from infants to adolescents.

The nature of the traumatic event

Terr carried out a lot of the early work into children's responses to trauma. She used a broader definition to that described by DSM-IV (American Psychiatric Association, 1994). Terr (1991) defined childhood trauma 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" (p.11). This definition included events that were sudden and a shock to the individual as well as events that were prolonged and anticipated like childhood sexual abuse. In her opinion children suffered from psychic trauma if the traumatic event was extreme enough and directly experienced by the child. This would be irrespective of the child's developmental, psychiatric and medical history, their parental relationships, the relationships of their parents to the community, their past psychic trauma and stressful events inside the family (Terr, 1991).

Terr divided childhood traumas into two basic types, Type I was a trauma resulting from unanticipated single events and Type II were disorders following exposure to repeated traumatic events. Terr described four characteristics of the children's presentation irrespective of which type of trauma they had experienced. They included visualised or otherwise perceived memories, repetitive behaviours, trauma-specific fears and changed attitudes about people, and aspects of life and the future. She believed that there were differences in the presentation of children who had experienced Type I and Type II traumas. Children who had experienced Type I trauma, a single traumatic event, were described as having full, detailed memories, "omens" or cognitive re-appraisals and mis-perceptions or mis-timings. Children who experienced single traumatic events were also able to give detailed descriptions of their experiences whereas children who had experienced multiple events appeared to have remembered in fragments rather than as a whole (Terr, 1988). Children who experienced single traumatic events attempted to find meaning about why the event happened to them or how the event could have been averted.

Children who fell into the Type II category experienced an absence of feeling, a sense of rage and unremitting sadness in addition to the four characteristics described earlier. These characteristics are similar to some of the features described by DSM-IV (American Psychiatric Association, 1994) of feelings of numbing of general responsiveness, detachment or estrangement from others, irritability or outbursts of anger, and restricted range of affect. Coping mechanisms the children used were denial, repression, dissociation, self-hypnosis and aggression against themselves. Research by Kiser et al. (1988) has supported the descriptions used by Terr (1991) for the presentation of children following repeated traumatic events, Type II trauma. At present there is some empirical evidence to support Terr's Type II distinction and it remains a hypothesis that requires further testing.

Methodological problems. These descriptions of the way children present following traumatic life events are based on three studies: a study of the Chowilla kidnapping (Terr, 1983); a study of 20 pre-schoolers (Terr, 1988); and a study of children and adolescent's responses to the Challenger space shuttle explosion (Terr, 1990 as cited in Terr 1991). Case material from 150 children who have experienced a variety of traumatic events also forms the basis of her observations. Since the three studies she carried out were retrospective assumptions were made about the link between the presentation of the children, and the traumatic event or events that they had experienced.

Terr assumes that the children only experienced the single traumatic event or repeated traumatic events that she identified and used to classify the children. It is possible that other events have occurred in the children's life since the initial traumatic event(s) that may have produced long-term effects. The research undertaken by Terr (1988) had a range between 5 months and 12 years between the event occurring and an evaluation being carried out. The presentation of the children may have changed over time and this was not accounted for in the descriptions of the children's reactions to trauma. Overall this research used a broader definition for what should constitute a traumatic event and this raises the question of whether the definition used by DSM-IV is appropriate and valid.

Assessment

Clinical interview is the main method of assessing traumatic reaction in children and this normally involves interviews with the parents and the child (see review by Yule, Perrin, et al., 1999). The interview with the parent covers the family history, the child's developmental history prior to the traumatic event(s) and the parents' perceptions about how the child has changed since experiencing the traumatic event. A detailed description of the trauma is given where possible.

A commonly held view is that parents often under-report the severity and extent of children's reactions (Yule, Perrin, et al., 1999). Reasons why this may occur are children not telling their parents what they are experiencing due to a desire to protect them or a wish to avoid talking about it. Parents may also wish to deny the extent to which children have been affected by traumatic events. It is only in recent years that children have been interviewed about their experiences. During the child's interview the child is usually asked about what they saw, what they thought about during the event and how they felt. Greenwald & Rubin (1999) reviewed the specific assessment tools that have been developed to assess the concept of PTSD in children. Other assessment methods that are used with children are to let the child draw something in relation to the event and to talk to the therapist about it (Eth & Pynoos, 1985).

Methodological problems. Semi-structured interview measures have been developed directly from the criteria for the concept of PTSD used with adults in DSM-IV (American Psychiatric Association, 1994). Since some of the criteria for PTSD used with adults do not fully reflect the post-traumatic stress reaction of children, there is a question of how valid these interview measures are to assess the responses of children to trauma.

Prevalence

At present research exploring the prevalence of PTSD among children in the community has not been undertaken. Several studies have looked at the prevalence of PTSD in at risk groups e.g. children exposed to war, sexual abuse, violent crime, and natural disaster. Prevalence rates in "at risk" children have varied widely from 0 to 100% of children developing PTSD following a traumatic event (Yule, Perrin, et al., 1999). There have been very few longitudinal studies that have demonstrated how the phenomenon of PTSD might change over time. One study by Yule, Bolton, Udwin, Boyle, O'Ryan, &

Nurrish (2000) found that 15% of children and adolescents had symptoms of PTSD 7 years after a civilian disaster.

Methodological problems. Among the methodological difficulties in estimating the prevalence rates of PTSD amongst children, have been differences in prevalence rates depending on which criteria for PTSD were used e.g. which DSM manual and the validity and reliability of screening instruments (Galante & Foa, 1986).

Summary

The research evidence suggests that children present in some similar ways to adults following trauma. There were also some differences that were described including re-enacting the trauma through behaviour, physical health problems and separation anxiety. The research also indicated that the phenomenon of PTSD is more complex than currently described by the criteria for PTSD in DSM-IV (American Psychiatric Association, 1994). Research by Terr identified different reactions from children who had experienced single events in comparison to children who had experienced multiple events, highlighting the importance of further research in this area.

The presentation of the concept of PTSD in individuals with learning disabilities
General clinical presentation

At present traumatic symptoms are significantly under-recognised in adults with learning disabilities (Hollins & Sinason, 2000). There has only been a limited amount of research that has explored the concept of PTSD in relation to individuals with learning disabilities (see reviews by McCarthy, 2001; Newman et al., 2000). There have been a number of single case studies that have described individuals with learning disabilities suffering a traumatic life event and demonstrating symptoms of PTSD using the criteria

from DSM-III-R (Cook, Kieffer, Charak &Leventhal, 1993; Davison, Clare, Georgiades, Divall & Holland, 1994; Hudson & Pilek, 1990; McCreary & Thompson, 1999). The traumatic life events described in the case studies were physical abuse, sexual assault and a motor vehicle accident. Individuals reported having flashbacks, intrusive thoughts, nightmares and insomnia. They also avoided reminders of the traumatic event, felt more irritable and angry than usual and showed exaggerated startle responses. In addition to these symptoms two of the individuals had depressive symptoms and had expressed suicidal ideation (Davison et al., 1994, McCreary & Thompson, 1999). Other case study evidence suggests that individuals with learning disabilities may also show signs of dissociation following traumatic events (Johnson, 2001).

Prevalence

There have been three studies that have looked at the prevalence of PTSD in individuals with learning disabilities in clinical populations. Ryan (1994) found 51 out of a sample of 310 consecutive adults referred to a psychiatric service met the DSMIII-R criteria for PTSD (American Psychiatric Association, 1987). The method of data collection involved psychiatric interviews with the client and people who knew the client well. Nearly all of those referred had suffered significant abuse or trauma, which suggests approximately 16.5% of adults with developmental disabilities in the sample suffered severe trauma and developed PTSD. Each adult had suffered at least two types of trauma. The trauma most frequently experienced was sexual abuse, physical abuse or life threatening neglect combined with other forms of abuse. Other types of trauma were included in the sample, for example seeing family members or close friends dying.

Firth et al. (2001) retrospectively reviewed case material from 43 children and adolescents with intellectual disabilities who were patients in a regional psychiatric

service. All of the participants had been involved with sexual abuse either as victims, perpetrators or both. Only one of the participants fulfilled the criteria according to DSM-IV for PTSD (American Psychiatric Association, 1994). There were a small number of victims and perpetrators who demonstrated post-traumatic symtomatology that did not fulfil the criteria for PTSD used by DSM-IV (American Psychiatric Association, 1994).

Hardan & Sahl (1997) retrospectively reviewed the medical charts of 233 children and adolescents with mental retardation and /or developmental disabilities presenting to a clinic over 12 months. Four participants were found to have a diagnosis of PTSD according to DSM-IIIR (American Psychiatric Association, 1987), who also had a diagnosis of either borderline or mild mental retardation.

Methodological problems. The research by Ryan (1994) was carried out with adults with developmental disabilities. Developmental disabilities has been defined as "severe, chronic disabilities that are attributable to a mental or physical impairment or a combination of mental or physical impairments" (Newman et al., 2000, p. 155). In the research conducted by Ryan (1994) developmental disability was not defined. Although she described the average range of mental retardation in her sample as moderate, it is possible that her sample may have included people who only had a physical impairment rather than a learning disability.

The studies undertaken by Firth et al. (2001) and Hardan & Sahl (1997) used case material and medical charts to screen for the diagnosis of PTSD. This could have underestimated the prevalence of the diagnosis of PTSD as the methodology has a number of potential problems. The reliability of the symptoms that were observed by those writing the case material or medical charts could be in question. The case material could have been affected by the reporting patterns of clinicians (Balogh et al., 2001). Appropriate questions identifying symptoms of PTSD may not have been asked in the clinical interview on which

the charts or case material was based. Features of the concept of PTSD for example avoidance, may have prevented the children from disclosing symptoms to clinicians. The diagnosis of PTSD was identified in children and adolescents who had milder learning disabilities. This may be due to the difficulty of using the current diagnostic concept of PTSD with children with moderate to severe learning disabilities. Another methodological limitation was that in the study undertaken by Balogh et al. (2001) participants were only included where it was suspected that they had been sexually abused. Due to difficulties in disclosure and under-reporting there may have been other patients in the psychiatric service who should have been included in the study.

The relationship between life events and behavioural difficulties

There have been several studies that have explored the relationship between life events, behavioural difficulties and psychiatric referral in the lives of adults with learning disabilities (Ghaziuddin, 1988; Monaghan & Soni, 1992; Stack, Haldipur & Thompson, 1987). Half of the adults with learning disabilities who were referred to psychiatric services were found to have experienced a life event in the 12 months prior to psychiatric referral (Ghaziuddin, 1988). Some of the types of life events that were described were family relationship problems, bereavement and illness in the family, and transition issues e.g. leaving school or starting a new relationship. Stack et al. (1987) also found that admissions to a psychiatric hospital were precipitated more frequently for people with learning disabilities by life events, involving conflicts or losses in comparison to a control group of adults in the non-disabled population. Referral to psychiatric services was linked to behavioural difficulties including aggressive outbursts, destructiveness, screaming, refusing to attend a day centre and sexually disinhibited behaviour (Ghaziuddin, 1988; Stack et al., 1987). Ghaziuddin (1988) found that adults with a diagnosis of mild mental

retardation who were referred due to difficult behaviour, were more likely to have a life event in the preceding 12 months than adults with more severe learning disabilities similarly referred.

Monaghan & Soni (1992) investigated the effects of significant life events on the behaviour of people with learning disabilities living in the community. An increase in the life events score, using the social readjustment scale (Holmes & Rahe, 1967 as cited in Monaghan & Soni, 1992), over a period of 6 months was shown to produce a significant deterioration in self care and behavioural difficulties. Some of the behavioural difficulties reported were physical aggression, destructiveness, self-injury and screaming/shouting. Adults with learning disabilities were only included if they lived at home with their family.

Methodological problems. The studies undertaken by Ghaziuddin (1988) and Stack et al. (1987) were retrospective studies trying to identify life events in the lives of adults with learning disabilities who had already been referred to particular services. Further research needs to be undertaken that is prospective and uses controlled groups that will compare the behaviour of adults with learning disabilities who are experiencing life events, with those who haven't experienced life events.

The nature of the traumatic event

Hollins & Sinason (2000) have identified disability, death and sexuality as traumatic experiences for people with learning disabilities. Research has explored the effects of bereavement and grief as a life event (Bonell-Pascual et al., 1999; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997). Harper & Wadsworth (1993) interviewed people with learning disabilities and staff and found that people with learning disabilities display a range of grief reactions similar to people without learning disabilities. Reported grief reactions included headaches, breathing difficulties, loss of body function,

disorientation, hyperactivity, suicidal statements, increase in sexual behaviour and pretending to be dead. In a controlled study Hollins & Esterhuyzen (1997) found that people with learning disabilities who were bereaved showed significant increases in irritability, lethargy, inappropriate speech and hyperactivity.

As previously stated, it has only been in the last decade that there has been an acknowledgement that some people with learning disabilities are the victims of sexual abuse (Beail & Warden, 1995; Fenwick, 1994; Moss, 1998; Turk & Brown, 1993). Research by Sobsey, Randall & Parilla (as cited in Strickler, 2001) suggests that individuals with disabilities are more likely to be abused than individuals without disabilities. However, a recent review of the literature (Newman et al., 2000) concluded that there was insufficient evidence to conclude that children with developmental disabilities were at greater risk of abuse and neglect than children who did not have developmental disabilities. Factors that may influence the risk of abuse are attachment difficulties, parental stress, gender, social isolation and dependency (see recent review by Strickler, 2001). Sobsey (1994) proposed an integrated ecological model of abuse for adults with developmental disabilities. Factors identified in the model that increased the vulnerability to abuse were limited skills, learned helplessness and dependency. Sobsey (1994) defined learned helplessness as "the belief that one's actions have no influence on future outcomes or as a generalized lack of responding after previous attempts to exert control fail" (p. 164).

There has been some research undertaken exploring the effects of sexual abuse on the lives of people with learning disabilities (Fenwick, 1994; Mansell et al., 1998; Moss, 1998; Strickler, 2001). Research has found that children with developmental disabilities show similar psychological and behavioural reactions to children without developmental disabilities who have been sexually abused (Mansell, et al., 1998). There is also evidence

that adults with learning disabilities show emotional and behavioural responses to abuse (Beail & Warden, 1995; Davison et al., 1994; McCreary & Thompson, 1999).

Methodological problems. One of the methodological problems with this type of research is the difficulty of trying to link changes in people's behaviour to a specific life event. It is difficult to establish whether behavioural reactions are the result of one particular life event or whether changes in behaviour were the result of a combination of life events e.g. moving house following bereavement. The quantitative studies described above have small sample sizes so the claim that they are representative of people with learning disabilities is questionable. There is a wide range of abilities from mild to severe learning disabilities so it is very difficult for quantitative studies to represent the range of learning disabilities. Another methodological limitation is that studies rely on information that was gathered from case material, staff members or primary carers.

Assessment

Nadarajah, Roy, Harris & Corbett (1995) reviewed the different life event schedules that have been used in life event research with people with learning disabilities. They discuss the advantages of using a semi-structured interview approach to gain valuable information from people with learning disabilities and their carers. No screening tool exists for the identification of the concept of PTSD, for specific use with individuals with learning disabilities.

Methodological problems. The review undertaken by Nadarajah et al. (1995) identified a lack of reliable measures to use in the assessment of life events. Research has focused on measuring behavioural change. There has been a lack of qualitative research that has asked people with learning disabilities about the effect of the life events on their lives.

Summary

Previous research undertaken with individuals with learning disabilities has suggested that they may respond to traumatic life events in ways similar to the concept of PTSD described by DSM-III-R. Research has also found that adults with learning disabilities present with behavioural problems following traumatic life events. Common methodological problems with research with individuals with learning disabilities have been the definition of developmental disability, using retrospective studies to link behaviour to specific life events, adequacy of sampling different levels of learning disability and reliance on carers and staff for information.

Implications from the research with children for future research with individuals with learning disabilities

General Clinical Presentation

There is case study evidence (Davison et al., 1994; Hudson & Pilek, 1990; McCreary & Thompson, 1999) to suggest that adults with learning disabilities may present in similar ways to the adult presentation of PTSD in DSM-IV (American Psychiatric Association, 1994). However, there is evidence from the literature that adults with learning disabilities may respond in some similar ways to children following traumatic life events. Studies exploring the reaction of adults with learning disabilities to bereavement and other life events suggest that one of the ways they respond to difficult life events is through their behaviour e.g. aggressive outbursts, lack of self care and self injury (Bonell-Pascual et al., 1999; Ghaziuddin, 1988; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Monaghan & Soni, 1992; Stack et al., 1987). Children also present with behavioural responses following traumatic life events including re-enactment of the trauma through play, irritability, anger outbursts and withdrawal (Pfefferbaum, 1997; Shah & Mudholkar,

2000; Terr, 1991). Therefore the assumption that adults with learning disabilities will react to traumatic events in the same way as adults without learning disabilities appears questionable.

Evidence from the literature about the presentation of children following traumatic life events also suggests that the concept of PTSD is not a fixed or static concept across the age range. It appears to vary across ages and depends on the level of cognitive, emotional and language development of the child. There is evidence that younger children who cannot communicate their distress verbally show their reactions to traumatic events through their behaviour. In a similar way adults with severe learning disabilities will have more difficulties communicating their needs verbally and may present their distress in different ways to adults with milder learning difficulties. Although the term adults with learning disabilities is used in research there is a wide variation in the range of learning disability included, from mild to severe or profound. The subjectivity of the criteria used by DSM-IV (American Psychiatric Association, 1994) makes it difficult to use these criteria with children who may not be able to give a verbal account of their experiences and therefore using these criteria to assess adults with learning disabilities may also be inappropriate. Future research is needed to give detailed clinical descriptions of the reactions of adults with mild learning disabilities and adults with more severe learning disabilities to traumatic life events.

Methodological problems.   There are a number of methodological problems that have been identified in research exploring the effects of life events with children and with individuals with learning disabilities. Retrospective quantitative studies that have explored the relationship between the behavioural reaction of children and adults and different types of traumatic events have had difficulties in determining which events evoked the specific

behavioural reactions. The measures that have been used to assess reaction to traumatic events have been adapted from measures that are used with adults in the non-disabled population and may not include appropriate criteria for children or individuals with learning disabilities. Also both types of research have predominantly relied on gaining information from third parties or case material, which lead to problems with under-reporting and reliability.

The nature of the traumatic event

Research exploring the presentation of PTSD in children raises the importance of the type of traumatic event that the person experiences and suggests that the type of traumatic event may have an effect upon the presentation of individuals (Terr, 1991). At present no distinction is made in the criteria for PTSD in DSM-IV (American Psychiatric Association, 1994), whether a person has experienced one traumatic event or several repeated events. It is assumed that children and adults will react in similar ways to traumatic events irrespective of the event and how many times it occurs. Work by Sinason (1992) has discussed the number of possible traumas and losses that have been experienced by children and adults with learning disabilities e.g. being born with a learning disability, institutionalisation. Potentially this could be an important difference from children in the non-disabled population who may have experienced fewer losses in their lives. Future research that is undertaken with adults with learning disabilities should identify the traumatic events the person has experienced.

There are some authors who would argue that the definition for a traumatic event is too narrow and does not account for how individuals interpret an event (Yule, Williams, et al., 1999). Evidence from the model developed by Ehlers & Clark (2000) highlights the importance of the individual's appraisal of the event. It is suggested that individuals who develop persistent PTSD are unable to see the trauma as a time limited event and that they

appraise the event as having a current threat either to their external world or their internal well-being. There is also evidence to suggest that people who report more overwhelming sensory impressions of an event and are unable to process it at the time may suffer from more persistent PTSD (Ehlers & Clark, 2000). This has clear implications for adults with learning disabilities who may have more difficulties in processing information in general (Clements, 1998) and therefore may be at more risk for developing PTSD. This model highlights the important question of what is a traumatic event for an adult with a learning disability. It may more appropriate to use a different definition to the one used by current criteria for the concept of PTSD (American Psychiatric Association, 1994) that takes account of the subjective experience of individuals with a learning disability. Further research is needed that defines what is a traumatic event for someone with a learning disability. Even if the definition used by DSM-IV (American Psychiatric Association, 1994) was used in future research then it may be that events like bereavement fulfil the criteria for adults with learning disabilities as they may elicit feelings of fear and helplessness.

Conclusions

The literature suggests that adults with learning disabilities may present with symptoms of that are similar to the concept of PTSD, however, it also suggested that this presentation is more complex than the current concept of PTSD, in DSM-IV (American Psychiatric Association, 1994). The presentation of PTSD in adults with learning disabilities will vary according to a number of factors including the level of a person's learning disability, their appraisal of the event and whether they have experienced repeated events. The research exploring the presentation of PTSD in children challenges the assumption that adults with learning disabilities will react in the same way to traumatic life

events as adults in the general population. This perception is also being challenged in other population groups for example, older adults (Weintraub & Ruskin, 1999).

Rationale for this research

Research is needed to explore the phenomenon of PTSD in the lives of adults with learning disabilities. The researcher identified two different possible types of studies. The first type of study was a quantitative study that used information from carers to look at cognitive and behavioural changes following trauma in a representative sample of people with learning disabilities. The second type of study involved interviewing a group of people with mild learning disabilities about the effect and meaning of traumatic events upon their lives. There were a number of methodological difficulties associated with the first study identified in research with children. There was an acknowledgement that it may be difficult to retrospectively try and link changes in behaviour to specific life events. Also the reliance on carers and staff in studies that involve children lead to the under-reporting of the severity and extent of children's reactions. It is only in recent years that children have been interviewed about their experiences of trauma. Therefore, the researcher chose to undertake the second study that involved interviewing people with learning disabilities about their experiences of trauma.

