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Reported responses to sexual trauma in people with intellectual disability:  
an analysis of clinical psychologists' psycho-legal reports

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the award of the degree of Master of Arts in Clinical Psychology

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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

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## ABSTRACT

While a large body of literature suggests that rape and sexual assault in the general population is pathogenic, there is a dearth of literature on its impact on people with intellectual disability (ID). Several studies have reported that individuals with ID may experience a range of psychopathology following rape that is similar to that experienced by adults and children in the general population (i.e. PTSD, Major Depression) but with stronger behavioural reactions. The main aim of this research was to identify the response of individuals with ID who had experienced sexual trauma. This was an archival study of the Sexual Abuse Victim Empowerment (SAVE) project's clinical psychologists' notes and psycho-legal reports from 2005 – 2009 on 295 female, child and adult, sexual assault/rape survivors with ID. It was hypothesised that in the different PTSD symptom criteria clusters there would be more symptoms of increased arousal than re-experiencing and avoidance, that there would be a difference in the number of reported symptoms between different levels of ID, and between the number of symptoms reported by the different psychologists who assessed the sample. Descriptive statistics were generated for the frequency of reported symptoms and the different trauma variables. Repeated measures analysis of variance (ANOVA) were used to test the three hypotheses. Principal findings indicated that symptoms of PTSD and depression were the most common with behavioural problems like aggression, oppositional and sexualised behaviours less frequently reported than in other literature. As hypothesised, symptoms of increased arousal were more prevalent than symptoms of re-experiencing and avoidance in the PTSD criteria clusters. This is possibly accounted for by the strong behavioural reactions people with ID reportedly have in response to trauma. A significant difference was found between the number of symptoms reported between the different ID levels. The moderate group reported the most symptoms and the profound group the least. This is not seen to reflect an absence of distress, but rather a difficulty in eliciting information from individuals in the more severe range by the assessing clinical psychologists. The latter highlights the need for clinicians to explore alternative forms of communicating with people with expressive language difficulties in order to be better able to access their subjective experiences. There was a significant difference in the number of symptoms reported depending on which psychologist did the assessment. Further research on the impact of sexual trauma on people with ID in South Africa is required.

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## **CHAPTER 1: INTRODUCTION**

Estimates of the prevalence of sexual violence in South Africa amongst the general population range from one in three, to one in five women having been raped (Jewkes & Abrahams, 2002). The recognition of rape and sexual abuse as a pervasive social problem has made the issue a national priority with efforts to measure its prevalence and provide appropriate treatment (e.g. Human Sciences Research Council, Medical Research Council, Childline, People Opposing Women Abuse, Rape Crisis). Despite evidence which suggests that people with intellectual disability (hereafter referred to as ID), are more vulnerable to abuse than the general population (Horner-Johnson & Drum, 2006; Sobsey, 1994; Brown, Stein & Turk, 1995), little has been done to collect comprehensive data on sexual trauma in the intellectually disabled population in South Africa.

The impact of rape has been recognised as pathogenic in the general population (Yuan, Koss & Stone, 2006; Resick, 1993). A large body of research suggests a relatively consistent pattern of reaction following rape. Most survivors experience a strong acute reaction in the immediate aftermath that lasts for three weeks to several months. Three months post-assault, most of the distress and turmoil has stabilised and diminished. Some survivors, however, continue to experience chronic problems that persist for years (Foa & Steketee, 1987; Resick, 1993; Koss, 2005). These problems can include Post Traumatic Stress Disorder (PTSD), depression, loss of self-esteem, sexual disorders, social adjustment problems, Generalised Anxiety Disorder, Obsessive Compulsive Disorder, alcohol abuse and dependence and drug abuse (Resick, 1993; Maw, Womersley & O'Sullivan, 2008).