The review of the literature in this area has identified the need for an exploratory study to provide a better clinical description of the presentation of adults with learning disabilities following traumatic life events. McCarthy (2001) and Newman et al. (2000) argued for further research to provide a better clinical description of different groups of adults with learning disabilities who have experienced particular types of traumatic events. Another gap that was identified was the need for research to consider the relationship

between the appraisal of an event by an individual and their response to it (Ehlers & Clark, 2000).

Therefore the researcher decided to employ a qualitative methodology for this research, which incorporated a two-stage study. The first stage was a pilot study that involved holding two focus groups for professionals working with adults with learning disabilities. This would enable professionals working with adults with learning disabilities to share their experiences of working with adults with learning disabilities who had experienced traumatic events. One of the main objectives for the focus groups was to help define what a traumatic event was for a person with learning disabilities. See methodology for further details.

The second stage of the research involved the researcher interviewing a small group of adults with learning disabilities about their experiences of traumatic life events. This involved semi structured interviews and adapting a quantitative measure that has been used with the non-disabled population. The aim of holding individual interviews was to explore in detail with people with learning disabilities the affects of traumatic events. The quantitative measure the PDS form (Foa, Cashman, Jaycox & Perry, 1997) was used to add to the information collected in the individual interviews.

There has been a lack of qualitative research that has sought the perceptions of people with learning disabilities in relation to difficult life events. A small number of studies have been published that have involved interviews with adults with learning disabilities including experiences of losing a keyworker and women's experiences of their sexuality including experiences of abuse (Mattison & Pistrang, 2000; McCarthy, 1999).

The researcher chose to speak to adults with learning disabilities about their experiences of difficult events in their lives, to gain an understanding about the sense that they had made of what happened to them and how the events had affected their lives. The

particular methodology that was chosen was Interpretative Phenomenological Analysis

(IPA). Phenomenological approaches have been used in previous research with adults

without learning disabilities to explore the reaction of adults to floods in North Dakota

(Prosse Keene, 1998). IPA was chosen because it is concerned with the meaning

individual's ascribe to particular events (Smith, 1996). The model developed by Ehlers &

Clark (2000) highlighted the importance of the individual's appraisal of the event in

relation to the development of post traumatic stress reactions. IPA considers how

interpretations of the language used by participants may be related to underlying cognitions

and beliefs a person has (Smith, 1996). See methodology for further details.

METHODOLOGY

Introduction

This chapter includes a general overview of qualitative research, a description of Interpretative Phenomenological Analysis (IPA), the methodology employed in the second stage of this study, and the rationale for choosing this approach. This is followed by a description of how the participants were identified and recruited and the procedures used for collecting and analysing the data. Issues relating to the methodological rigour of qualitative research are then discussed.

Qualitative research

In the 1990s qualitative research began to have a greater impact upon the discipline of psychology (see Richardson, 1996 for a review of this development). An explanation for the lack of impact prior to the 1990s is psychology's long standing commitment to the scientific method, to experimentation and to positivist epistemologies in general (Henwood, 1996; Madill, Jordan & Shirley, 2000). Positivism has several versions and is not a single approach (Bryman, 1988). Central to the epistemology, however, is the importance of objectivity, the relationship between "cause" and "effect" and the testing of hypotheses derived from theory (Parker, 1994). It is a widely held view that much of quantitative research is based on positivism and that as a consequence it reflects its aims and tenets (Bryman, 1988; Parker, 1994).

Qualitative research has been described as a field of enquiry in its own right that cuts across disciplines, fields and subject matter (Denzin & Lincoln, 1994). Parker (1994) gave a simple definition of qualitative research referring to it as the " interpretative study of a specified issue or problem in which the researcher is central to the sense that is made" (p2). Acknowledging the subjectivity of the researcher is a rejection of the objective stance

required by positivistic epistemologies. Although there are a number of different approaches and methodologies used in qualitative research there are a number of unifying themes. Qualitative research is concerned with the role of interpretation in making sense of the meanings people attribute to different phenomena (Denzin & Lincoln, 1994) and understanding linguistic meanings within textual material (Madill et al., 2000). The debate about the relative strengths and weaknesses of quantitative and qualitative research, has been discussed elsewhere (see Bryman, 1988; Denzin & Lincoln, 1994; Stevenson & Cooper, 1997).

Madill et al. (2000) argued that qualitative research was not a homogenous field and they outlined three broad epistemological strands of qualitative research: realist, contextual constructionist and radical constructionist. There are three realist epistemologies described by Madill et al. (2000) naïve, scientific and critical. Scientific realism relates to positivism in that it is a position that believes scientific method can reveal the truth about the world. The position of contextual constructionist epistemology is that researchers construct versions of the world through activities as social or political subjects and do not merely reflect an objective reality (Henwood, 1996). Researchers working within the contextual constructionist framework also do not assume that there is one reality that will be revealed through using the correct methodology (Madill et al., 2000). Researchers working from this position accept that findings are context specific, affected by the interaction between the researcher and the participants. The third position is that of radical constructionism which challenges the notion that there will ever be an absolute foundation for knowledge, rejecting the notion that language can represent reality (Madill et al., 2000). This research adopted a contextual constructionist position, which is explained in more detail by looking at the philosophies underlying Interpretative Phenomenological Analysis (IPA).

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) has been developed from the theoretical positions of phenomenology and symbolic interactionism (Smith, 1995; Smith, 1996). Phenomenology was first defined by Hegel as "knowledge as it appears to consciousness, the science of describing what one perceives, senses and knows in one's immediate awareness and experience" (p26, Moustakas, 1994). Husserl developed transcendental phenomenology at the beginning of the twentieth century (see review by Giorgi, 1995). Phenomenology was concerned with exploring another individuals' perspective or personal account of an event rather than trying to provide an objective statement about it (Smith, 1996).

Symbolic interactionism has been influenced by phenomenology and represents a rejection of the positivist paradigm. It was concerned with the meanings attributed by individuals towards events or objects and argued that these meanings were obtained through a process of interpretation, as the result of social interaction (see review by Denzin, 1995). IPA recognises that the researcher's perspectives about a phenomenon will have an effect on this interpretative process (Smith, 1996). The issue of reflexivity will be discussed further later in this section.

IPA was chosen in preference to other qualitative methodologies, for example grounded theory, as the researcher was interested in the relationship between individuals' perceptions of traumatic events, how they made sense of what had happened to them and the impact the traumatic events had upon their lives. The methodology of IPA is concerned with how an individual perceives an event and the meaning they ascribe to it, rather than obtaining a factual account of what they have experienced (Smith, 1996). The researcher was also interested in the beliefs that were held by individuals about the traumatic events they had experienced. The methodology of IPA is concerned about individuals' beliefs and

understanding what a participant thinks about the phenomenon under discussion. IPA recognises that the language used in an interview transcript, through a process of interpretation reveals underlying beliefs and thoughts that individuals have about a phenomenon (Smith, Jarman & Osborn, 1999). In this way IPA differs from discourse analysis (Smith, 1996). The methodology of IPA focuses on an individual's experience or a small number of research participants rather than trying to establish general laws about human behaviour (Smith, Harre & Langenhove, 1995).

IPA has been used extensively in the field of health psychology to explore the relationship between illness and underlying patient beliefs (e.g. Chapman, 2002; Duncan, Hart, Scoular & Bayrigg, 2001; Flowers, Smith, Sheeran & Beail, 1997; Kay & Kingston, 2002; Osborn & Smith, 1998). A number of studies have also been published demonstrating the use of IPA to explore psychological phenomena in other clinical areas (Carradice, Shankland & Beail, 2002; Jarman, Smith & Walsh, 1997; Knudson & Coyle, 2002; Macran, Stiles & Smith, 1999; Smith, 1999).

Rationale for using a qualitative methodology

It has been argued that qualitative research has advantages in comparison to quantitative research when studying psychological phenomena that have not been widely researched (Turpin, Barley, Beail, Scaife, Slade, Smith et al., 1997). Qualitative research has been shown to be particularly appropriate where the aim of the research is to understand participant's perspectives and to define phenomena in terms of experienced meanings (Elliot, Fischer & Rennie, 1999). It typically involves exploring interwoven aspects of the phenomenon under discussion (Yardley, 2000). Smith (1995) also argued that the use of semi-structured interviews were suitable when researching topics that were controversial and personal. Exploring the relationship between traumatic life events and

post traumatic stress in adults with learning disabilities has been a neglected area of research (see recent reviews by McCarthy, 2001; Newman et al., 2000). All of the research that has explored the relationship between people with learning disabilities and traumatic life events has been quantitative. The main methodological limitations of this type of research have been discussed in the review of the literature.

In the first stage of the research semi structured interviews were used in focus groups for staff from different professions working with adults with learning disabilities to explore their perceptions of how adults with learning disabilities present following traumatic life events. Focus groups have been defined as "a research technique that collects data through group interaction on a topic determined by the researcher" (p6, Morgan, 1997). Focus groups have been commonly used a preliminary method of collecting data. They have a role in gaining consensus on an issue and obtaining greater understanding on exploratory topics (Morgan, 1997).

Feedback from the focus groups was then used to inform the second stage of the research, which involved interviewing people with learning disabilities about their perception and experiences of traumatic life events and the meanings they had attributed to them. A quantitative measure, the Post-traumatic Diagnostic Scale (Foa et al., 1997), used with adults in the non disabled population, was used to supplement the data collected from the interviews. The IPA methodology was chosen as the review of the literature in this area and feedback from the focus groups suggested that it was wrong to assume that adults with learning disabilities will respond to traumatic life events in the same way as adults in the non disabled population. Therefore an exploratory study was undertaken with a small group of adults with learning disabilities to look at the meaning of traumatic life events.

Ethical Issues

There were a number of ethical issues identified by the researcher. Due to the sensitive nature of the topic under discussion, the researcher did not approach any person with learning disabilities directly and ask them if they were willing to be interviewed about their experiences. The researcher talked to several staff teams and staff members agreed to speak to individuals with learning disabilities, who fulfilled the criteria for the study, about whether they would be willing to be interviewed. This procedure was chosen so people with learning disabilities would not feel obligated to the researcher to take part in the research, if they did not want to.

People with learning disabilities participating in the study were all receiving ongoing support from a member of a learning disability team. The researcher acknowledged that due to the nature of the topic individuals could become distressed during or after the interview. There were occasions during a couple of the interviews when the researcher perceived that participants were getting more agitated and upset. In this situation the researcher asked the person if they were okay to continue to talk about that subject and whether they wanted to carry on with the interview. At the end of one of the interviews one of the participants became quite angry and with the participants permission, the researcher contacted the clinical psychologist who was working with them. The researcher contacted two other staff members involved with participants with the individual's permission.

Since the researcher was on a clinical placement in one of the locations where the research was undertaken, the researcher explained to participants living in that area, that there was the option of continuing to meet with the researcher after the interviews were finished. One participant met with the researcher for four individual sessions following her interview. The limits of confidentiality were discussed with all of the participants at the

beginning of the interviews. The researcher also reminded one participant about confidentiality during their interview. The researcher explained that the information shared in the interviews was confidential apart from when there was a risk of harm to the individual or to others.

Ethical approval was sought from two ethical committees, since there were concerns about recruiting enough participants for the main study. Ethical approval was granted with the requirement that serious adverse reactions or events were reported to one of the ethical committees (see Appendix No.2).

Pilot Study

Procedure

Participants

There were ten participants who attended the focus groups in total. There were three participants who attended the first focus group including a clinical psychologist, a community nurse and a day centre officer. Seven participants attended the second focus group. The composition of the second focus group consisted of a psychiatrist, a clinical psychologist, a trainee clinical psychologist, a social worker, a student nurse and two community care officers. Most of the participants attending the focus groups held professional qualifications or were in the process of training to be professionally qualified. Three participants were not professionally qualified, however, all three participants had over ten years of experience of working with adults with learning disabilities.

Recruitment

Guidelines by Morgan (1998a, 1998b) were used to plan for the first focus group. Recruitment to the first focus group involved the presentation of the research to the local

clinical psychology department and to a meeting for professionals interested and actively participating in research. Information was also shared with the local community learning disability teams via the clinical psychologists who were working in the teams and through word of mouth. Letters of invitation to attend one of the focus groups were sent to staff who had expressed an interest in participating in the research. Owing to the low attendance at the first focus group more direct methods were employed to recruit participants for the second focus group. These included telephone invitations to specific individuals as recommended by Krueger (1998a). The researcher telephoned all of the leaders of the community teams and heads of the different professions to try and recruit participants. Follow up letters with a date by which to confirm attendance were sent to each member of the community learning disability teams and to members of each profession to try and ensure that there were representatives from the different professions at the focus group. The information was also distributed to another learning disability service since ethical approval from the Local Trust had been granted during the interim period.

Data Collection

The methodology selected to explore staff perceptions of the presentation of adults with learning disabilities following traumatic life events was focus groups. Staff members representing different professions were invited to attend focus groups to discuss whether PTSD was a useful way of thinking about people with learning disabilities who have experienced trauma. There were a number of reasons why focus groups were chosen. Firstly, a review of the literature suggested that the definition of traumatic event, for someone with learning disabilities, was open for debate. One of the aims of the focus group was to generate criteria to identify a group of people with learning disabilities who could be interviewed about their experiences.

The second reason was to help to construct the interview schedule. Since there has been so little research in this area the focus groups were designed to stimulate potential areas that could be developed in individual interviews. The third reason for holding focus groups was to help with recruiting participants for the individual interviews. Due to the sensitive nature of the subject area recruitment could have been a problem as staff members may have been reluctant to help the researcher to find participants. It was hoped that staff members who participated in the focus groups and saw the value of the research might be more willing to assist the researcher with recruitment.

The interview schedule used in the focus groups was developed using guidelines written by Krueger (1998b) and subsequent discussions with research and field supervisors (see Appendix No. 3). The structure of the interview schedule included an opening question to help the participants feel at ease, an introductory question aimed at introducing the topic, three key questions which tried to elicit the views of the participants about the main topic of the research, and closing questions. The interview schedule also included a brief explanation at the beginning prior to the discussion about the current diagnostic criteria used for PTSD. The interview schedule was piloted with two colleagues and changes were made prior to using it in the two focus groups. The changes included sending out copies of the PTSD criteria to potential participants to help familiarise them with the criteria prior to the focus groups. The pilot group was also used as an opportunity for the researcher to practise moderating a focus group and to use the guidelines suggested by Krueger (1998c) concerning effective ways to moderate focus groups. Each focus group was approximately an hour and a half in duration. Permission was sought to audio-tape the focus groups and each participant gave consent for the researcher to do this. The researcher had an assistant in the focus groups, helping with tasks such as ensuring that the tape recorder was switched on and taking notes of what was said during the groups. Following

the focus groups there was a debriefing session that was audio-taped. The focus group

discussions were transcribed verbatim by the researcher.

Data Analysis

A descriptive thematic analysis was undertaken on the transcripts from the two

focus groups using guidelines outlined by Krueger (1998a) and Morgan (1997). The aim

of the focus groups was to inform the remainder of the study with particular reference to

the types of events that might be considered to be traumatic by people with a learning

disability and to consider topics that could be included in the interview schedule. The

method of data analysis reflected these aims.

Main Study

Procedure

Participants

All of the participants were receiving regular input from learning disability services

and were described as having mild to moderate learning disabilities. To participate in the

research the adults with learning disabilities had to fulfil three criteria, which were derived

from descriptive analysis of the focus groups and discussions with supervisors. The criteria

were that they were able to give informed consent to be interviewed, that they had

experienced a key life event that has caused them distress, which was significant to them

and had changed their life and they were receiving ongoing support from the health trust's

learning disability services. Six individuals were interviewed including two women and

four men aged between 23 years old and 57 years old. All of the participants were white

and British. The participants lived in a range of accommodation including family homes, a

medium secure unit and 24 hour supported housing. The researcher discussed with each participant, the place and time they wanted to be interviewed.

Recruitment

Information about the criteria for participants was distributed via staff in the community learning disability teams, psychiatry, clinical psychology, speech therapy, occupational therapy and management in the day centres. Staff members were asked to contact the researcher if they wanted further information about the study or they knew of people who fulfilled the criteria who could be willing to talk about their experiences. The researcher met with a number of staff members to talk about specific individuals and to discuss whether they fulfilled the criteria for the research. When the criteria were met staff members were given information sheets to share with the individuals concerned that explained the purpose of the research and the staff member discussed with the person whether or not they wished to participate in the study. When the staff members had obtained permission from the individuals to take part in the research the researcher met with them to go through the information sheet, the complaints form and the consent form.

Participants were informed that the researcher was training to be a clinical psychologist and that parts of the interviews would be written in a report for the university. They were also informed that they would have anonymity when the research was written up i.e. names would be changed. The researcher also talked with the participants about their right to stop the interview at any time. Information was also given to the participants about how they could complain about the research if they were unhappy about the way they had been treated. Each participant signed a consent form. Copies of the information sheet, the consent form and the complaint form can be found in Appendix No. 4.

Data Collection

The format of data collection was for the researcher initially to ask them about previous traumatic events they had experienced in their life using Part One of the Post-traumatic Diagnostic Scale (PDS) (Foa et al., 1997). This is a quantitative measure that is used with adults without learning disabilities to screen and assess for PTSD. The purpose of using part one of the PDS was to record the number and type of traumatic life events they had experienced. Usually in the second meeting the researcher asked the participant to pick one of the events to talk about. The semi-structured interview schedule was used to explore the meaning of the event with them. Semi structured interviews were the main method of data collection and these ranged between forty-five minutes and an hour and a quarter long for each participant. The researcher interviewed two individuals on two occasions. The children's literature suggested that researchers may need more than one session to gather information since the memory of the event including the person's thoughts and feelings about it may be fragmented (Terr, 1988). All of the interviews were audio-taped. The final meeting with each participant involved completing the remainder of the PDS form (Foa et al., 1997). The PDS form was completed after the interviews so the participants were not influenced in the type of responses they made during the interview process. The completion of the PDS was used to add to the data collected in the individual interviews, it was not used to validate the answers given in the individual interviews (Madill et al., 2000). The goal of triangulation within contextualist research is completeness rather than validation.

All of the interviews were transcribed verbatim. The researcher transcribed two of the interviews and four interviews were transcribed by a professional audio-typist. The researcher listened to all of the interviews and checked the transcripts against them. Amendments made by the researcher included correcting parts of the transcript that had

been misunderstood or were incomplete. The audio-typist had some difficulties understanding participants' speech due to the quality of the recordings.

Data Analysis

The data analysis of the individual interviews using IPA was conducted following guidelines outlined by Smith et al. (1999) using an idiographic, case study approach. An idiographic approach begins with particular examples before working towards more general categorisation (Smith, 1995). The first transcript from the pilot interview was read over a couple of times then the transcript was analysed line by line and comments were made in the left margin. The comments included summaries of what was said, questions, assumptions that had been made and preliminary interpretations. In the right hand margin emerging themes were written. All of the emerging themes were then listed on a separate piece of paper and connections made between them to find clusters of themes and concepts. When the themes clustered together superordinate themes emerged that included a number of themes that had previously been identified. A table of the superordinate themes and sub-themes was created for the individual transcript, giving examples of where each theme could be found in the transcript. The researcher presented the table of themes that emerged from the first transcript to a research supervisor to check that the interpretations made were well grounded in the data (Osborn & Smith, 1998). The main issues identified were the tension of whether to talk or not, feeling unprotected by others, experiencing negative consequences of the event and identifying oneself as someone to whom bad things happen.

Each individual transcript was analysed by going through the stages outlined above and a table of themes were produced for each interview that were then compared together to make an overall master table of themes for all the participants. New themes that

emerged from the later transcripts were tested against earlier transcripts. For example revenge was identified as a theme in the third transcript, however, checking back over the previous transcripts revenge was also identified as a theme in the first transcript. During the process of data analysis notes were made in a reflexive diary about how the clusters of themes related together and how they might fit within a coherent framework. Cue cards were also used to consider how each theme related to other themes and a core organising principle was identified. In order to produce a master table of themes some minor themes were not included. The analysis of the data continued during the writing up of the results. A section of analysed transcript is included in Appendix No. 6.

Reflexivity

Reflexivity acknowledges that the subjective experiences of the researcher will affect the method of exploration chosen and the subsequent interpretation of the data collected (Parker, 1994). Reflexivity is concerned with the process of self-reflection and critical evaluation by the researcher throughout the research. This includes reflecting on the selection of the research topic, the design of the research and the experience of undertaking the research (Wilkinson, 1988 as cited in Richardson, 1994). My position as a researcher is stated here thinking about the subjective experiences that were brought to the research process and that influenced the design and the interpretation of the research.

I am a white thirty-year-old British woman. I have worked with adults with learning disabilities for over six years, as a support worker, a development worker, an assistant psychologist and whilst training to be a clinical psychologist. During my work experience I have worked with people with learning disabilities, on an individual and group basis, who have been physically and sexually abused. From this work experience I developed an interest in undertaking research with people with learning disabilities who

had experienced trauma in their lives. I have mainly used a cognitive framework to formulate people's difficulties and to provide interventions. I also worked for almost three years in an advocacy project for people with learning disabilities. From that experience I developed an interest in enabling people with learning disabilities to have a voice in their lives and to share their stories with others.

Trustworthiness

Stiles (1993) used the term "trustworthiness" to address reliability and validity in qualitative research. Reliability was understood to refer to the trustworthiness of data and validity to refer to the trustworthiness of interpretations. Several researchers have attempted to develop criteria to review the trustworthiness of qualitative research (Elliot et al., 1999; Stiles, 1993; Yardley, 2000).

Disclosure of Orientation. Elliot et al. (1999) and Stiles (1993) stressed the importance of the researcher owning their perspective and specifying their theoretical orientation and personal experience. The position of the researcher prior to this research has been previously stated. McLeod (2001) questioned this guideline asking how readers could judge whether a researcher's perspective is authentically conveyed.

Adopting a contextualist constructionist epistemology in this research has implications for the criteria of reliability and objectivity that are used predominantly within the positivistic or realist framework (Madill et al, 2000). Contextualism is concerned with the extent to which the analysis is determined by the particular situation in which it has been produced and the prior attitudes of the researcher (McLeod, 2001). An example of the effect of context in this research was that the researcher was interviewing people with learning disabilities about very personal experiences. The extent to which they were

willing to talk about those experiences with the researcher, who was a stranger, could potentially have been very different to a conversation they could have with someone they had known for many years. The aim of researcher in this study was to offer one possible interpretation of the meaning of traumatic life events for a group of people with learning disabilities.

Sensitivity to cultural context. Stiles (1993) and Yardley (2000) have written about the importance of thinking about the culture of participants and how the findings of the research could be influenced by cultural contexts. Individuals with learning disabilities are often dependent on others for care and this cultural aspect is included within the interpretation of some of the findings from the main study. Another cultural consideration made by the researcher is the acknowledgement that the interviews may have been influenced by an imbalance of power between the researcher and the participants. Elliot et al. (1999) wrote about the importance of providing basic descriptive data about participants and their situations. This was included in an earlier section of this chapter.

Transparency. Several authors have stressed the importance of providing examples of the data to illustrate the analytic process and the interpretations that have been made (Elliot et al, 1999; Smith, 1995; Smith et al., 1999; Stiles, 1993). This process of grounding the interpretations of the research in the data allows readers to appraise the interpretations and to conceptualise alternative meanings and explanations. The researcher discussed extracts from the transcripts with a group of peers to explore possible interpretations and emerging themes. Extracts from the transcripts from this research have been included in the results to give transparency to the interpretative process.

Coherence. It has been argued by several authors that it is important to provide a coherent narrative or framework for understanding the data that has resonance with the reader (Stiles, 1993; Elliot et al., 1999; Yardley, 2000). Stiles (1993) referred to coherence as the apparent quality of the interpretation itself. The interpretation should be a convincing construction of reality, have clarity and be recognised by the readers as a meaningful account. The researcher presented the framework of themes to peers and to supervisors to check whether the framework of themes had resonance and was coherent in presentation. An initial presentation of the main themes to a supervisor did not produce a coherent account and the researcher continued with the process of analysis until a central organising concept emerged.

Impact and Importance. Yardley (2000) argued that the decisive criterion by which to judge any piece of research is its impact and utility. In the discussion the interpretations of this research are related to previous research on this subject and the clinical implications for future work with people with learning disabilities are outlined.

Developing the Interview Schedule

Although broadly the guidelines outlined by Smith (1995) were used to devise the interview schedule the types of questions that were asked had to be adapted for people with learning disabilities and different strategies used to maximise their responsiveness. For example the researcher tried to use questions that were simply phrased without jargon (Wyngaarden, 1981). It has been argued in previous research that using open questions with adults with learning disabilities provided answers that have more validity in comparison to yes –no question formats (Sigelman, Budd, Winer, Schoenrock & Martin, 1982). Sigelman et al. (1982) favoured multiple choice questions arguing they were

potentially a useful alternative to open questions. Research by Sigelman and her colleagues suggested that adults with learning disabilities had a tendency to acquiescence when interviewed (Sigelman, Budd, Spanhel & Schoenroock, 1981; Sigelman et al., 1982). This work has been influential amongst people interviewing adults with learning disabilities (Chapman & Oakes, 1995; Holland & Meddis, 1997; Prosser & Bromley, 1998), though it has recently been challenged and criticised (Rapley & Antaki, 1996). The research by Rapley & Antaki (1996) argued that the social context of the interviews was important that if interviewees perceived the interviews to be a test they could change their position in response to demands by the interviewer. They demonstrated the influential role of the interviewer in guiding the interviewee to produce acceptable answers and also presented examples when interviewees had resisted pressure from the interviewer to change their answers.

The use of prompts has been a successful way of yielding appropriate and extended answers from people with mild to moderate learning disabilities (Chapman & Oakes, 1995; Mattison & Pistrang, 2000). The interview schedule used in the main study included questions with some prompts that were used when the person failed to respond or said they didn't know in response to a question. Other strategies that were used by the researcher to elicit a full response from the participants were being prepared to rephrase the questions different ways (McCarthy, 1999; Wyngaarden, 1981) and reflecting back what the participants are saying to check understanding (McCarthy, 1999). Rapley & Antaki (1996) argued that rephrasing questions in response to perceived incomprehensible or incorrect answers given by the interviewees could lead the interviewees to change their position to provide more acceptable answers.

Where possible open questions were used by the researcher, however, if yes-no questions were used the participant was asked to give examples to support their answer.

Also at the beginning of the interview participants were told that there were no right or wrong answers to the questions they would be asked and that what the researcher was most interested in were their experience of difficult events in their life. It was hoped that this would mean that participants were less likely to perceive the interview as a test.

The interview schedule was developed using the guidelines presented by Smith (1995), the descriptive themes that emerged from the focus groups and a review of the literature on this topic (see Appendix No. 5). The aim of the first few minutes of the interviews was to develop rapport with the participants and to put them at ease by talking about what they had been doing during the day or the previous weekend. The next step involved the researcher asking the participants which event they wanted to talk about, getting a description of what happened at the time of the event and finding out what their current thoughts and feelings were about it. Finally the participants were asked about how the traumatic event had affected their lives. Following each interview the researcher wrote down immediate perceptions and thoughts about the interview in a reflexive journal. The interview questions were piloted on one participant and amended as a result of the pilot interview. Questions that were added to the interview schedule were "Could you tell me about the hardest thing that happened to you?" and "Which one do you think about the most?" anticipating that most participants had experienced multiple traumatic events. Other amendments made to the interview schedule were prompts that were added to the question "How has the event affected your life?". These included "How has your life changed since the event happened to you?" and "If your mum or husband/wife were in the room what would they say?". These prompts were added because the participant in the pilot interview had difficulty answering questions about the meaning of the event in her life. The data from the pilot interview was included in the data analysis.

Using the PDS

The PDS (Foa et al., 1997) has been used as a self-report measure with adults in the general population (See Appendix No. 7). To the researcher's knowledge it has not previously been used with adults with learning disabilities in a published study. As previously stated in the literature review at present there are no quantitative measures available to assess post- traumatic responses to events specifically for use with people with learning disabilities. Although the PDS is based on the criteria for PTSD from DSM-IV (American Psychiatric Association, 1994) it has been recommended not as a means of diagnosing a person with PTSD but as a screening tool for research and clinical practice (Foa et al., 1997). When tested on adults in the non-disabled population it had a high internal consistency on each cluster of symptoms. The coefficient alpha was 0.92 for total symptom severity, 0.78 for re-experiencing, 0.84 for avoidance and 0.84 for arousal (Foa et al., 1997). The test-retest reliability was also high and there were only small changes in the effect sizes of each symptom cluster over a period of two to three weeks. When compared to other quantitative measures used to assess for PTSD there was a high agreement supporting the validity of the PDS to screen for symptoms of PTSD as defined by DSM-IV (American Psychiatric Association, 1994).

In previous research self-report measures that have been used with adults in the general population have been adapted for use with people with learning disabilities (e.g. Beail & Warden, 1996; Sturmey, Reed & Corbett, 1991). When self-report measures have been used with adults with learning disabilities they have sometimes been used in an interview format by researchers (e.g. Beail & Warden, 1996; Kellet, Beail, Newman, & Mosley, 1999). The researcher used an interview approach in this research since most of the participants were unable to read. One of the reasons why the PDS was chosen in this study was the ease with which it could be adapted for people with learning disabilities. The

language it used was less complex than other comparable measures, though for most of the participants the language needed to be simplified further by the researcher. The PDS also used fewer categories than some other measures (Turner & Lee, 1990) to look at the severity of the symptoms. The researcher devised a visual scale of buckets with different quantities of liquid in them to represent the categories of 0 to 3. Another reason for using the PDS was that it was quite short and quick to administer. Since the semi-structured interview was the main method of collecting data from participants and the purpose of using this scale was to supplement the findings of the interview the researcher believed this was justified.

RESULTS

Pilot Study

Introduction

This section includes the descriptive thematic analysis of the data collected from the focus groups used in the pilot study. The analysis of the main study uses an IPA methodology to explore the experience and meaning of traumatic life events to a group of people with learning disabilities.

This section begins by using the experiences of participants from the focus groups to define what is a traumatic event for someone with a learning disability. Following this there is an exploration of how these descriptions of the experiences of people with learning disabilities are similar and different to the concept of PTSD described by DSM-IV (American Psychiatric Association, 1994). Next there is a discussion of other factors that need to be considered and the usefulness of the concept of PTSD in relation to people with learning disabilities. The main findings and the implications of the findings for the main study are summarised.

Defining Traumatic Events

The initial questions asked participants to think about what types of events they considered to be traumatic for people with learning disabilities. Most of the participants from each focus group gave several examples of people they had worked with who had been sexually abused.

Joyce, Focus Group 1: "I'm working with a woman who is forty two and she was sexually abused as a child...she didn't know what was happening to her until a long time afterwards."

One or two participants from each focus group also mentioned people who had been physical abused. It was also expressed by several participants from each focus group that bereavement of parents was a traumatic event especially when complicated with having to move into a residential home, witnessing the parent dying or finding them dead.

David, Focus Group 1: "His parents died within the space of a few months about twenty five years ago. He found one of them dead in the garden...it's central to unresolved things."

Debbie expressed similar comments to those given above concerning bereavement. Another traumatic event that was mentioned by a few participants from each focus group was when people with learning disabilities had their children taken into care.

Joyce, Focus Group 1: "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."

Elaine and James gave similar examples. Other types of events that were mentioned by at least one of the participants from the focus groups were a car accident, a house fire, burglary and offences against others.

Multiple life events. Some participants from the focus groups gave examples of people with learning disabilities who had experienced a single traumatic event. However, the majority of participants gave examples of people with learning disabilities they had worked with who had experienced multiple traumatic events.

Vicky, Focus Group 2: "one of the women I am thinking of she was sexually abused by her father after her mother died...her father made her pregnant, the baby was taken away and she had umm, she had a breakdown."

Staff working with people with learning disabilities expressed difficulties in determining which event was the most distressing one for the person with learning disabilities, if they had experienced multiple events.

Elaine, Focus Group 2: "I think you were talking about somebody whose brother abused her, if that happened, that might have seemed like a relatively normal event. But then she's asked to leave the house and to go into an institution so it may have been actually the secondary, the thing of leaving the house and having to go and live somewhere else was actually more traumatic than the abuse itself."

The focus of the criteria for PTSD in DSM IV (American Psychiatric Association, 1994) is on a single acute stressor. The criteria allow for the multiple nature of traumatic events, however, there is no distinction made between the reaction to one event and the reaction to multiple events.

Similarities between participants' experiences and the concept of PTSD

Re-experiencing the event. The focus groups were asked about the similarities that they had observed between the PTSD criteria in DSM-IV (American Psychiatric Association, 1994) and how people with learning disabilities presented following traumatic events. There were some participants from both of the focus groups who gave examples of people re-experiencing the event. Participants talked about people having flashbacks, nightmares and distressing dreams associated with the traumatic event.

Chris, Focus Group 2: "now one was sort of regular continual physical abuse by his father and that has left him with these sort of flashbacks."

James, Focus Group 2: "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."

Another theme expressed by some participants from both focus groups was people with learning disabilities who became distressed when they were reminded about the traumatic event in some way.

Elaine, Focus Group 2: "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."

One participant described how people with learning disabilities, in a similar way to children, might re-enact what has happened to them through their behaviour.

Ruth, Focus Group 1: "They snatch at the props and then they can show you exactly what's happened to them. It's quite dramatic."

Avoidance. Avoidance of reminders of the traumatic event was another common theme that was expressed. A few participants from each focus group gave examples of this type of behaviour.

James, Focus Group 2: "I've got a couple of people who have that similar thing, where they come up to you and say (whispers) stop saying that word whatever it is. 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 which have some, some kind of linkage back to some event."

Increased arousal. There was general agreement by participants in both groups that some people were hyper-vigilant about bad things happening to them again.

Fiona, Focus Group 2: "I worked with 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... She didn't know how to discriminate between who was potentially dangerous and who wasn't potentially dangerous. So as far as she was concerned everybody was dangerous, so she spent her whole life in terror really."

For some people with learning disabilities this included a preoccupation with reminders of the traumatic event.

Sheila, Focus Group 1: "he scans the news and the teletext for single death related event."

James, Focus Group 2: "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."

A few participants from the focus groups spoke about people getting angry in response to the traumatic event sometimes culminating in the assault of others.

Chris, Focus Group 2: "In fact, I can think about all of the people that I have mentioned they're all quite aggressive or assaultative themselves."

Differences between participants' experiences and the concept of PTSD

The link between traumatic events and behavioural reactions. A strong theme expressed by the majority of participants from the focus groups was how people demonstrated through their behaviour a reaction to the traumatic events. The PTSD criteria in DSM-IV (American Psychiatric Association, 1994) included behavioural responses when looking for reactions in children but not for adults. Examples of the types of behavioural responses given by participants were self-harm, disorganised behaviour, agitation, afraid of being left or abandoned, withdrawal, outbursts of distress and ambivalence about being involved in relationships and activities.

Vicky, Focus Group 2: "I mean I know somebody else who was sexually abused by her brother, as a consequence of that when she was sort of like in her early teens she was basically put into an institution to live. Umm came out of the institution to live in the community and has extreme self-harming behaviours umm, which weren't apparently were not there prior to the sexual abuse."

Elaine, Focus Group 2: "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."

There was general agreement by the majority of participants from both focus groups that staff members tried to make sense of behaviour of people with learning disabilities and tried to link it back to past traumatic events.

James, Focus Group 2: "what we've got is actually, you've got this kind of slightly, this sort of odd expression of a, distressed behaviour you're almost rewinding back."

Vicky, Focus Group 2: *"When you delve into you know the behaviour, the person's past history, you can go back to a whole variety of traumatic events that have happened. But it's then working out where the behaviour, whether it's a result of that, or is it a result of going into an institution. And sort of like some of it's learned behaviours, some of it's a coping strategy."*

One or two participants acknowledged that sometimes staff tried to eliminate the behaviour without trying to understand what it meant.

Ruth, Focus Group 1: *"It's us getting the understanding of what the behaviour really means, often we try and sort out the behaviour and get rid of it and you know cure it, whatever, when actually we're not understanding what it really means."*

Physical health problems. A theme expressed by participants in Focus Group 1 was that some people demonstrate their distress following traumatic events through physical health problems.

Ruth, Focus Group 1: *"I'm thinking the women that have been abused, the lady who lost most of her hair that's a very physical reaction."*

Sheila and Joyce expressed similar views to the one given above.

Position of people with learning disabilities in society. A strong theme running through both focus groups, was the effect of the environment and the position that people with learning disabilities hold within society. A few participants from each focus group spoke about the position of people with learning disabilities in society as powerless and they questioned the traumatising effects of being institutionalised.

Vicky, Focus Group 2: "I mean the woman that I know who seriously self harms, I mean whether or not that's as a result of the abuse, or whether it's a result of being institutionalised or, it's not clear."

Helplessness is one of the criteria for PTSD in DSM-IV (American Psychiatric Association, 1994) but this may be unhelpful when thinking about the post traumatic stress reactions of people with learning disabilities, who may experience this as a consequence of their position in society.

Chris, Focus Group 2: "I suppose one of the differences is for people who um, in everyday life might experience those sort of things, it's the feelings of helplessness in the situation which is unusual.... Most people with learning disabilities that we work with are you know socialised into a helpless sort of state almost they're not regarded as competent."

Rebecca and Fiona made similar comments to those expressed above, questioning the effect of being in an institution. Another problem with the criteria for defining a traumatic event that were used by the PTSD criteria in DSM-IV (American Psychiatric Association, 1994), was expressed by one participant in Focus Group1. She questioned whether a threat to psychological and physical integrity should be used rather than just a threat to physical integrity.

Duration of the reaction to traumatic events. The criteria for the concept of PTSD used in DSM-IV (American Psychiatric Association, 1994) included a classification for chronic PTSD, where symptoms last for longer than three months. A common issue described by participants from both groups was the long duration of people's distress in relation to particular events. Participants described people with learning disabilities who

had traumatic experiences as children, who still remained very distressed by those experiences in later life.

Chris, Focus Group 2: "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."

James, Focus Group 2: "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."

Some of the examples that were shared by a few participants from the focus groups concerned people who had been abused many years ago, or as children, who only years later were able to talk about their experiences.

Ruth, Focus Group 1: "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."

This could be true also for the general population where adults recovered memories of childhood sexual abuse. There is a classification in the criteria for the concept of PTSD, according to DSM-IV (American Psychiatric Association, 1994) of delayed PTSD, when the symptoms following a traumatic event are delayed by six months or longer. There was agreement in the first focus group that it was only when people felt secure and safe that they were willing to begin talking about their traumatic experiences. Some of the participants in the second focus group talked in a similar vein about the importance of acknowledging people's experiences even if they were a long time ago.

Ruth, Focus Group 1: "I very strongly identify with something you were saying a bit earlier about how 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."

Elaine, Focus Group 2: "People don't know what to do to help people. They do just brush it, oh don't worry you know it happened ages ago. And I think the important thing is even if you don't really know what the next step is, to acknowledge it at least is the first step and it makes, it gives validity to people's feelings."

Other factors that need to be considered

Appraisal of the event. There was a discussion during the second focus group that previous life experience could affect the appraisal of the event by the person with a learning disability. Debbie and Elaine questioned whether people would react in different ways to traumatic events based on their previous experience i.e. whether they had experienced a prior traumatic event. There was also general agreement in the second focus group that the understanding people with learning disabilities had about the concept of death would have an impact on their appraisal of an event that was life threatening.

Fiona, Focus Group 2: "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 in threat of dying then would that mean you would appraise it in a different way?"

There could be a wide variation amongst the views of people with learning disabilities in relation to this concept, which may be influenced by level of cognitive ability and previous experience of death. People who do not have learning disabilities may

appraise events in a different way if they have higher cognitive ability and understand that their life is in danger.

The role of the supportive environment. A theme that occurred in both focus groups was the importance of a supportive environment. The culture surrounding people with learning disabilities could be very different to the type of environment surrounding people without learning disabilities. Some participants from both focus groups gave examples of family or staff members who found it difficult to hear or talk about the traumatic event. *Fiona, Focus Group 2: "This lady found it very difficult to tell people so she tried to tell her mum that she'd been raped, her mum would say 'how can you talk about that to me that's awful'. And she talked to her sister and her sister said ' oh that's terrible I don't want to hear about it'. So she sort of tried different people and they couldn't tolerate it...because people couldn't cope with the idea that the lady with learning disabilities had been raped they couldn't, they couldn't deal with it. "*

Vicky, Focus Group 2: " The child care social worker who was involved talked about it as "shared care" foster placement, would be lovely and tried to sell it to her that you won't have any sleepless nights....You know it's like you can't sanitise it you know you can't turn it into something nice and fluffy. "

The usefulness of PTSD as a concept

One or two participants from each focus group talked about people with learning disabilities they had previously worked with who fulfilled the criteria for PTSD. One participant expressed the view that the concept of PTSD was likely to be more appropriate for people with milder learning disabilities.

A strong theme recurring throughout the second focus group was a discussion about how appropriate is was to use the concept of PTSD with people with learning disabilities, and the problems associated with it. Some participants talked about people who did not fulfil all of the criteria for the concept of PTSD but who did present with distress around a particular event. There was agreement in the second focus group that the concept of PTSD was less helpful if people could not verbalise their experience i.e. if they could not tell you they were having flashbacks or nightmares.

James, Focus Group 2: "there's a whole kind of spectrum so some people like the first lady who seem to be more classic through to people who have no speech who become agitated around a certain situation then staff make a link."

Summary of the main findings of the pilot study

There were three main types of traumatic events that were considered to be traumatic for people with learning disabilities: sexual and physical abuse; bereavement, that was complicated by seeing the person dying or having to move at the same time; and having children removed by social services. There was a general consensus in the focus groups that many people with learning disabilities experience multiple traumatic events in their lives.

People with learning disabilities were reported to demonstrate some reactions to traumatic events that were similar to the concept of PTSD. These types of reactions were re-experiencing the event through flashbacks, nightmares and distressing dreams; becoming distressed at reminders of the event; avoiding reminders of the event and hypervigilance and increased arousal.

Potential differences to the concept of PTSD were described as behavioural responses to traumatic events; physical health problems and duration of the response to

trauma. Other factors that need to be considered when thinking about how people with learning disabilities respond to trauma are the appraisal of an event and support in the person's environment.

The concept of PTSD, according to the criteria in DSM-IV (American Psychiatric Association, 1994) can be useful for some individuals with milder learning disabilities, however, for individuals with more moderate to severe learning disabilities it may be less helpful as they may not be able to verbalise their experiences.

Implications for the main study

The main implications for the main study were as follows:

1. The researcher made the decision not to use Criterion A in DSM IV for PTSD, which only included people who have experienced or witnessed events that involve actual or threatened death or serious injury to others. Instead people with learning disabilities were included in the study who had experienced traumatic events that were identified in the pilot study including sexual and physical abuse, bereavement of a loved one and having children taken into care.

2. Another decision that was made was not to have criteria that excluded people who had experienced a traumatic event many years ago, since the findings of the focus groups suggested people could show post-traumatic reactions to events many years later. The eligibility criteria for the study were: a person who had experienced a traumatic event more than three months ago, that was significant to them, had changed their life and was something they still talked about.

3. The researcher decided not to exclude people with learning disabilities who had experienced multiple traumatic events from the study, acknowledging the likelihood that many people with learning disabilities have experienced multiple trauma in their

lives. Specific questions were included in the interview schedule that addressed this issue. People were asked to say which event bothered them the most, which one they thought about the most and to pick one event to talk about in the interview.

4. In response to the findings that people with learning disabilities may show reactions that are similar to and different from the concept of PTSD, according to DSM-IV (American Psychiatric Association, 1994), the researcher designed the interview schedule with questions that asked how the person was re-experiencing the event and what their thoughts and feelings were in response to the event. It also included questions about how they were sleeping and how the traumatic event affected them in their body.

5. Another factor highlighted by participants of the focus groups was the role of support in the environment. The researcher decided to ask questions about support in the interview schedule. The person was asked questions about whether they had talked about what happened at the time of the event, which person they had chosen to talk to and what the response had been. Also what their feelings were about talking about the event in the interview.

6. The importance of how the person with learning disabilities appraises a traumatic event was one of the findings of the pilot study. This supported the researcher's use of the IPA methodology to explore with individuals the meaning of the life event to the person with learning disabilities. Questions about what the person expected to happen to them at the time of the event and how the event had affected their life were included in the interview schedule (see the interview schedule in Appendix No. 5)

Main Study

Introduction

The first aim of the main study was to explore the impact of traumatic life events

on the lives of adults with learning disabilities. This was achieved using the PDS form and

the individual interviews with participants. The second aim was to explore the appraisal of

the trauma by adults with learning disabilities looking at how they make sense of their

experiences. The term trauma has been used in this chapter to refer to different numbers

and types of traumatic events, as many participants spoke about more than one traumatic

event in their interview.

The Posttraumatic Diagnostic Scale (PDS)

Six of the participants completed Part 1 of the Posttraumatic Diagnostic Scale (Foa

et al., 1997). Five of the participants completed the remainder of PDS following the

individual interviews. The sixth participant prior to a third meeting experienced a number

of events that were related to the original trauma and therefore it was considered

inappropriate to administer the remainder of the form.

Table 1: Types of events experienced

Name	Types of traumatic events marked in Part 1 of the PDS	Traumatic event chosen to talk about in the interview and using the PDS
Rachel	Non sexual assault by someone you know, sexual assault by a family member, life threatening illness	Sexual assault by family member
Mary	Sexual assault by a family member, non-sexual assault by a family member, sexual assault when younger than 18 with someone 5 years older than you, children removed by Social services	Having children removed by social services
Craig	Non-sexual assault by a family member, other traumatic event – mum dying	Mum dying
Ricky	Non-sexual assault by a family member, non-sexual assault by a stranger – a gang of girls beat him up, sexual assault by someone you know, sexual assault by a stranger, sexual contact when younger than 18 with someone 5 years older	Sexual assault by stranger
Robert	Serious car accident, non-sexual assault by someone you know, other traumatic event - dad involved in a pit strike	Dad's involvement in a pit strike
Simon	Sexual contact when younger than 18 with someone 5 years older than you, sexual assault by a family member, neglect	Childhood sexual abuse and neglect by parents

Table 2: Results from the PDS

Name	Does the symptom severity meet each Criterion?						Fulfil PTSD Criteria
	Criterion A	Criterion B	Criterion C	Criterion D	Criterion E	Criterion F	
Rachel	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Craig	No	Yes	No	No	Yes	No	No
Ricky	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Robert	No	Yes	Yes	Yes	Yes	No	No
Simon	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Summary of findings from the PDS

Ricky, Rachel and Simon said that the traumatic event that bothered them the most was a sexual assault by others. All three participants fulfilled the criteria for PTSD, according to DSM-IV (American Psychiatric Association, 1994). They believed that their life was in danger and they felt helpless or terrified. They re-experienced the trauma in different ways, used avoidance as a coping strategy and experienced anger or sleep problems. They indicated that two or more areas of their life were affected by the trauma. All of them experienced symptoms that began at least six months after the traumatic event occurred. Craig and Robert did not fulfil the current criterion A for PTSD, defined by DSM-IV (American Psychiatric Association, 1994). Robert did not witness his dad being seriously injured although he feared that would happen and Craig did not feel helpless or terrified at the time of his mother's death. Craig and Robert also stated that the problems they identified in the PDS form were not interfering with any areas of their life.

Four of the participants answered questions on the PDS about traumatic events that had occurred more than five years ago. The other participant, Craig talked about an event that had happened two years ago.

IPA analysis of the individual interviews

Through the process of data analysis an organising conceptual principle emerged around which super-ordinate themes and sub-themes were constructed into a coherent framework. Methods that were used by the researcher to identify the organising conceptual principle were reading "Tricks of the trade" by Howard Becker (1998), using cue cards to think about the relationships between themes and explaining the main themes of the research to a colleague. The organising conceptual principle that emerged from the data was whether the person with learning disabilities perceived the world as a safe place,

where people could be trusted or a dangerous place, where people couldn't be trusted. The model that was constructed following the emergence of themes from the data will be presented first to help the orientation of the reader.

The main super-ordinate themes with sub-themes in brackets are described as follows:

1. The impact of the trauma (things remind me about the trauma; I have thoughts and pictures about the trauma; I have sleep problems, physical health problems and feel angry; I worry about the future)

2. I avoid things that remind me of the trauma (I can't avoid my family, even if they have hurt me as I depend on them for care)

3. I am prepared for danger in the future (I need to protect myself in the future; I want revenge; others will look after me and protect me)

4. The tension of talking or not talking (Talking about it makes me feel better; I can't talk about it; I need to hide it; my physical appearance betrayed me)

5. The struggle of who to blame (I blame other people; I blame myself; other bad stuff has happened to me; I couldn't stop it from happening; I didn't see it coming)

Figure 1. Framework of themes

The Impact of the trauma
- Things remind me about the trauma
- I have thoughts and pictures about the trauma
- I have sleep problems, physical health problems and feel angry
- I worry about the future

I try to avoid thoughts or reminders about the event

I can't avoid my family, even if they have hurt me as I depend on them for care

I am prepared for danger in the future
- I need to protect myself in the future

- Others will look after me and protect me

The world is a dangerous place

The world is a safe place

The tension of talking or not talking
- Talking about it makes me feel better

- I can't talk about it

The struggle of who to blame
- I blame other people

- I blame myself

Key to Figure 1

Two-way relationship between themes   ←———→

A process relationship between themes   ———→

Conflict   ←——→

Organising concept: Is the world a dangerous or a safe place?

The world is a dangerous place
↕
The world is a safe place
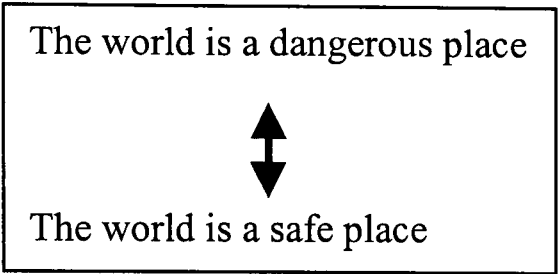
The world is a dangerous place

The theme that participants believed the world to be a dangerous place developed

from the analysis in a number of ways. The first factor concerned the occurrence of trauma

where the person believed there was a risk or harm to themselves or others. The person's

response to this was to feel scared and upset. The other factor suggesting to the person that

the world is a dangerous place was the lack of protection and care demonstrated by others

either at the time of the event or in response to reminders of the event. This raises the issue

for the person with learning disabilities about who they can trust in the world.

I thought either others or myself were going to die

Most of the participants talked about trauma where they believed that either they or

a family member were going to die at the time of the event or shortly afterwards. The

following participant described his belief that his parents might kill him because his family

told the police that they were being sexually abused.

Interviewer: *"What do you think might have happened to you?"*

Simon: *"Might (2) kill me.... 'Cause we tell the police." L949-59*

Another participant spoke of his belief that the perpetrator might have killed him during the sexual abuse.

Ricky: "well I thought he was going to kill me 'cause he had a sharp knife." L269

Two of the participants were concerned that members of their family were hurt by the trauma. One example of this was a participant whose father continued to work during a pit strike in Nottinghamshire.

Interviewer: "What did you think might happen to your dad?"

Robert: "(keep thinking he) got injured." 317-322

I felt upset and scared

Some of the participants also mentioned feeling upset and feeling scared at the time of the trauma.

Interviewer: "So what did you think would happen to you, did you know?"

Craig: "No I didn't think anything about er moving, I just a bit worried about my mum." L397-400

Interviewer: "how did you feel then when you thought he'd got injured,?"

Robert: "thinking worried, upset." L326-333

The lack of protection and care from others

During and after the trauma there was a lack of protection and care demonstrated by others. The majority of participants give examples of behaviour by family members that was neglecting and abusive. The following excerpt is taken from one participant's account.

Craig: "And he came up to my Grandma's, picked me up and <u>he slung me through the</u> <u>glass doors.</u>" L20-1

This participant described the attempted rape by her brother:

Rachel: "me brother asked me ex-husband, if he'd go to the shop for him because he didn't feel very well....and while he was gone he started loving me or someat." L66-78

There was only one participant who didn't refer to a lack of care by their family. However, he referred to the lack of protection given to horses, men and police during the pit strike.

Robert: "in pick, picket line (stood) horses, its, its cruel those horses like that". L30-31

"stones the horses, the horses fell down." L56

Interviewer: "How did you feel when you saw these people throwing stones at the drivers?"

Robert: "They shouldn't erm, police come...police injured." L1165-7

It is possible that for some participants their belief that the world is a safe place was shattered by the trauma that they spoke about in the interview. For other participants who had different family histories, which may have included other trauma, the belief that the world is a dangerous place may have been a belief that they already held.

The world is a safe place

The world is a safe place is a belief that also emerged from the data as a theme. Factors that developed the belief that the world was safe were receiving support from

others following trauma, ongoing support at the present time and recalling times prior to the trauma when they felt cared for.

Receiving support from others

Most participants gave examples of times when other people supported them following trauma. The following participant described the support he received from staff following his mother's death.

Craig: "She rung Sharrow Road told 'em Craig's mum had died and then, the next minute the erm table was laid and they'd got me dinner out" L478-80

This participant gave an example of when his neighbours accompanied him to see his Grandma's dead body.

Robert: "next door neighbour they come with me (.) his sons come with me, keep me company." L2194-5

Some participants who had moved since the trauma occurred spoke about the current support that they were receiving from others.

Interviewer: "What do you like about it?"

Simon: "Good staff, look after me" L1570-6

Half of the participants recalled care they had received in the past and remembered good times prior to the trauma.

Rachel: "you know if it's a nice film and somebody dies in it, it brings back memories to me"

Interviewer: "what sort of memories,?"

Rachel: "how me mam was good to me." L227-31

Nostalgically recalling people in the past may have comforted the participants as they remembered times when the world was a safe place for them. People with learning disabilities rely on their families and staff that work with them for support and care. When family or staff members have abused that relationship it is hard for people with learning disabilities to know whom they can trust. The relationship between the beliefs that the world is a dangerous place or the world is a safe place will be discussed in relation to each super-ordinate theme.

Theme 1: The Impact of the trauma

Participants were impacted on by the trauma mentally, emotionally and physically as a consequence of the belief that the world was a dangerous place for them.

The Impact of the trauma
- Things remind me about the trauma
- I have thoughts and pictures about the trauma
- I have sleep problems, physical health problems and feel angry
- I worry about the future

Things remind me about the trauma

The majority of participants mentioned things that reminded them of trauma in the past. They described how they felt fearful or upset when reminded about the trauma. An interpretation of this response is that it reminded them of a time when they were vulnerable

and unprotected. One participant described situations at the time and years later that reminded her of her children who had removed by Social services.

Mary: *"All the babies were crying and I could not get to sleep. Kept moving me from one room to another I didn't know where to put my face, when I saw them babies"*

Interviewer: *"How did you feel when you saw the babies?"*

Mary *"it upset me, made me cry." L1411-1424*

Mary *"seeing 'em in push chairs carrying 'em. Yep, still upsetting me even when I go out with Dave." L1440-1*

Other participants described watching television and remembering aspects of the trauma. This is an excerpt taken from a participant who gave an example of something on television that reminded him of the pit strike.

Robert: *"In India, Pakistan there… (Man with stones) chucking stones at each other." L1400-9*

I have thoughts and pictures about the trauma

Some participants spoke about constantly thinking about the trauma, as if they were preoccupied with what had happened to them. For a couple of participants this pre-occupation seemed to help to keep the memory of loved ones alive.

Interviewer: *"Are there particular times when you think about her and,?"*

Craig: *"Always do." L644-6*

Thinking about loved ones reminded the participant of a time when they felt cared for and protected prior to the trauma. However, for another participant thoughts about the event intruded into his daily life leaving him feeling out of control.

Ricky: "BANG, it's there again and <u>I can't get rid of it (2). It's doing my head in.</u>"

L429-30

Ricky: "I went loopy 'cause it was constantly, constantly going through me head." L398-9

Most of the participants talked about images that they could see in their heads that were associated with previous events they had experienced. For some participants the images they recalled were the faces of their perpetrators.

Ricky: "Every time it's in me head I can always, I can always see him." L332

Interviewer: "What do you see when you close your eyes?"

Simon: "see picture…about my real mum and dad." L1336-42

I have sleep problems, physical health problems and feel angry

The majority of participants described some sleeping problems that were related to thoughts, feelings and images associated with the trauma. This participant described his experience of thinking about the trauma and sleeping problems.

Ricky: "yeah it's like getting into me head all time and a load of like, er nightmares that's why (we had to move) and I offend and that [um] that's why I'm sleepless at night." L114-6

For some participants there was a link between having pictures in their heads about the trauma and having problems sleeping.

Interviewer: "Do you ever have any problems sleeping?"

Simon: "little bit"

Interviewer: "What sort of problems do you have?"

Simon: "Worried about my real mum and dad"

Interviewer: "What do you worry about,?"

Simon: "Might come in, in here." L1259-81

Interviewer: "What do you see when you close your eyes?"

Simon: "see picture...about my real mum and dad." L1336-42

An interpretation of the link between thoughts, feelings and images associated with the trauma and sleeping problems is that participants were reminded of a time when they or others were in danger which caused them to worry about being in danger in the future. Another explanation of the link between thoughts and sleeping problems is some participants may have been ruminating and struggling with why the trauma had happened to them and what they could have done to prevent it from happening.

A few of the participants mentioned they had physical health problems as a consequence of having thoughts and worries about the trauma. This excerpt described the effect that thinking and worrying about her daughters had upon one participant.

Mary: "Yeah, it's all in me head all the time...get a lot of headaches worrying about 'em." L370-4

Half of the participants, who were all men talked about feeling angry as a consequence of the trauma.

Ricky: "<u>I know</u> *it's in the past, but it's still going through my head, I always get angry, I always take it out on certain people.*" *L361-2*

Interviewer: "*Do you remember what you thought about that,?*"

Simon: "*I was too angry, I was too angry.*" *L149-51*

There appeared to be a link for a couple of participants between feeling angry and difficult behaviour that challenged others. Ricky talked about his violent behaviour.

Ricky: "*I was a really violent person...only my anger wise.*" *L831-6*

Interviewer: "*so did you hurt somebody who worked here then,?*"

Ricky: "*I've hurt somebody but that's with me fist, 'cause he said something about me mother and I just hit him like a header.*" *L849-52*

I worry about the future

All of the participants talked about fears they had for the future that were related to the trauma they had experienced in their lives. One participant spoke of his fear that his dad might find him again and start to physically abuse him again.

Craig: "*If I see him now he would have done it again and again...if he finds out I'm in Sharrow, he will find, find this place and comes in and starts again.*" *L165-70*

Another participant spoke of his fear that his mum and dad might hurt someone else.

Simon: "*Might, might do it someone else, like hurt someone else in here*"

*Interviewer:*   "*What do you worry they might do to someone?*"

Simon: "*Might touch 'em.*" *L1486-98*

These participants had specific fears about family members who had hurt them in the past finding them and hurting them or others again. Other participants appeared to have developed more global beliefs about danger in the world. This excerpt is taken from the transcript of a participant who had developed a belief that all men were potentially dangerous.

Rachel: "I'd never marry again that's how I feel (8) I mean if I met somebody now, a nice young bloke he could turn out the same...same as Paul." L446-56

Theme 2: I avoid thoughts or reminders about the trauma

This theme is concerned with how participants use avoidance, as a method of trying to cope with the impact of the trauma upon their lives.

I avoid thoughts or reminders about the trauma

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I can't avoid my family, even if they have hurt me as I depend on them for care
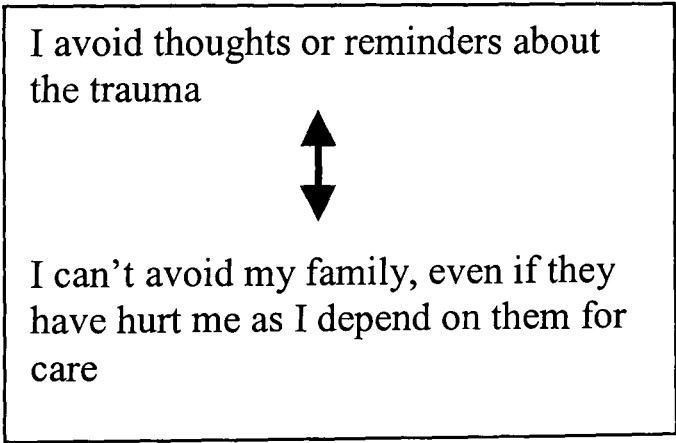
I avoid thoughts or reminders about the trauma

All participants spoke about trying to forget and ignore thoughts and reminders about the trauma. One possible interpretation for this behaviour is that the thoughts reminded them of a distressing time in their lives as the following participant described.

Interviewer: " What happens if it comes into your head?"

Rachel: "I just try and forget about it...well it's not a very nice thing to remember."

L284-7

The participant also spoke about the way she used distraction to help her forget.

Rachel: "I just, I just look at me telly...Put different stations on I do, not a very nice thing to remember." L293-7

An interpretation of this action is that thoughts and reminders of the trauma reminded participants that at the time of the trauma the world had been a dangerous place for them, which is why they wanted to try and ignore them. To cope with worrying that they were at risk of being harmed in the future most participants avoided people and places that were associated with the trauma. This participant talked about a situation she avoided because she was worried that she would be hurt again.

Mary: "I daren't go in the bath 'cause he might do it again...so I always have a wash down." L1470-1

Avoiding thoughts and reminders about the trauma meant that participants created the illusion that the world was safe for them again. Unfortunately this was not an effective strategy because it meant that the participants did not challenge their thoughts or beliefs that the world was a dangerous place for them. Consequently the trauma continued to impact upon their lives and their beliefs were maintained.

I can't avoid my family, even if they have hurt me as I depend on them for care

There was one participant who talked about the conflict of wanting to avoid his parents for what they did to him but also wanting to live with them again under the condition that they would never hurt him again. Early on in the interview he was adamant that he didn't want to see them again.

Interviewer: " Have you ever met them again?"

Simon: *"Don't want to"* 749-51

Simon: *"Never again, don't want to see them any more."* L1036

It could be interpreted that his perception was that he was keeping himself safe by not seeing them. Then later in the second interview he spoke about them looking after him again with conditions.

Interviewer: *"Is there anything you'd like to say to them,?"*

Simon: *"I'd tell 'em don't touch my lower parts again...You have to look after me properly this time."*

Interviewer: *"Right, so, so you would tell them that they had to look after you properly.?"*

Simon: *"Yes, got to...My real mum dad got, must look after me properly.*

Interviewer: *"Right, would you want them to look after you again Simon,?"*

Simon: *"Yeah."* 1881-1899

Although his parents had not looked after him well Simon believed that if he told them to look after him properly he would be safe in their care. Another participant faced a similar dilemma. She was told by the police to keep away from her brother but could not keep away from him. Here is her explanation for going to see him again.

Rachel: *"I says I just can't keep away from my own brother can I ?...well it was me own blood warn't it?... I had to go up and he told me not to come up no more."* L169-173

One interpretation of the dilemma faced by these two participants is that they have a belief that although their family members have treated them badly in the past because they are family they can be trusted not to hurt them again. They may know there is a risk

that they will be hurt again but because they are family members and they depend on their care they can't keep away from them. In general this may be a dilemma that people with learning disabilities face because although they want to avoid reminders of the trauma they are also dependent on the care their family provides.

Theme 3: I am prepared for danger in the future

The theme of being prepared for danger in the future emerged from the analysis. It can be understood in relation to the lack of care and protection that was given by others in the past and worrying about dangerous situations in the future. Participants spoke about proactively protecting themselves in the future from further harm and depending on others to protect them.

I am prepared for danger in the future
- I need to protect myself in the future
- I want revenge

⬍

- Others will look after me and protect me
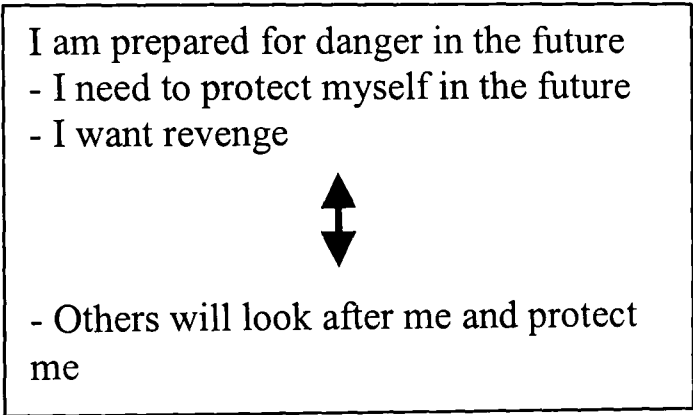
I need to protect myself in the future

Most participants spoke about ways that they would protect themselves in the future. This behaviour can be understood in relation to a global belief that the world still is a dangerous place and other people can't be trusted to protect me from future harm. This participant who had been sexually abused talked about exercising regularly and standing up for himself.

Interviewer: "*so you weren't physically strong*"

Ricky: "*...I am now...you see the people in here they don't, they don't erm challenge me you know like wind me up, 'cause I stick up for mysel or just ignore it at the time. <u>Bang that's it I just get in there.</u>*" *L670-682*

I want revenge

Several of the participants spoke about punishing those who had hurt them or getting revenge. This included three of the men. Getting revenge could be perceived as a way of getting rid of what the participants consider to be dangerous in the world so that they feel safe again. Psychologically it is an effective means of dealing with angry feelings towards others about the trauma and the fear that the trauma might happen again. This participant spoke about getting revenge on his parents:

Interviewer: "*Do you think that they'd ever do that to you again?*"

Simon: "*No, never, I'd do Karate on 'em*"

Interviewer: "*Would you?*"

Simon: "*Kill 'em*"

Interviewer: "*Yeah? Would You?*"

Simon: "*Revenge, doing my revenge on 'em.*" *1504-26*

Others will look after me and protect me

Some participants talked about staff and family members looking after them and keeping them safe from future harm. This participant talked about what would happen if his father became ill in the future.

Interviewer: "*If you worry about something happening to your dad what do you do?*"

Robert: "*...if heart attack mummy phone ambulance.*" *L2280--3*

Robert had a close relationship with his family and he trusted them to help him in the future. He also had not been neglected or abused by them in the past, which was a different experience to many of the other participants. Other participants spoke about members of staff protecting them in the future.

Interviewer: *" And do you think the staff would ever let anybody in or not?*

Simon: *" Not my real mum and dad...yeah, they'd fetch police." L1450-61*

Simon demonstrated the belief that some participants held of seeking to protect themselves from further abuse but also recognising that they could trust others to help them. The participants that were able to talk about others protecting them had developed trusting relationships with staff members. There were a couple of participants who did not talk about family or staff members protecting them in the future, a belief that was probably linked to a global lack of trust of others to help them.

Theme 4: The tension of talking or not talking

The theme of the tension between talking about the trauma and the impact of the trauma and not talking about them emerged from the data. This theme focused on the issue of whether people could be trusted or not and was linked to the central theme of whether other people were perceived to be safe or dangerous. Also included in this theme were the reasons people chose to talk or not talk about the trauma to others, trying to hide what had happened and being betrayed by your physical appearance.

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│ makes me feel better │          │                      │
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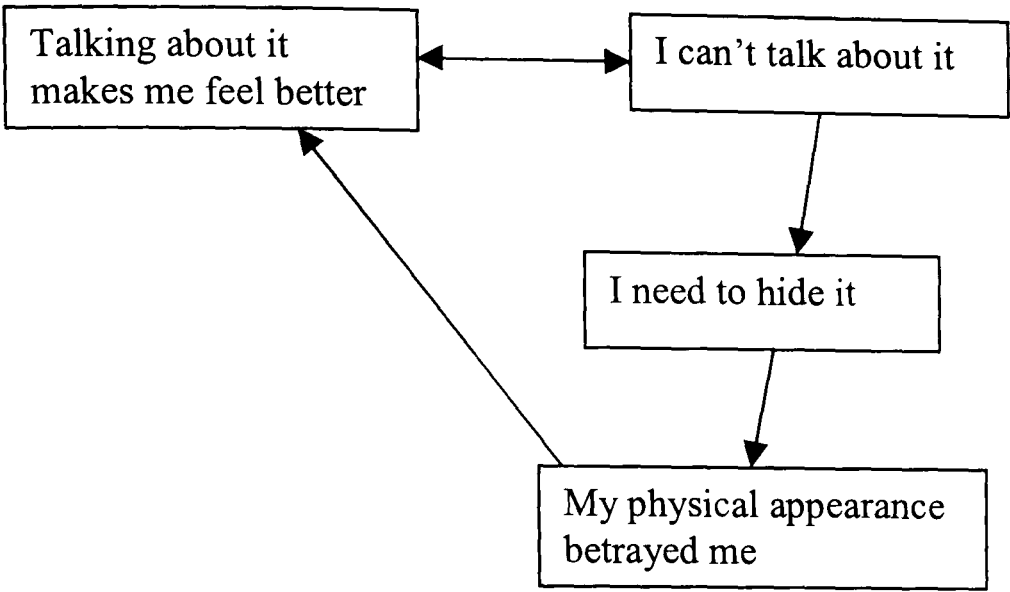
Talking about it makes me feel better

All of the participants gave examples when they had talked about the trauma and

the impact of the trauma to others. The main reason they gave for talking about it was that

it made them feel better.

Interviewer: Did you talk about it with anyone?"

Robert: "yeah, told my dad" L1446-8

Interviewer: "and how did you feel when you talked about it?"

Robert: "alright"

Interviewer: "Did it help you talking to your dad?"

Robert: "yeah."   L1462-8

Interviewer: "Does it help to talk about them?"

Mary: "Course it does" L1053

Robert was a person who talked about spending time with his family and he was

able to talk to his father about things that reminded him about the pit strike. This

participant talked about the consequences they experienced if they didn't talk about how

they were feeling.

Rachel: "It's best to talk about a thing than to keep it back in your mind...cos...if you keep it back in your mind it sort of builds up and builds up, and then you come out with it bursting out crying. "L301-9

Some participants talked about having mixed feelings as a result of talking about the trauma.

Mary: "I want to talk about 'em it makes me a bit better, and a bit sad." L1347-51

An interpretation of the ability of people to talk about the trauma or the impact of the trauma is that they feel they can trust the person they were talking to. Even if people perceive that there is still danger in the world they have found a safe person to whom they can talk about their experiences. The consequences of being able to talk about their experiences with others could challenge their belief that the world was a dangerous place for them and improve their psychological well-being.

I can't talk about it

Finding it difficult to talk about the trauma or reminders of the trauma was a common theme expressed by the majority of participants. This excerpt is taken from one participant having trouble sleeping.

Rachel: "Last time I rung the buzzer, she got out of bed.. whats up Rachel? I couldn't tell her." L541-2

Interviewer: "What was it that made it hard to tell her?"

Rachel: " I just didn't want to tell her....I've never really told anybody." L547-58

For three participants not talking about the trauma was related to wanting to avoid thoughts about the trauma.

Interviewer: "What sort of thoughts do you have about your mum now?"

Craig: "I just don't mention her... but it's hard, it's hard to think about it." L603-9

Not talking about the trauma means that participants can avoid thinking about a time when they were distressed, vulnerable and afraid. It also maintains the belief that the world is a dangerous place for them. There were many reasons given by participants about why they did not want to talk about the trauma or the impact of the trauma. Some of the reasons related to the concept of not knowing which person to trust with the disclosure. These reasons included being afraid of telling others and wondering what people might think of you if you told them what's happened to you.

Ricky: <u>*"I can't tell anybody 'cause I'm scared to tell" L438-9*</u>

Interviewer: *"So you're scared what they'll think about you?"*

Ricky: *"Yeah they might call me a queer bastard or whatever." L462-4*

The reaction of others to his initial disclosure of abuse was very important to this participant as it discouraged him from talking in the future. Another reason shared by a different participant was worrying that what he said would remain confidential.

Interviewer: *"And were you able to talk to anyone at the time about how you felt,?*

Craig: *"No. No I just couldn't face it, I couldn't even face it to tell other people, you see, you've got to be, I've got to be careful (.) w-what I say about it (or they say) 'oh Craig said this' or 'Craig said that'. It always comes back to me you see.' L437-441*

Thinking about the concept of the world being a dangerous place, participants were unsure which person was a safe person to talk to. The participants in the study were predominantly people who had been abused and mistreated by family members close to them, a likely consequences of this abuse is that people are left feeling unsure whether they

can trust anyone. An interpretation of these findings is that if you can't trust your own family then it is difficult for people to judge who you can trust in the world.

Other reasons shared by participants for not talking about what had happened were knowing that it wouldn't change the trauma, finding it hard to talk to people you don't know very well, not being believed, other people not wanting to listen to them and being too young to tell people. Another interpretation why participants found it difficult to talk to other people about the trauma is that they believed that they were partly to blame for what happened to them and they felt ashamed. Two participants in the study who found it very difficult to talk to others about their experiences also partly blamed themselves for the trauma. The psychological consequences of not talking about the trauma and not being challenged by others maintained their belief that they were partly to blame for the trauma.

I need to hide it

Linked to not talking about the trauma or the effects of it were the attempts by some participants to hide what had happened to them or to hide how they were feeling about the trauma. A possible interpretation of this behaviour is that people were afraid to talk about the trauma or how they were feeling because they perceived that they were still in a dangerous situation and saying something may have made the situation worse for them. This excerpt is taken from a participant who initially hid the fact that her brother had attempted to rape her.

Rachel: "So I heard Stephen say, me ex, where's Rachel? So I says I'll not be long I'm having a wash, cos I didn't want to say nought infront of Paul." L89-93

By saying nothing maybe she believed that she was keeping herself safe from further harm. None of the participants in the study talked about being threatened by others to keep quiet about the abuse they were experiencing.

My physical appearance betrayed me

The participant, who initially felt unable to tell her husband about what her brother had done to her, was betrayed by her physical appearance. This resulted in the disclosure to her husband about what had happened to her.

Rachel: "as soon as I went outside with Stephen I went as red as anything and he could tell what was up. He says <u>what's wrong</u>, he says I know there's someat wrong. I said I don't like saying nowt (.) but while you were gone he tried to touch me up." L123-7

The disclosure resulted in her husband calling the police, something she didn't want, which resulted in a loss of trust towards her husband and the police and a fear of talking about the experience again. The participant was unable to say why she had gone red, possible interpretations were that she felt ashamed about what had happened to her or that she felt angry. For another participant being betrayed by his physical appearance in a Doctor's surgery lead him to be removed from the abusive situation by his mother.

Craig: "And he looked at my body and he says bloody hell Craig and I says what's the matter? and he says you've got about 32 bruises all around your body." L 129-31

Participants gave other examples of times when their physical appearance betrayed their emotions about the trauma or reminders of the trauma. This participant talked about the relationship between his physical appearance and how he was feeling.

Interviewer: "so how do they know if you're worried, what do you do?"

Robert: " little bits tears in me eyes." L607-9

The conflict of whether to talk or not talk

Some participants talked about the conflict of whether to talk about the trauma and the impact it had on their life or whether to keep it to themselves. Here is an example taken from one of the interviews where the participant wanted to talk about how she was feeling about missing her children and what the consequences would be if she did.

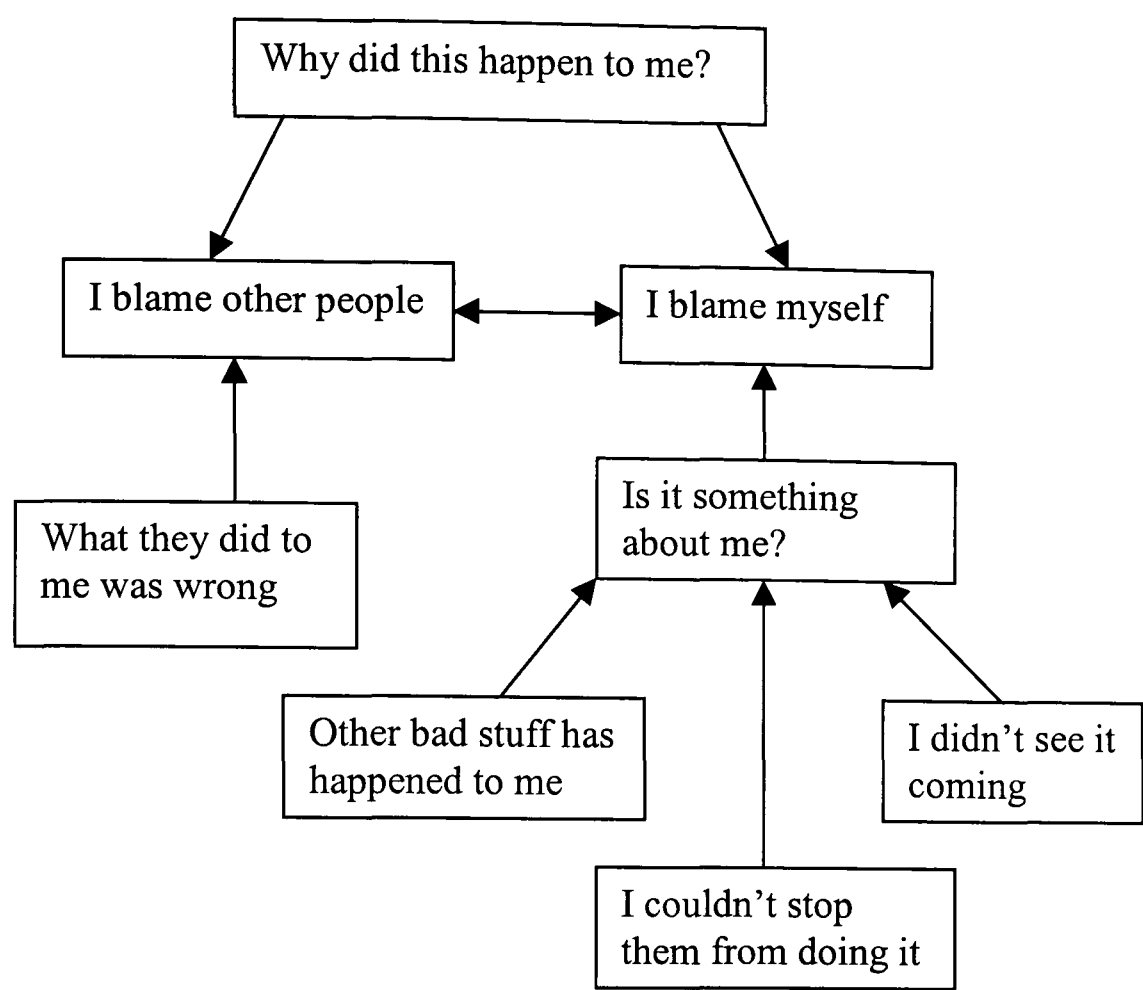*Mary: "I want to talk about 'em but he don't." L1061*

Interviewer: "How do you think it's affected your life then?"

Mary: "It's breaking a marriage up... 'cause I keep talking about 'em don't I?" L1078-90

The tension of whether to talk or not can be interpreted as a struggle to know whether the person you want to talk to is trustworthy or not. If you feel that they can be trusted and you have found a place that is safe in the world then you are more likely to open up and talk about the trauma and its impact upon you. If you find it hard to trust others or you believe that talking will cause you distress and harm in the future then you will be less likely to talk about your experiences. The tension of whether to talk or not also appears to be related to whether you are using avoidance as a strategy to protect yourself and how much you think you are to blame for the trauma.

Theme 5: The struggle of who to blame

Experiencing difficult events in their lives lead the participants to try and make sense of what had happened to them. This theme centred on the question of why the trauma occurred and whether they or others were to blame.

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Why did this happen to me?

Half of the participants appeared to be searching for an explanation why they or

others had been hurt in the past. This is an excerpt taken from a participant who questioned

her husband's behaviour.

Mary: "I want to know why he's hurting me." L1464

Other participants asked similar questions.

Robert: "why, why, why use police horse, why use police horses pit strike, it's stupid, it's,

it's cruel on horses cruel." L544-5

In the struggle of trying to make sense of why the trauma had happened to them,

participants sought someone to blame for what had happened to them.

What they did to me was wrong

Most of the participants talked about other people behaving in ways that were wrong and that they shouldn't have done the things they did. This view was held about a variety of events including sexual abuse, neglect from parents, having children removed and the pit strike. This excerpt was taken from the interview of a participant who was sexually abused by her brother.

Rachel: "He started... undressing me and kissing me and things like that which shouldn't have been." L81-3

Another participant gave his opinion on the pit strike.

Robert: "NO, NO, NO, NO, IT'S WRONG doing that...they shouldn't, they shouldn't strike first place." L1077-85

I blame other people

Over half of the participants explicitly stated that they blamed someone else for the trauma. Three participants blamed one of their parents for what had happened to them. This excerpt was taken from a participant who had been physically abused by his father.

Craig: "And what we found out was he had too much work at the police station than at King's Road that drove him mad." L91-2

This participant had her children removed by social services and she blamed social services and her mother.

Mary: "We didn't sign no papers (1) they didn't give me a chance. Had everything for that baby, had everything, clothes, teddy bears, the lot." L158-9

Mary: " she'll think we can't cope I know but I can cope"

Interviewer: "who said you couldn't cope,?"

Mary: "mum." L1008-12

A possible psychological consequence of blaming others for the trauma is that participants continue to believe that the world is an unpredictable, dangerous place for them. If other people are to blame for what has happened to them, it is out of their control and there is a threat that people could hurt them again in the future. Several participants who blamed others for the trauma talked about feeling angry and wanted revenge to protect themselves from future harm. Another participant who blamed his father for the trauma did not talk about feeling angry and trusted that others would take care of him in the future.

Blaming others may also make the person feel better psychologically as they acknowledge what happened to them wasn't their fault and they don't need to feel ashamed or guilty. It may also make them more likely to talk about their experiences of the trauma and this in turn may challenge their beliefs that the world is still a dangerous place for them.

Is it something about me?

Analysing participants' accounts of the trauma suggested that some participants were questioning whether they were in some way to blame for what had happened to them.

Other bad stuff has happened to me

Some of the participants talked about the difficult lives they had experienced and gave other examples of the bad things that had happened to them in the past.

Rachel: "too many things has happened in my past...well first that bloke whipped me within our old back yard." L316-8

Half of the participants gave examples of other bad events they had experienced that they had not previously mentioned on the PDS Form at the beginning of the interview. These events included bereavements, a marriage breaking up, nearly being run over, being in hospital many times and being sexually assaulted.

Mary: "Then a woman tried to pick me up on a ca- a ta- a car, she wanted er (1) she was thinging herself in the car. And she wanted me and I started screaming and she wouldn't take me home and she dumped me at the corner. That's when David was inside prison."
L620-23

It could be argued that by using the PDS Form at the beginning of the interview to ask questions about the different traumatic events they had experienced primed the participants to talk about difficult events in their lives. Another interpretation is that participants talked about other difficult events in their life because they perceived themselves to be victims, people who attracted bad things in life. Possibly they were wondering if there was something wrong with them, to make them attract such events. Participants may have held the belief that the world is a dangerous place and also believed there was something about them that attracted danger.

I didn't see it coming

There was a sense from all of the interviews that people did not expect the trauma to happen to them. This occurred irrespective of the type of event they experienced. This excerpt is taken from the account of a participant who did not anticipate what was going to happen to him next.

Ricky: *"we started laughing and messing about you know and then they started beating me up and shit." L37-8*

I couldn't stop it from happening

Most of the participants gave examples of traumatic events that they were powerless to stop. This participant spoke about trying to stop the abuse he was experiencing.

Craig: *"He says right, on that bed, 'ere and he were ruddy belting me, and I kicked him, I pushed him, I hit him. And when I hurt him he was really quite bad again." L75-7*

Reasons the participants gave for not being able to stop the event were being too young to tell anyone, not being strong enough and others not listening to them. A couple of participants were able to give examples of times when they had been able to stop someone from continuing to abuse them. The participant who earlier tried in vain to stop his father from physically abusing him was able to stop him from having custody of him.

Craig: *"But what he wanted to do, he wanted to take me away from me mum, and I says no." L146-7*

I blame myself

The two participants in this study who believed that they were partly to blame for the trauma also found it difficult to talk about what had happened to them with others. The consequences of this were that they developed global beliefs that the world was a dangerous place and they experienced intrusive thoughts and pictures and had sleep problems. The strategy they used to cope with these effects was to avoid reminders and thoughts of the trauma, which maintained their psychological difficulties. Both participants

attempted to regain control by talking about how they would protect themselves in the future, one used a strategy of avoiding men and the other made himself physically stronger than others.

The conflict of whether to blame others or blame myself

Many of the participants blamed others for the trauma though there were also some implications that they also partly blamed themselves. Half of the participants gave explicit examples of this conflict.

Interviewer: "*so do you blame yourself then for what happened?*"

Ricky: "*some parts I do, some parts I don't whereas if he was gay then he's gay but he ain't got the right to do what he did.*" *L750-1*

In summary the dilemma of who to blame is a complex one. If you blame yourself you may be left feeling guilty and ashamed though the world may seem more in your control. If you blame others you may feel better knowing it wasn't your fault yet fearful for it happening again.

Summary of findings from the Main Study

Three participants fulfilled the criteria on the PDS from for PTSD, defined by DSM-IV (American Psychiatric Association, 1994). The three participants had all experienced forms of sexual abuse.

A central organising principle was identified from the data collected in the individual interviews, which was whether participants perceived that the world to be a safe or a dangerous place. Participants believed the world to be dangerous when they thought themselves or others might die at the time of the trauma and when they experienced a lack

or care and protection from others. Conflicting with this belief was the evidence shared by participants that people had supported them and helped them after the trauma. As a consequence of the trauma it was difficult for the participants to know who could be trusted in the future.

Participants described many impacts of the trauma upon their lives, which included seeing pictures about the trauma, feeling upset at reminders of the trauma, worrying about danger in the future, having sleep problems, physical health problems, feeling angry and violent behaviour towards others. Strategies that participants had developed to cope with the impact of the trauma were avoiding thoughts and reminders and preparing themselves for danger in the future. One participant gave an example of wanting to avoid their family but also to have them care for him again even though they had hurt them in the past. Examples of preparing themselves for future danger given by participants were standing up for themselves, seeking revenge and relying on others to help them.

Participants described a dilemma they experienced between wanting to talk about the trauma to help themselves to feel better and not wanting to talk about it due to a lack of trust of others and wanting to avoid thinking about it. Some participants tried to hide the trauma or the effects of the trauma upon their lives and were betrayed by their physical appearance.

In the struggle to make sense of what had happened to them participants tried to find someone to blame. The evidence shared by participants about why they might be to blame was talking about other bad things that had happened to them, not expecting it to happen and being powerless to stop it from happening. The participants who partly blamed themselves for the trauma found it hard to talk to others about their experiences, which maintained their belief that the world was a dangerous place for them. Most participants blamed others for the trauma, which caused them to worry about being hurt in the future

and they prepared to protect themselves. For some participants blaming others lead them to

feel angry and to seek revenge.

DISCUSSION

Introduction

This section begins by relating each theme identified in the main study to previous research in this subject area. The methodological difficulties of doing this type of research are then discussed. Following this there is a description of the main implications of the findings for clinical psychologists working with people with learning disabilities who have experienced traumatic life events. Finally the researcher offers a reflection of the experience of doing this type of research and gives examples of questions that could be helpful when assessing a person with learning disabilities and their carer following trauma.

Relating the results to previous research

Is the world a dangerous or a safe place?

The majority of the participants when asked what they thought would happen to them at the time of the traumatic event spoke in the individual interviews about fearing that either others or themselves were at risk of harm or death. Participants also reported this on the PDS form. The only participant who did not talk about the threat of serious injury or death talked about fearing that she was going to be raped. Some participants also spoke about feeling worried, scared or upset at the time of the trauma. These findings were similar to Criterion A for the concept of PTSD, according to DSM-IV (American Psychiatric Association, 1994) (see Appendix No. 1). The perception that there was a threat to life has been found to be related to the distress from intrusive thoughts and the severity of the symptoms of PTSD in adults in the non-disabled population (Steil & Ehlers, 2000).

An individual's understanding about the concept of death was discussed in the second focus group in relation to the appraisal of an event. Research by Harper &

Wadsworth (1993) found the majority of people with learning disabilities they interviewed in a study about bereavement had some understanding about the concept of death, which included people with more severe learning disabilities. If the participants in this study had some understanding of the concept of death then this may have lead to feelings of fear at the time of the trauma.

One of the factors that may have contributed to the belief that the world was a dangerous place was the lack of care and protection shown by others. Most of the participants in the main study reported that they had either been physically or sexually abused on more than one occasion. Two of the participants chose to talk about other events though they both referred to the experiences of abuse in the interview.

There have been a number of reasons identified in the literature looking at why people with learning disabilities may be vulnerable to a lack of protection and care by others. Factors that have been identified that could increase the risk of abuse are attachment difficulties, parental stress, gender, social isolation, learned helplessness and dependency (see reviews by Sobsey, 1994 and Strickler, 2001). Individuals with learning disabilities may have attachment difficulties with parents who are grieving the loss of an "ideal" child. If individuals develop attachment styles that are insecure then this could affect their ability to relate to others and form trusting relationships in the future. Parents of individuals with learning disabilities may also experience more stress trying to attend to the needs of a disabled person and experience more social isolation. Learned helplessness may be another explanation why adults with learning disabilities are vulnerable to a lack of care and protection from others. If people attempt to stop one traumatic event and fail then they are more likely to believe they cannot stop future traumatic events, so they don't try to stop them. Individuals with learning disabilities may be more likely to experience a lack of

care from others due to a combination of reasons including difficult attachment relationships, parental stress, social isolation and learned helplessness.

Most participants in the main study gave examples of times when other people supported them following trauma. There are a number of researchers who have maintained that positive social support following trauma helps the survivor to recover psychologically from their experiences (see reviews by Janoff-Bulman, 1985; Joseph, 1999b). Research with rape survivors has demonstrated a positive relationship between social support following the trauma and adjustment, both immediately and over time (see review by Fairbank et al., 1995).

The Impact of the Event

The findings from the pilot study and the main study suggested that adults with learning disabilities responded to trauma in some ways that were similar to the concept of PTSD according to DSM-IV (American Psychiatric Association, 1994). The reactions by adults with learning disabilities included having intrusive thoughts and pictures related to the trauma, worrying about future trauma, sleep problems and anger.

There were a few participants who described having constant thoughts about the trauma although others said they only thought about the trauma occasionally. Most participants spoke about having pictures in their heads that were related to the trauma and some of the participants talked about seeing the pictures when they were trying to get to sleep. Research with adults has found that re-experiencing of the event is usually sensory impressions, predominantly visual sensations (see Ehlers & Clark, 2000). All of the participants who completed the PDS questionnaire fulfilled criterion B, which evaluated the re-experiencing the traumatic event.

All of the participants in the main study also spoke about worrying about future traumatic events. The cognitive model proposed by Ehlers & Clark (2000) for the concept of PTSD included individuals over-generalising the event to believe that normal activities are more dangerous than they really are to produce a current threat to life. Most of the participants reported some sleep problems though few mentioned distressing dreams. These findings are similar to previous case study findings of the effects of traumatic events on the lives of people with learning disabilities (Davison et al., 1994; Hudson & Pilek, 1990; McCreary & Thompson, 1999).

The findings from the pilot study and the main study suggest that the reactions of adults with learning disabilities may differ from the reaction of adults in the non-disabled population in a number of ways. The participants in the focus groups gave examples of different behavioural reactions in adults with learning disabilities who had experienced trauma with whom they had worked. Examples of the types of behavioural responses were self-harm, disorganised behaviour, agitation, afraid of being left or abandoned, withdrawal, outbursts of distress and ambivalence about being involved in relationships and activities. Previous research found that people with learning disabilities demonstrated their distress through their behaviour (Bonell-Pascual et al., 1999; Ghaziuddin, 1988; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Monaghan & Soni, 1992; Stack et al., 1987). Some of the participants in the main study also demonstrated behavioural reactions to the events e.g. one participant who was sexually abused committed a sexual offence against a teenager. Balogh et al. (2001) found that two thirds of male perpetrators and all of the female perpetrators in their research sample of children and adolescents with intellectual disabilities were also victims of sexual abuse.

Since the focus in the main study was to explore with adults with learning disabilities the meaning of traumatic life events little attention was focused on behavioural

changes that occurred. More research is needed with carers and staff working with people with learning disabilities to explore changes in behaviour following trauma. As previously stated this research would be particularly valuable with adults with severe learning disabilities who are not able to verbally communicate their distress. Future research could be prospective, similar to research undertaken by Monaghan & Soni (1992) measuring aspects of behaviour prior to and following traumatic events, or retrospectively asking carers for detailed descriptions of changes in behaviour following traumatic events, recording the different types of trauma that have occurred.

Another theme that emerged in the pilot study and the main study was the effect of trauma on the physical health of people with learning disabilities. In focus group 1 examples of physical health problems that developed in individuals with learning disabilities following trauma were asthma attacks, hair falling out and stomach aches. A few participants in the main study also talked about having headaches and eating problems following traumatic experiences. Physical health problems have been identified as a possible effect of trauma in children (Ainscough & Toon, 1993; Shah & Mudholkar, 2000). There has been a lack of attention paid to the impact of trauma on the physical health of adults in the general population (Yule, Williams, et al., 1999). Herman (1992) described a number of physical health problems experienced by adults in the non-disabled population who had experienced multiple traumatic events including headaches and stomach problems. One of the participants described having panic attacks in response to reminders of the event. It was beyond the scope of this research to explore the co-morbidity of post traumatic stress reactions with other mental health problems. Future research trying to find a better clinical description of how adults with learning disabilities respond to trauma should explore physical health reactions and co-morbidity.

Findings from the pilot study and the main study described people with learning disabilities having reactions to trauma that lasted over a number of years. Research with children has also shown the long-term effects of trauma. Yule et al. (2000) found that 15% of children and adolescents had symptoms of PTSD 7 years after a civilian disaster. One explanation why participants interviewed in this research were demonstrating a reaction that has lasted for many years is that the coping strategies they were using to cope with reminders and reactions to the trauma like avoidance were maintaining the traumatic reaction. Further longitudinal research is needed with individuals with learning disabilities to explore the long-term psychological effects of trauma.

The majority of people with learning disabilities who were spoken about in the pilot study and all of the participants interviewed in the main study were people who had experienced multiple life events. Most of the participants in the main study had either been physically or sexually abused on more than one occasion. The other participant witnessed a pit strike on the television on many occasions that involved his father.

There are a number of reasons why people with learning disabilities may be vulnerable to multiple events. Identified risk factors for developing PTSD include parental poverty, childhood trauma and prior life events (see review by Fairbank et al., 1995). Adults with learning disabilities are disadvantaged within society and often grow up in poverty and have low incomes and therefore may be at more risk of experiencing multiple life events. As previously argued learned helplessness may be another explanation why adults with learning disabilities may be more vulnerable to multiple traumatic events. If individuals with learning disabilities are more likely to experience multiple traumatic events then they may also experience higher rates of post-traumatic reactions to trauma.

Terr's work with children (Terr, 1983, 1988, 1991) and work by Herman (1992) with adults suggested that children and adults in the non-disabled population reacted

differently to multiple events than to a single traumatic event. A number of studies with adults in the general population have shown that exposure to multiple interpersonal traumatic events is associated with higher levels of symptoms (see review by Green et al., 2000). Interpersonal trauma included rape, physical abuse and violent crimes and childhood sexual abuse. The impact on the participants with learning disabilities in this research may be related to this experience of multiple interpersonal traumatic events. Further exploratory research is needed with to compare adults with learning disabilities who have experienced multiple events with adults with learning disabilities who have experienced a single event.

I avoid things that remind me of the trauma

All of the participants in the main study gave examples of distraction or avoidance of reminders of the trauma. Avoidance has been associated with not wanting to re-experience the distressing thoughts and feelings caused by the trauma (Brewin, 2001). Thought suppression or trying to push thoughts of the trauma out of your mind has been found to be related to an increase in intrusive recollections of the trauma (see review by Ehlers & Clark, 2000). Research with adults in the non-disabled population showed that using avoidance strategies maintained intrusive thoughts about the trauma and was also related to the severity of PTSD (Steil & Ehlers, 2000). In the model proposed by Ehlers and Clark (2000) the belief that there is a current threat to the person, causes the individual to avoid situations that remind them of the trauma, which maintains beliefs about the current threat in the world. Most of the participants in the main study were struggling to cope with the impact of the trauma and used avoidance as a strategy to help them. However, by using avoidance they were maintaining the impact of the trauma upon their lives and the belief that the world was a dangerous place to them. Further research is

needed to see if other people with learning disabilities use the avoidance strategies shown by these participants in response to trauma; also whether the strategies of avoidance used by people with learning disabilities are similar to those used by adults in the non-disabled population.

A couple of the participants spoke about the dilemma of whether to avoid their family or to continue seeing them. In a similar way to children, adults with learning disabilities are dependent on others for the care they provide. If the people who provide them with care abuse them or neglect them, which was true for over half of the participants that were interviewed, they may feel that they have no choice but to stay in the abusive relationship to receive the care they need. Being abused by family members or being neglected may provide stronger evidence for the belief that the world is a dangerous place than other types of events. This may have serious consequences for the person's belief about trust because if you can't trust your family, then it is difficult to assess the trustworthiness of others.

I am prepared for future danger

Most participants spoke about ways that they would protect themselves in the future. Holding the belief that the world was a dangerous place and worrying about danger in the future caused the participants to talk about how they would protect themselves if they experienced danger again. Many of the traumatic events that happened were unexpected and unpredictable and participants appeared to have developed the belief that they needed to take precautions to prepare themselves for danger in the future so they would not be caught by surprise again. The beliefs that participants had about why the trauma had happened to them also appeared to be related to the methods of protection chosen by participants. For example one participant who described himself as too young at

the time of the abuse talked about what he would say to his parents if he saw them again. Safety behaviours have been described as behaviours that prevent a change in the appraisals about an event (Salkovskis, 1996 as cited in Ehlers & Clark, 2000). When participants engaged in particular behaviours to protect themselves they did not challenge their belief that the world was a dangerous place to them.

Several participants spoke about punishing those who had hurt them in the past or getting revenge. This included most of the men. An explanation why some of the men talked about revenge could be that it is more culturally acceptable for men to talk about revenge and behaving in a physically aggressive manner. Another participant spoke about her mother punishing her brother if she had been alive. Talking about revenge probably helped participants to feel more in control of their world and to cope with their fears that the perpetrators might harm them again (see review by Joseph, 1999a).

Some of the participants talked about family and staff members protecting them from future danger. These participants had built up trusting relationships with their family and staff members. Some of the participants had specific fears about their parents who had abused them in the past, finding them and hurting them or others again, however, they had not developed global beliefs that no-one could be trusted to help them in the future. One explanation for this is that they had positive experiences in the past of other family members who had supported them and protected them from harm.

The tension of talking or not talking

In the pilot study clinicians talked about the importance of people with learning disabilities needing to feel safe and secure before they are able to talk about previous trauma. When people have experienced a betrayal of trust clinicians have to work very hard to create an environment of safety that could facilitate people to talk about traumatic

experiences. All of the participants in the main study gave examples when they had talked about the trauma to others. They had been able to build relationships with staff over time that had enabled them to begin to talk about their traumatic experiences. As previously discussed the role of positive support following trauma has been related to psychological recovery from trauma (see reviews by Janoff-Bulman, 1985; Joseph, 1999b).

Finding it difficult to talk about the trauma or reminders of the trauma was a common theme expressed by the majority of participants in the main study. There were many reasons shared by participants about why they found it difficult to talk including: not knowing who to trust; feeling scared; wondering what people would think of them; knowing it wouldn't change what had happened; not being believed and being too young. As previously discussed participants described using avoidance strategies to cope with the impact of the trauma. Not talking about the trauma or the impact of the trauma to others could also be interpreted as a form of avoidance, a strategy that prevents them reliving the distress of the trauma. Some participants in the main study talked about wanting to hide the trauma or to hide how they were feeling about the trauma. At times the participants were betrayed by their physical appearance, which lead to a disclosure about the trauma and how they were feeling. Research exploring the role of shame suggests that when people experience shame this also causes them to avoid and to deny traumatic experiences (see review by Joseph, 1999a). When participants blamed themselves for aspects of the trauma and felt ashamed about what had happened to them this may have prevented them from talking about their experiences to others.

The response of others to attempts by the person with learning disabilities to communicate their experiences is very important. Family and staff members may feel uncertain about what to say to a person with learning disabilities who have experienced trauma and may avoid talking about it because they want to protect the person and do not

want to upset them further. This could be similar to the reaction of parents to children who have experienced trauma. It is possible that people with learning disabilities could interpret this behaviour by staff as suggesting they were in some way to blame for the trauma or that others do not care about them (Ehlers & Clark, 2000).

Another explanation why people with learning disabilities don't talk about the trauma or the impact of it upon their lives is that there is still a culture in learning disability services that does not want to hear about people suffering (McCarthy, 2001). In the pilot study staff members gave examples of family members and clinicians finding it difficult to listen to people with learning disabilities talk about suffering and traumatic events. This culture in learning disability services can reveal itself in different ways for example clinicians not asking questions to find out whether someone is suffering from reminders of trauma. They may also transmit a message through their behaviour that they can't cope with listening to experiences of trauma by changing the subject or trying to focus on positive examples about how the person has changed. Clinicians have a responsibility to be aware of their own feelings and behaviour and to monitor whether they are preventing people from talking about traumatic experiences.

The struggle of who to blame

Some participants in the main study appeared to question whether they were in some way to blame for what had happened to them. Evidence for this was some of the participants talked about the difficult lives they had experienced and gave examples of other traumatic events that had happened to them. They also perceived the trauma as unexpected and gave examples where they felt they were powerless to stop the trauma from happening to them. In the model proposed by Ehlers & Clark (2000) it is suggested that some of the evidence used by individuals to exaggerate the threat of future events is

the fact that the trauma happened to them, therefore there must be something about them that attracts disaster.

It has been proposed that there are two types of self-blame following trauma; behavioural self-blame which involves attributions of blame towards your behaviour at the time of the trauma and characterological self-blame, which involves attributions of blame towards enduring personality traits (see review by Janoff-Bulman, 1985). Behavioural self-blame has been associated with adaptive coping responses to trauma whereas characterological self-blame has been associated with depression. Research with children and adults in the non-disabled population following shipping disasters found that more internal causal attributions for disaster related events were associated with higher subsequent rates of depression, anxiety and intrusive thinking (Joseph, Brewin, Yule & Williams, 1991; Joseph, Brewin, Yule & Williams, 1993).

One explanation for this is that when survivors blame their behaviour for the trauma, for example I was attacked because I was walking alone at night, their perception is that if they can modify their behaviour the world is a controllable, safe place again. If survivors believe there was something about them that made them vulnerable to trauma, for example that they were poor judges of character, since these traits are perceived as stable and difficult to change the world is a dangerous place for them. Participants in this research experienced multiple traumatic events in situations where they felt powerless to stop what was happening to them. This may have resulted in attributions by participants that there was something about their character that made them vulnerable to trauma. This is one explanation for the impact of the trauma upon participants and the prolonged reaction to the trauma years after the event.

Over half of the participants explicitly stated that they blamed someone else for the trauma. Research suggests that blaming others for trauma is linked to a poor adjustment

following trauma (see review by Tennen &Affleck, 1990). Tennen & Affleck (1990) offer an explanation for this finding that when the victim blames someone else for the trauma they perceive the effects of the trauma to be beyond their control.

Methodological Limitations

Using the concept of PTSD

The criteria for the concept of PTSD, according to DSM-IV (American Psychiatric Association, 1994) were used as a starting point for discussion in the focus groups. The researcher felt justified in using this approach because of the lack of research that had been undertaken in this subject area. The research was exploratory and this methodology achieved some consensus in helping to define the nature of the traumatic event for a person with learning disabilities and in devising the interview schedule. The researcher tried to have a limited influence on the focus groups and to allow the discussion to move into subject areas that had not been anticipated, which generated new avenues of thought. One example of this was the theme of the role of support in the environment, which was incorporated in the interview schedule. The researcher accepts that there were limitations in using the criteria for PTSD in the focus groups, however, it was felt to be the best compromise available for the research.

The interview schedule was developed using guidelines from Smith (1995) and using the themes that were generated by the focus groups. It is possible that this may have biased the data collected in the interviews towards the criteria for the concept of PTSD. There were genuine attempts made by the researcher to facilitate the interviews and to be lead by the participants into new subject areas that were relevant to the topic. Qualitative research acknowledges that there are biases that the researcher brings to the research process. Another potential bias brought by the researcher was an interest in interviewing

people with learning disabilities, which influenced the methodology chosen for this research. There is a recognition in using the IPA methodology that the researcher's perspectives will also have an effect on the interpretative process (Smith, 1996). The researcher's previous work experience with people, who have been abused, including the use of a cognitive framework, influenced the interpretation process. The researcher sought to ground the themes that developed through the analysis of the data and the interpretation process by providing verbatim quotes from the participants.

Using a retrospective methodology

It may have been difficult for participants to recall exactly what they thought or how they felt at the time of the traumatic event, since it occurred many years ago. The factual accuracy of the participant's accounts may not have been reliable. This study did not try to provide a factual description of the changes experienced following one traumatic event. All of the participants experienced multiple traumatic events and it is likely that the impact and meaning of the trauma for the participants was a consequence of the multiple traumatic events they had experienced. There is also an acknowledgement that participants may have been experiencing symptoms like poor sleep or physical health problems prior to the trauma. All of the participants were interviewed at different time periods following trauma, one participant was interviewed after two years another after eighteen years. The time that had elapsed since the trauma may have affected the participant's descriptions of the impact and meaning of the trauma. Further longitudinal research is needed to explore the effects of trauma over time.

Using a retrospective methodology had some limitations. However, it would have been very difficult to carry out a prospective study in the time available since there were small numbers of people with learning disabilities experiencing traumatic events that could

potentially be interviewed about their experiences. It was felt that a retrospective approach was justified since this research was not trying to provide a factual account of the trauma. It was interested in how people with learning disabilities make sense of trauma in their lives, in accordance with the IPA methodology that was used (Smith, 1996).

The Pilot Study

There were problems in recruiting professionals to the focus groups. This is traditionally one of the main problems of focus groups (Morgan, 1995). Clinicians who were expected to attend the first focus group did not attend, which meant the attendance of the first focus group was low. The researcher employed a number of different recruitment methods for the second focus group including recruiting too many professionals knowing that there would be a high drop out rate (Morgan, 1995). A number of professionals representing different specialities were invited personally on the telephone. There was a higher attendance of the second focus group. The two focus groups fulfilled the aims for the pilot study, which were to inform the remainder of the research particularly in relation to what was a traumatic event for a person with learning disabilities and in helping to devise the interview schedule.

The Main Study

There were difficulties in recruiting individuals for the main study. The researcher aimed to recruit eight to ten individuals for the main study but could only recruit and interview six individuals in the time available. Although six participants is a small number for a qualitative thesis it fulfils the guidelines proposed by Turpin et al. (1997) that qualitative theses need to involve more than five participants. The researcher was reliant on the help of staff members to recruit individuals. This meant that it was not possible to

recruit a sample of people with learning disabilities who had experienced the same singular event in the time available.

All of the participants who were interviewed in the main study reported that they had experienced multiple traumatic events in Part 1 of the PDS form. In the interview people were given a choice about which event they wanted to talk about in more detail. One of the participants didn't want to talk about the trauma that bothered him the most, the physical abuse by his father. A hypothesis related to this is that the participant was demonstrating one of the reactions to the trauma, in that he wanted to avoid talking about the abuse. The criteria for the concept of PTSD, according to DSM-IV (American Psychiatric Association, 1994) include avoiding talking about the trauma. All of the participants spoke about wanting to avoid reminders and people and places in relation to the trauma and in some of the interviews people wanted to avoid talking about their thoughts and feelings in relation to the trauma. It is possible that wanting to avoid talking about the trauma may have affected the responses they gave to questions. This is a difficulty with any research that is concerned with interviewing people about traumatic experiences in their lives.

The researcher needed to adapt the IPA methodology for use with people with learning disabilities. The interview schedule used open questions but included many prompts that could be used if people struggled to comprehend what they were being asked. Most participants had difficulties with self-reflective questions and questions that involved judgements about time and age. Generally unhelpful questions were "how do you think the event has affected your life?" and "how would someone close to you like your mum say you have changed as a result of the event?". Some participants talked about how things were different now rather than comparing themselves before and after the event. Questions that were helpful were "When the event happened what did you think would happen to

you?" and asking about "how are you sleeping?". These questions often revealed people's beliefs about the trauma. At times the researcher had to ask leading questions when people gave brief answers to the open questions. These responses were not included in the final analysis unless participants had expanded on their answers and provided further evidence. There were a few occasions during the interviews when the phenomenon of pseudo-acquiescence was observed (Rapley & Antaki, 1996). On these occasions the researcher did not accept the first answer given by participants and attempted by further questioning to change their response. These responses were not included in the analysis.

Using the PDS

There were a number of difficulties associated with using the PDS (Foa et al., 1997). Some of the language that was used in the PDS was difficult for people to understand and needed to be rephrased for some participants. Asking questions about whether someone felt emotionally numb or whether they were reliving the traumatic event could have been difficult concepts for people to understand. It is possible that attempts to rephrase the questions for example, asking if they feel like they are back where the trauma occurred and it was happening to them again, instead of using reliving the trauma was equally unhelpful to aiding the comprehension of the person with learning disabilities. It is questionable whether participant's answers to the PDS reflected their experiences and reactions to the trauma.

There is also the question of how appropriate it is to use the PDS form with people with learning disabilities. The review of the literature of children who had experienced trauma outlined the problems of adapting measures for children that were used to assess PTSD in adults (Galante & Foa, 1986). Sturmey et al. (1991) stressed the need for further research that assesses the reliability of psychiatric diagnoses in adults with learning

disabilities. The interpretations of the interviews reflected the experiences of a small group of people with mild learning disabilities and their interaction with the researcher. The research did not seek to provide general laws about how all people with learning disabilities respond to trauma. Research is needed with different groups of people with learning disabilities, for example people who have all experienced the same type of traumatic event, to provide a better clinical description of adults with learning disabilities following trauma. Future research with different groups of people with learning disabilities could lead to the development of a measure to use with people with learning disabilities that investigates post traumatic stress reactions following trauma.

Clinical Implications

Implications for clinical assessment.

There are a number of clinical implications of the research that could be applied by clinicians in their work with people with learning disabilities who have had similar traumatic experiences. There are indications from the literature and this research that people with learning disabilities may respond to trauma through their behaviour (Bonell-Pascual et al.,1999; Ghaziuddin, 1988; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Monaghan & Soni, 1992; Stack et al., 1987). If people with learning disabilities are referred to a service with difficult behaviour, questions should be asked about whether the person has experienced a traumatic event. Clinicians need to take a detailed history of the traumatic events that people have experienced in their life. This may involve clinicians initially spending time building up rapport with clients to create an atmosphere of trust and safety so the person is willing to disclose any previous trauma and the effects that the trauma is having upon them. A possible form of clinical assessment to

use with people with learning disabilities and their carers is included at the end of this section.

One of the reasons why people with learning disabilities may find it difficult to talk about traumatic experiences is that they may be experiencing difficulties in communicating what they have experienced. Research with children would suggest that using alternative methods of assessment like props and drawing materials could facilitate communication about traumatic experiences (Eth & Pynoos, 1985).

Facilitating Disclosure

One of the main clinical implications of this research arises from the tension of talking or not talking theme and particularly the reasons given by the participants about why they don't talk to others about traumatic events or their effects. Some of the reasons people gave were focused on a lack of trust of others. People feared that they would be made fun of, that they would be blamed for what happened or that others would not keep the information confidential. The first focus group discussed the importance of people with learning disabilities feeling safe before they will disclose trauma. It is important that staff members build positive relationships with people with learning disabilities to create an environment of trust, to facilitate people in talking about past trauma and the effects they have had upon their lives.

Some of the fears of talking expressed by participants appear to stem from the experience they had when they initially disclosed the traumatic event to someone. One participant said others made fun of him so he retracted his disclosure. Another participant told her husband that her brother had been touching her up, and her husband involved the police. According to the participant the police responded by telling her to keep away from her brother. These experiences discouraged participants from talking about these events

again. Ongoing training is needed for all staff working with people with learning disabilities to provide education about how to respond to people who disclose abuse. Research with adults in the non-disabled population has raised doubts about debriefing the person immediately following trauma and there are indications that this may make the symptoms of the person worse (see review by Kenardy, 2000).

Staff training should include believing the person's disclosure prior to investigation and validation of the person's experience. Some of the participants in the focus groups spoke about staff members struggling to work with people who are experiencing difficult events. There is still a culture of people working in learning disability services who do not want to think or hear about the difficult things people have experienced in their lives as it is too painful for people to hear them. The training should also include space for staff to talk about their feelings in relation to working with adults with learning disabilities who have experienced trauma.

Police should also receive training about how to work with people with learning disabilities who disclose abuse. The police who told the participant to stay away from her brother were probably trying to protect her from future abuse. Unfortunately the message she received was that she was partly responsible for what happened, which was very psychologically damaging.

Therapeutic Intervention

Reviews of psychological therapies support the use of exposure therapy, cognitive behaviour therapy and stress inoculation and relaxation techniques as effective treatments for people in the non-disabled population experiencing PTSD, in response to a variety of trauma (Adshead, 2000; Foa, 2000). Exposure therapy involves imaginal exposure, which involves the repeated recall of the traumatic memory in detail in the therapy room

including the images and emotions connected with the trauma. It can also involve systematic desensitisation to the external world, when the person becomes gradually more exposed to objects and situations related to the trauma. These types of therapies have been effective in reducing levels of avoidance and the intrusive re-experiencing of the event including flashbacks (see review by Adshead, 2000).

The participants in this study believed that the world was a dangerous place and they were fearful of other traumatic events occurring in their life. The research with adults in the non-disabled population would suggest that cognitive strategies and exposure therapy could be effective in challenging these beliefs. Cognitive behaviour therapy has been used effectively to challenge the beliefs of people with learning disabilities (see review by Stenfert Kroese, Dagnan & Loumidis, 1997). Clinicians working with a similar population of people with learning disabilities need to assess people's appraisals of trauma to assess whether participants perceive the world to be a dangerous or a safe place.

The review by Adshead (2000) also discussed shame reactions to traumatic events, which are linked to blaming the self. These experiences are also referred to as "complex PTSD" (Herman, 1992) and are usually the result of prolonged exposure to trauma, with the first experience at an early age. This can include child abuse and domestic violence, which were experiences that were described by some of the participants. Since the abuse often took place in an ongoing relationship building a relationship between the client and the clinician is far more difficult. Adshead (2000) suggests that group psychotherapy may be an effective treatment for people who have had these types of experiences. Clinicians need to explore with clients their beliefs about who was to blame for what happened to them and to consider which type of therapy may be most effective. If people find it difficult to trust others as a result of the trauma they have experienced then it may be difficult to undertake one to one therapy. Outcome studies are urgently needed to apply

these therapeutic approaches that have been shown to be helpful with the non-disabled population.

Reflections about the research process

This section is included to encourage clinicians considering undertaking similar types of research to think about the personal impact of doing this type of research. All of the participants who were interviewed about their experiences of trauma were receiving ongoing support from learning disability services. There were points during some of the interviews, however, when there was a temptation to act as a therapist rather than as the researcher. When participants were struggling to talk about their experiences out of a sense of blaming themselves for what happened it was difficult not to intervene. McCarthy (1999) discusses this dilemma in relation to her work. When the researcher had concerns about the effects of the interview on an individual permission was gained from the person with learning disabilities to talk to the staff member working with them on an ongoing basis. This was undertaken with a couple of the participants.

Previous researchers (Booth & Booth, 1994; McCarthy, 1999) have acknowledged the impact on the researcher of interviewing people with learning disabilities about traumatic experiences. Traumatic countertransference or vicarious trauma is a phenomenon that has been described by therapists working with traumatised individuals (see review by Herman, 2001). During the main study the researcher experienced strong emotional responses during and following some of the interviews. One example of this was when one of the participants described occasions when she sat on the edge of her bed at night, feeling scared. The researcher left the interview with this visual image in her mind feeling compassion towards the person but also feeling upset about what she'd heard. Listening to the traumatic experience of this individual also reminded the researcher of previous work

she had undertaken with another person with learning disabilities who had been raped. Methods that were used successfully by the researcher to try and contain the emotional response to the interviews were seeking support from research supervisors, sharing concerns about participants with staff members involved in ongoing work with them and writing in a reflective journal.

Conclusions

This was the first study, to the researcher's knowledge that has used IPA to explore the experience of trauma with adults with learning disabilities. Other research has used quantitative methods to consider the emotional and behavioural effects of traumatic life events upon the lives of adults with learning disabilities, however, this research was the first to use a qualitative methodology to look at the meaning of the traumatic events for people with learning disabilities.

The key findings of this research were:

1. The perception of harm to self or others and the role of social support at the time of the trauma appeared to mediate people's beliefs about the world being a safe or a dangerous place.

2. People with mild learning disabilities respond to trauma in some similar ways to the description of the concept of PTSD in DSM-IV (American Psychiatric Association, 1994). However, they were also some differences in their reactions to trauma.

3. Attempts by people with learning disabilities to use avoidance as a coping strategy may be compromised by their dependency upon the abuser.

4. People with learning disabilities experiencing multiple traumatic events can develop attributions of blame towards themselves, which leads to difficulties in talking about the trauma to others.

Several areas of further research have been identified by this study. There is a need for research with carers and staff to explore changes in the behaviour of people with learning disabilities following trauma. As previously stated this research would be particularly valuable with adults with severe learning disabilities who are not able to verbally communicate their distress. The findings of this study were based on the accounts of six individuals with learning disabilities and there is a need for more research that will provide a better clinical description of different groups of people with learning disabilities following trauma. Further research could look at co-morbidity and the impact of single traumatic events compared with multiple traumatic events. Research is also needed to further investigate changes in beliefs following trauma and the interaction between attributions of blame and responses by people with learning disabilities to trauma.

Is the concept of PTSD a helpful one for adults with learning disabilities? Young (2000) argued that PTSD was a socially constructed concept developed as a historical legacy of the Vietnam War to legitimise the experiences of the Vietnam veterans so that they would receive the appropriate treatment. As research continues to be undertaken in this area the concept of PTSD will continue to evolve and change as we learn more about the effect of traumatic events on people's lives. Further research exploring the concept of PTSD in the lives of adults with learning disabilities could be beneficial if it raises the profile of the suffering that has been experienced by adults with learning disabilities following trauma. Mental health problems in adults with learning disabilities remains a neglected area of research and one that needs to be tackled in the next decade so that individuals with learning disabilities can start receiving appropriate support.

Questions that could be used in a Clinical Assessment

Suggested questions to ask the person with learning disabilities

What did you think would happen to you at the time of the traumatic event?
What did you think would happen to other people at the time of the traumatic event?
Did you think that your life or someone else's life was in danger?
Were you able to talk to anyone about the traumatic event at the time?
Who did you talk to and what did they say to you?

What do you think about the traumatic event now?
Do you have any pictures in your head? What are the pictures of?
What do you do if thoughts or pictures pop into your head about it?
How do you feel about the traumatic event now?
Do you worry that it will happen again?
How is your sleeping? Do you have any problems sleeping?
How is your physical health?

Do you talk to anyone about the traumatic event now?
How does it feel talking about it to other people?
Do you blame anyone for what happened to you? Who do you blame?

Suggested questions to ask carers

Does the person perceive the world to be dangerous or safe?
What fears do they have about the future? Do they worry about the traumatic event happening again?

Does the person talk about thoughts or pictures they have that relate to the trauma?
Is the person avoiding people, places or reminders of the traumatic event?
Does the person avoid having conversations about the traumatic event?
Is the person able to talk to others about what has happened to them?
Does the person have any sleep problems? What are they?
Has the person's behaviour changed following the event? In what ways has it changed?
Does the person have physical health problems that they didn't have prior to the event?

Do they blame anyone for what happened to them? Who do they blame?
Do they have any plans for revenge?

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Criteria for PTSD taken from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association, 1994)

A. The person has been exposed to a traumatic event in which both of the following were present –

1. The person experienced, witnessed or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.

2. The person's response involved fear, helplessness or horror. Note: In children, this may be expressed instead by disorganised or agitated behaviour.

B. The traumatic event is persistently experienced in one (or more) of the following ways:

1. Recurrent and intrusive distressing recollections of the event, including images, thoughts or perceptions. Note: In young children repetitive play may occur in which themes or aspects of the trauma are expressed.

2. Recurrent distressing dreams of the event. Note: In children there may be frightening dreams without recognisable content.

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). Note: In young children, trauma specific re-enactment may occur.

4. Intense psychological distress at exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event.

5. Physiological reactivity on exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event.

C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:

1. Efforts to avoid thoughts, feelings, or conversations associated with the trauma.

2. Efforts to avoid activities, places, or people that arouse recollections of the trauma.

3. Inability to recall an important aspect of the trauma.

4. Markedly diminished interest or participation in significant activities.

5. Feeling of detachment or estrangement from others.

6. Restricted range of affect (e.g. unable to have loving feelings).

7. Sense of foreshortened future (e.g. does not expect to have a career, marriage, children, or a normal life span).

D. Persistent symptoms of increased arousal (not present before the trauma) as indicated by two (or more) of the following:

1. Difficulty in falling or staying asleep

2. Irritability or outbursts of anger

3. Difficulty concentrating

4. Hypervigilance

5. Exaggerated startle response

E. Duration of the disturbance (symptoms in criteria B, C, and D) is more than one month.

F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Specify if:
Acute: if duration of symptoms is less than three months
Chronic: if duration of symptoms is three months or more

Specify if:
With delayed onset: if onset of symptoms is at least six months after the stressor

ICD-10 Criteria for Post-traumatic Stress Disorder

This disorder should not generally be diagnosed unless there is evidence that it arose within six months of a traumatic event of exceptional severity. A 'probable' diagnosis might still be possible if the delay between the event and the onset was longer than six months, provided that the clinical manifestations are typical and no alternative identification of the disorder (e.g. as an anxiety or obsessive-compulsive disorder or depressive episode) is plausible. In addition to evidence of trauma, there must be a repetitive, intrusive recollection or re-enactment of the event in memories, daytime imagery or dreams. Conspicuous emotional detachment, numbing of feeling, and avoidance of stimuli that might arouse recollection of the trauma are often present but not essential for the diagnosis. The autonomic disturbances, mood disorder, and behavioural abnormalities all contribute to the diagnosis but are not of prime importance.

Research and Development Directorate

Please ask for: Janet Boothroyd, R&D Manager, Ext. 44307
Ruth Doyle, Data Manager, Ext. 44771
Linda Ellis, Administrative Assistant, Ext. 41049
Debbie Cocks, Secretary/Administrator Ext. 35117

Our Ref: **EX030104**

3rd April 2001

Mrs A K Mitchell
University of Leicester
Centre for Applied Psychology - Clinical Section
Ken Edwards Building
University Road
Leicester
LE1 7RH

Dear Mrs Mitchell

Re: An **Exploratory Study Into How Adults With Learning Disabilities Present Themselves Following Traumatice Life Events**

Thank you for submitting the above project for consideration by the Ethics Committee. The Committee met on the 2nd April 2001 and is happy to approve the project including the protocol, GP letter, Clinicians Information Sheet, Information Sheet, Careres Information Sheet, Carers Consent Form and Clients Consent Form.

The Ethics Committee requires that:

iv)   Serious adverse reaction/events, which occur during the course of the project, are reported to the Committee.

v)   Changes in the protocol are submitted as project amendments to the Committee.

vi)   Yearly reports and a final report on the project to be submitted. (Forms will be sent to Lead Investigator for completion).

Kind regards

Yours sincerely

Dr I M Holland
Honorary Secretary
Ethics Committee

University Hospital
Nottingham NG7 2UH
Telephone (0115) 9249924
Direct Line (0115) 9709049
Fax External (0115 8493295) Internal 35295
Dr Ian Holland, Honorary Secretary, Ethics Committee
Queens Medical Centre, Nottingham, University Hospital NHS Trust

Sherwood Forest Hospitals NHS

Our ref: AV/MHpw.am582oct

Your ref:

08 October 2001

Mrs Anna Mitchell
85 Westwick Road
Beauchief
Sheffield
S8 7BU

King's Mill Centre
Mansfield Road
Sutton in Ashfield
Nottinghamshire
NG17 4JL

Tel: 01623 622515
Ext No: 3731/3735

Direct Line: 01623 672207

Dear Mrs Mitchell

An exploratory study into how adults with Learning Disabilities present themselves following traumatic life events
Reference No. NNHA/582

At the meeting on 1 October 2001 the Committee considered your application and could see no ethical reason why your study should not proceed.

Please note that if any data is to be stored on computer, you have the personal responsibility of ensuring registration with the Data Protection Officer. In addition, please note that all data computerised or otherwise, must be securely stored for a minimum of ten years.

Please find attached a list of members of the Committee at the date of the meeting. It is not the Committee's policy to indicate which members were present when a particular protocol was reviewed, however, I can assure you that the meeting was quorate and conducted in accordance with the Constitution.

The Committee wishes you well with your project, and would welcome details of the outcome in due course.

Yours sincerely

Dr Allan Voice
CHAIRMAN NORTH NOTTINGHAMSHIRE
LOCAL RESEARCH ETHICS COMMITTEE

Chairman Brian Meakin FCA
Chief Executive John Mattheson

Leicestershire and Rutland **NHS**
Healthcare NHS Trust

Research & Development Office
Daisy Peake Building
Towers Hospital
Gipsy Lane
Leicester
Tel: 0116-225-6307
Fax: 0116-225-6618
David.Clarke@lrh-tr.trent.nhs.uk

DC/AM

21 November 2001

Mrs. Anna Mitchell
85 Westwick Road
Beauchief
Sheffield
South Yorkshire
S8 7BU

Dear Anna

Re; An exploratory study into how adults with Learning Disabilities present themselves following traumatic life events.

Thank you for the information regarding ethical approval for the above project, including copies of approval letters from both the QMC and North Nottinghamshire Local Research Ethics Committees. On the basis of this information, I am happy to confirm that Leicestershire & Rutland Healthcare NHS Trust is prepared to offer research indemnity for this study. This letter also serves as formal <u>Trust Approval</u> to undertake the study.

This is on condition that the study is conducted according to the agreed protocol, the reporting of any adverse events or critical incidents and the requirements of your ethical approval are met. It would also be useful if the results of the study are fed back to the Trust in the form of a summary report, and that should there be any subsequent publications, details are forwarded to the Trust.

Can I take this opportunity of wishing you every success with your project, and please get in touch if you require any further assistance.

Regards,

Dr. Dave Clarke
[R&D Manager]

Interview Schedule

Welcome and thank you for coming to this focus group.

Introductions
It would help me if we could go around the group and for everyone to introduce themselves and to say a little bit about what your job is?

I know that you are all busy people so I appreciate that you have given up time to come along to the group today. Each of you has been asked to come along as your point of view is important to help inform the rest of the research. I need to talk briefly about confidentiality. I would like your permission to tape the focus group. I want to make it clear that I will not be using clients real names and also I will give you false names so you will be anonymous. I'm going to send a list round so you can indicate that you give permission for the group to be taped. Does anyone have any objections to the focus group being taped?

The primary purpose of the focus group is to find out about your ideas and views about how adults with learning disabilities react to traumatic life events. If you talk about a client who has had a traumatic life event this doesn't commit you to be involved in the next stage of the research, which is approaching people with learning disabilities to see if they are willing to be interviewed about their experiences. Although if you do have someone in mind that I could approach, can you talk to me at the end.

Guidelines
There are a few guidelines that I would like you to follow during the focus group interview. Firstly you don't have to speak in a particular order, when you've got something to say please say it. Secondly I would ask that you'd try not to speak when someone else is talking. Sometimes it's tempting to jump in but I'd ask you not to. Thirdly I would like to hear from all of you not just one or two of you. Finally we have limited time together so I may need to move you on sometimes or to redirect our discussion. Does anyone have any questions?

Talk about PTSD

- PTSD what is it?

- Post traumatic stress disorder (PTSD) first appeared in 1980 as a diagnostic syndrome.

- It developed from an understanding that people will respond in a similar way to a variety of traumatic experiences.

Has everyone had a copy of the diagnostic criteria for PTSD – I will go through them very quickly

DSM-IV Criteria for PTSD

A. The person has been exposed to a traumatic event in which both of the following were present –
1. The person experienced, witnessed or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.
2. The person's response involved fear, helplessness or horror. Note: In children, this may be expressed instead by disorganised or agitated behaviour.

Included are events like war, natural disasters like earthquakes, hurricanes, sexual abuse/ physical assault, motor vehicle accidents, mass transport disasters. In relation to sexually traumatic experiences in children this can include developmentally inappropriate experiences without threats or actual injury.

B. The traumatic event is persistently experienced in one (or more) of the following ways:
1. Recurrent and intrusive distressing recollections of the event, including images, thoughts or perceptions. Note: In young children repetitive play may occur in which themes or aspects of the trauma are expressed.
2. Recurrent distressing dreams of the event. Note: In children there may be frightening dreams without recognisable content.
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). Note: In young children, trauma specific re-enactment may occur.
4. Intense psychological distress at exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event.
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C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:
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3. Inability to recall an important aspect of the trauma.
4. Markedly diminished interest or participation in significant activities.
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This disorder should not generally be diagnosed unless there is evidence that it arose within six months of a traumatic event of exceptional severity. A 'probable' diagnosis might still be possible if the delay between the event and the onset was longer than six months, provided that the clinical manifestations are typical and no alternative identification of the disorder (e.g. as an anxiety or obsessive-compulsive disorder or depressive episode) is plausible. In addition to evidence of trauma, there must be a repetitive, intrusive recollection or re-enactment of the event in memories, daytime imagery or dreams. Conspicuous emotional detachment, numbing of feeling, and avoidance of stimuli that might arouse recollection of the trauma are often present but not essential for the diagnosis. The autonomic disturbances, mood disorder. and behavioural abnormalities all contribute to the diagnosis but are not of prime importance.

Prevalence rates for children and adults
How many people develop PTSD?
- Depends on the nature and severity of the event. Epidemiological studies of the general population have estimated a prevalence of 1%, other studies of people exposed to specific traumatic events have found a prevalence rate of 5-15%.
- Children's prevalence – No study that has looked at prevalence of PTSD in general children's population. Several studies looked at PTSD in at risk groups like children exposed to war, violent crime and natural disaster. Varied from 0 to 100% depending on what assessment measures have been used and how reliable they are.
- Ryan (1994) study of people with ld referred to a psychiatric service 51 out of 310 consecutive people seen went on to develop PTSD (16%)

Not all people who witness a traumatic event go on to develop PTSD
PTSD and learning disabilities - Very little research has been done, few case studies and some work on the effect of life events on the lives of people with learning disabilities

Unfortunately I'm not going to be able to talk further about PTSD because we don't have the time today. If people want to know more then I would be happy to talk to them another time. I will be around for a year so contact me at Highbury.
Any quick questions?

Introductory
When I say the words traumatic life event, thinking about the clients you have worked with, what comes to mind?

Prompts
Which life events do you consider to be traumatic for a person with a learning disability?
Are there events that you feel strongly about that should be included?
Are there others that you feel more uncertain about?
Single v Multiple events?

Key Question
In your opinion should the criteria used to define PTSD for adults without learning disabilities be used to define a traumatic life event for adults with learning disabilities-
The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others. That the person's response involved fear, helplessness or horror. Note: In children, this may be expressed instead by disorganised or agitated behaviour.

Presentation
Thinking about a client that you have worked with who has experienced a traumatic event, can you describe what changes you observed in the person following the event?

Prompt
Can you tell us what the client's circumstances were, the nature of the event they experienced, how long ago that it (they) happened

Prompts
What did you observe about their behaviour before and after the event?
Would you say that the person relived the event in any way? How did you observe this?
How did the person respond to reminders of the event? (Were they happy to talk about the event and visit the place where it had happened?)
In your opinion was there a difference in the person's level of arousal following the event? How could you tell this? (sleep, ability to concentrate, etc.)
How was the person's daily life affected following the traumatic event? i.e. did they continue to do the same things as before? Did you notice any changes in the activities they participated in?
In your opinion how long did the person with learning disabilities show a reaction to a traumatic event?

Key Question
In your opinion how would you say adults with learning disabilities reactions were similar to PTSD?

Key Question
How would you say adults with learning disabilities reactions were different to PTSD?

Ending
We are running out of time is there anything we should have talked about but didn't?

I am going to attempt to summarise some of the key ideas we have heard.....
What would you like to add to my summary?

There were several subjects that were touched upon that we didn't have time to complete discussing in the focus group.

General prompts
I'm wondering what others in the group think?
Can I ask you to elaborate on what you mean?
Would you all say you agree with X about that?
You've told me three things, which would you say was the most important?

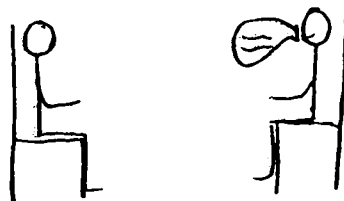# Nottinghamshire Healthcare **NHS**
NHS Trust

Information Sheet

My name is Anna Mitchell. I am training to be a Clinical Psychologist at Leicester University.
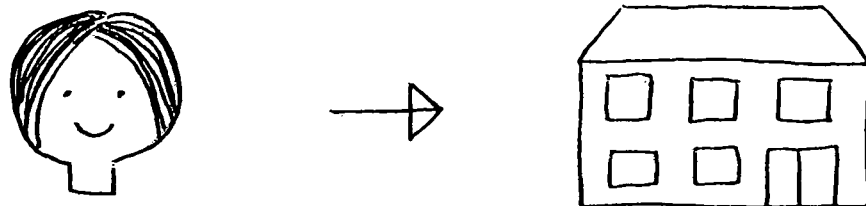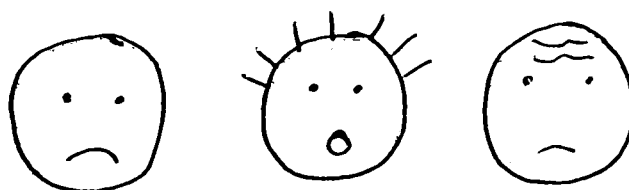
As part of my training I have to write a thesis (report).
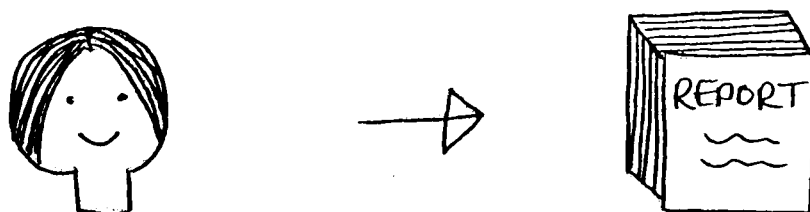
I would like to interview people who have experienced difficult things in their life.

I will be asking some questions about the feelings and thoughts people have had since the difficult thing happened to them.
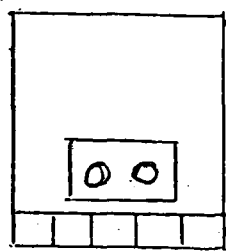
After people have been interviewed they can continue to meet with me to talk about what has happened to them.
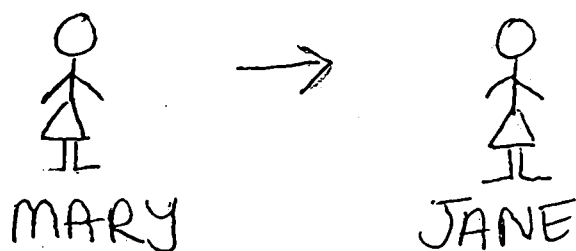
The interviews will be taped if you agree to this.

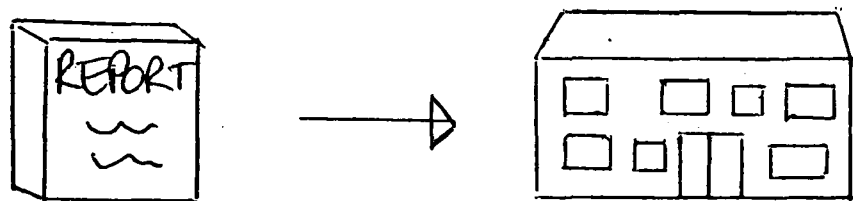No one will be able to tell who has been interviewed. People's names will be changed.
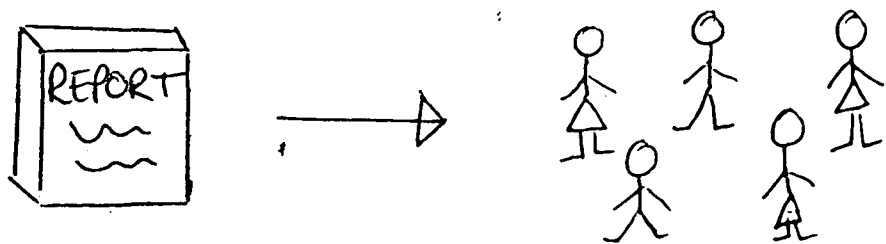

MARY → JANE

I will listen to what you tell me about what it feels like to have difficult things happen to you.
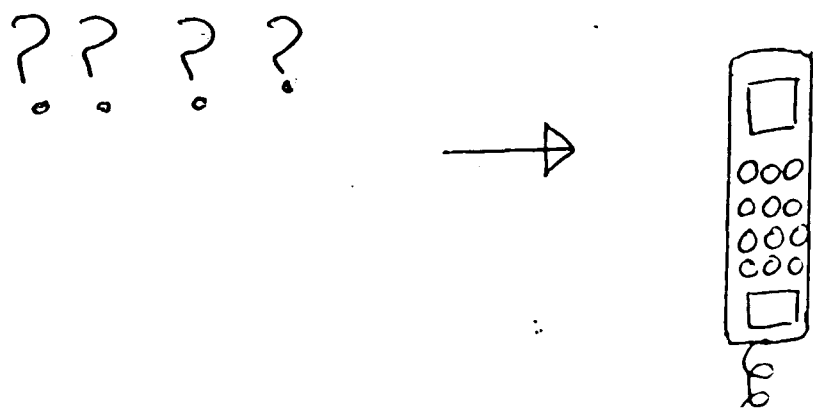

I will write my thesis (report) and hand it in to the university.

I will try and get a report published in a journal so other psychologists can understand how it feels when difficult things happen to people.

If you have any questions, please telephone me on (0115) 952 9462

Nottinghamshire Healthcare

Clients Consent Form

I have had an information sheet.

I understand that you want to learn more about how people feel after something difficult has happened to them in their life.

I have met you and had a chance to ask questions about why and how you would like me to help you.

I understand that you will not tell anyone my name, and what I say will be kept private.

I can decide to stop talking to you at any time.

I can decide to stop the interview if I want to and this will not affect my future treatment.

I agree that you can tape record what I say.

I understand that you will write up your research.

SIGNED: NAME:
                                 Date:

I believe that the person above understands what is involved in the research and agrees to participate in it.

WITNESS   NAME:
SIGNATURE: Date:

Nottinghamshire Healthcare

NHS

NHS Trust

How to make a complaint

If you have any reason to complain about the study, for example the way it has been carried out or the way you have been treated, please contact:-

Dr Jennifer Clegg (Senior Lecturer in Clinical Psychology) who is the supervisor of this study.

She can be contacted at the:

Learning Disabilities Service
Highbury Hospital
Bulwell
Nottingham
NG6 9DR

Tel: (0115) 952 9462

INVESTOR IN PEOPLE

<u>Interview Schedule</u>

<u>Introduction – making the person feel at ease</u>

Ask them about their day what they have been doing.
If you would like to ask me any questions I'll try my best to answer them. There are
no right or wrong answers to the questions I'm going to ask you I'm interested in
learning about your experiences. If you find any of the questions difficult to answer or
if you want to stop the interview at any time let me know. I will also check that out
with you.

<u>The event</u>
Do you remember when I came to talk to you before and you told me about some of
the difficult things that had happened in your life (remind them).

Could you tell me about the hardest thing that happened to you?

Which one do you think about the most?

If you had to choose one to talk about today, what would it be?
- Can you tell me why you picked x to talk about?
- Can you tell me why you picked x and not one of the other things that has
  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?

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 long time ago – What stopped you from talking about it?

<u>How they see the event now</u>
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?

How does x affect you physically in your body?
- 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 of the event to their life

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

Thank you very much for letting me talk to you. How did it feel to be interviewed?
Out of all the things you have said what is the most important thing for me to know?
Is there anything else you want to say? Anything you think it is important for me to know?
Do you have any questions you want to ask me?

Additional prompts
Could you give me an example of that?
How did you feel about that?
What do you do when you feel like that?
What did you think about that?
Can you remember the last time that happened?
Can you tell me more about that?

648   I   both right

649

650   R   'cause one I aint gay I prefer women instead of blokes

651   *I may like men but I prefer women*

652   I   right   *Confusion?*

653

654   R   oh Christ it makes me <u>ill</u>

655

656   I   so it makes you feel ill about what he did to you,?

657

658   R   mm

659

660   I   you said it makes you feel sick about yourself,?

661

662   R   yeah (.) 'cause I let him do it

663

664   I   right

665

666   R   plus I-I-I couldn't be doing anyway [right] I was like you [mm] I'm not

667   that way I mean skinny [oh right yeah] arms [right] and I couldn't lift

668   him up   *← reason he let him do it*

669   *Wasn't strong enough*

670   I   so you weren't physically strong

671

672   R   no

673

674   I   no

675

676   R   I am now

677   *Nobody will do it to me again*

678   I   right right

679

680   R   And then now (.) you see people here they don't (2) they don't erm

681   challenge me you know like wind me up (.) 'cause I stick up for mysel

682   [mm] or just ignore it at the time. Bang, that's it, I just get in there and I

683   don't care how fat they are or skinny they are or how small they are I

684   just go in there.

685

686   I   so like at the time you, you weren't very strong and he was much

687   bigger than you and much stronger than you

688

689   R   he was (.) his arms was that <u>thick</u>

690

691   I   right, right

692

693   R   he must have been a body builder

      is this why he lifts weights?

694

695   I   was he? and so you couldn't stop him, but now you're doing the body

696   building, is that so it won't happen again to you and that you'll be

697   strong,?

*Consequence
of event
→confusion re
sexuality*

*Blames
himself
powerless to
stop him*
*wasn't strong
enough*

*Giving
protecting
self in
the future*

P D S ™

Edna B. Foa, PhD

_____ me or Identification Number

_____ Date

NCS™

Product Number
51623

Part 1

Many people have lived through or witnessed a very stressful and traumatic event at some point in their lives. Below is a list of traumatic events. Put a checkmark in the box next to ALL of the events that have happened to you or that you have witnessed.

☐ Serious accident, fire, or explosion (for example, an industrial, farm, car, plane, or boating accident)

☐ Natural disaster (for example, tornado, hurricane, flood, or major earthquake)

☐ Non-sexual assault by a family member or someone you know (for example, being mugged, physically attacked, shot, stabbed, or held at gunpoint)

☐ Non-sexual assault by a stranger (for example, being mugged, physically attacked, shot, stabbed, or held at gunpoint)

☐ Sexual assault by a family member or someone you know (for example, rape or attempted rape)

☐ Sexual assault by a stranger (for example, rape or attempted rape)

☐ Military combat or a war zone

☐ Sexual contact when you were younger than 18 with someone who was 5 or more years older than you (for example, contact with genitals, breasts)

☐ Imprisonment (for example, prison inmate, prisoner of war, hostage)

☐ Torture

☐ Life-threatening illness

☐ Other traumatic event

If you marked Item 12, specify the traumatic event below.

_____
_____

IF YOU MARKED ANY OF THE ITEMS ABOVE, CONTINUE. IF NOT, STOP HERE.

Part 2

(14) If you marked more than one traumatic event in Part 1, put a checkmark in the box below next to the event *that bothers you the most.* If you marked only one traumatic event in Part 1, mark the same one below.

☐ Accident
☐ Disaster
☐ Non-sexual assault/someone you know
☐ Non-sexual assault/stranger
☐ Sexual assault/someone you know
☐ Sexual assault/stranger
☐ Combat
☐ Sexual contact under 18 with someone 5 or more years older
☐ Imprisonment
☐ Torture
☐ Life-threatening illness
☐ Other

In the box below, briefly describe the traumatic event you marked above.

_____
_____
_____
_____
_____

Below are several questions about the traumatic event you just described above.

(15) How long ago did the traumatic event happen? (circle ONE)
 1 Less than 1 month
 2 1 to 3 months
 3 3 to 6 months
 4 6 months to 3 years
 5 3 to 5 years
 6 More than 5 years

For the following questions, circle Y for Yes or N for No.

During this traumatic event:
(16) **Y N** Were you physically injured?

(17) **Y N** Was someone else physically injured?

(18) **Y N** Did you think that your life was in danger?

(19) **Y N** Did you think that someone else's life was in danger?

(20) **Y N** Did you feel helpless?

(21) **Y N** Did you feel terrified?

Part 3

is a list of problems that people sometimes have
experiencing a traumatic event. Read each one
fully and circle the number (0–3) that best describes
often that problem has bothered you IN THE PAST
TH. Rate each problem with respect to the
atic event you described in Item 14.

Not at all or only one time
Once a week or less / once in a while
2 to 4 times a week / half the time
5 or more times a week / almost always

0 1 2 3 Having upsetting thoughts or images about the traumatic event that came into your head when you didn't want them to

0 1 2 3 Having bad dreams or nightmares about the traumatic event

0 1 2 3 Reliving the traumatic event, acting or feeling as if it was happening again

0 1 2 3 Feeling emotionally upset when you were reminded of the traumatic event (for example, feeling scared, angry, sad, guilty, etc.)

0 1 2 3 Experiencing physical reactions when you were reminded of the traumatic event (for example, breaking out in a sweat, heart beating fast)

0 1 2 3 Trying not to think about, talk about, or have feelings about the traumatic event

0 1 2 3 Trying to avoid activities, people, or places that remind you of the traumatic event

0 1 2 3 Not being able to remember an important part of the traumatic event

0 1 2 3 Having much less interest or participating much less often in important activities

0 1 2 3 Feeling distant or cut off from people around you

0 1 2 3 Feeling emotionally numb (for example, being unable to cry or unable to have loving feelings)

0 1 2 3 Feeling as if your future plans or hopes will not come true (for example, you will not have a career, marriage, children, or a long life)

(34) 0 1 2 3 Having trouble falling or staying asleep

(35) 0 1 2 3 Feeling irritable or having fits of anger

(36) 0 1 2 3 Having trouble concentrating (for example, drifting in and out of conversations, losing track of a story on television, forgetting what you read)

(37) 0 1 2 3 Being overly alert (for example, checking to see who is around you, being uncomfortable with your back to a door, etc.)

(38) 0 1 2 3 Being jumpy or easily startled (for example, when someone walks up behind you)

(39) How long have you experienced the problems that you reported above? (circle ONE)
1 Less than 1 month
2 1 to 3 months
3 More than 3 months

(40) How long after the traumatic event did these problems begin? (circle ONE)
1 Less than 6 months
2 6 or more months

Part 4

Indicate below if the problems you rated in Part 3 have interfered with any of the following areas of your life DURING THE PAST MONTH. Circle Y for Yes or N for No.

(41) Y N Work

(42) Y N Household chores and duties

(43) Y N Relationships with friends

(44) Y N Fun and leisure activities

(45) Y N Schoolwork

(46) Y N Relationships with your family

(47) Y N Sex life

(48) Y N General satisfaction with life

(49) Y N Overall level of functioning in all areas of your life