There is a dearth of literature documenting the psychological reactions of people with ID to sexual trauma. Several studies suggest that the intellectually disabled population may experience a range of psychopathology following rape that is similar to what is experienced by individuals without intellectual disability (e.g. PTSD, Major Depression and Generalised Anxiety Disorders) but with stronger behavioural reactions (Mitchell & Clegg, 2005; Sequeira, Howlin & Hollins, 2003; McCarthy,



2001). Most of what is known about sexual trauma in the ID population is derived from developed countries like the United States and United Kingdom, with sample groups very different to South Africa (Womersley & Maw, 2009).

The paucity of literature, as well as the lack of a standardised diagnostic tool to assess the effects of sexual trauma contributes to difficulty in recognising symptoms in a population group whose capacity to communicate internal psychological states may be impaired. This research is part of a project intended to contribute to local knowledge about trauma and ID. The study is both exploratory and descriptive, and aims to delineate the most frequently reported symptoms of psychological distress in individuals with ID who have a confirmed history of sexual trauma. It also explores whether there is a difference in the number of reported symptoms between the different levels of ID.

Following this chapter is a literature review which provides an overview of the conceptual changes that have affected contemporary perceptions of ID. The prevalence of rape in South Africa and the vulnerability to sexual trauma in people with ID is discussed. A summary of the theoretical understanding of the impact of sexual trauma and its implications for people with and without ID is provided. Thereafter follows a discussion of research findings on intellectually disabled people's responses to sexual trauma and a brief description of the rationale for this study.

Chapter three begins by contextualising the study and outlining its aims. Details of the design of the data capturing form and its different variables are then explained. The data analysis section includes the method for the generation of the descriptive statistics, how the symptoms were clustered, and the different statistical tests that were used to test the three hypotheses. The chapter concludes with ethical considerations.

Chapter four presents the findings of the study, beginning with descriptive statistics for the characteristics of the sample and the different sexual trauma variables. Thereafter, the frequencies of reported symptoms for the total sample, as well as

according to the different levels of ID are given. Results of the tests conducted to test the three hypotheses are provided.

Chapter five discusses the results of the abovementioned analysis in relation to the findings that were presented in the literature review. Chapter six concludes this thesis with a summary of the study's key findings, reference to identified limitations, and suggestions for future research.

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## **CHAPTER 2: LITERATURE REVIEW**

The chapter begins with definitions of key terms and an historical overview of the conceptual changes that influenced paradigm shifts with regards to societal attitudes and clinical understanding of ID. Discussion of the estimated prevalence of rape in South Africa and the vulnerability to sexual trauma in intellectually disabled people follows. Thereafter is a summary of the body of literature on the impact of sexual trauma and its implications for people with and without ID. The next section presents a discussion of research findings on intellectually disabled people's responses to sexual trauma and some implications thereof, and concludes with a brief description of the rationale for this study.

### **2.1. Intellectual Disability**

The DSM-IV-TR (APA, 2000), describes Mental Retardation as significantly below average general intellectual functioning that is accompanied by significant limitations in adaptive functioning. Significantly below average intellectual functioning is defined as an IQ of about 70 or below, as measured by a valid and appropriately standardised psychometric assessment instrument e.g. Wechsler Adult Intelligence Scale–III (WAIS-III) or the Senior South African Individual Scale–Revised (SSAIS-R). The disability must occur before the age of 18 years. Mental retardation cannot be diagnosed unless there are significant deficits or impairments in adaptive functioning in at least two of the following skill areas as measured by a standardised tool of adaptive functioning, such as the Vineland Adaptive Behaviour Scales (VABS): communication, self-care, daily living skills, social/interpersonal skills, functional academic skills, work, leisure, health, and safety (Sadock & Sadock, 2007). The following ranges are used in DSM-IV-TR (APA, 2000) for sub-classification of mental retardation by level of intellectual functioning: mild: IQ level 50-55 to 70, moderate: IQ level 35-40 to 50-55, severe: IQ level 20-25 to 35-40 and profound: IQ level below 20-25 (DSM-IV-TR, 2000).

The United States is one of the few countries which still uses the term mental retardation (Greenspan & Switzky, 2003). In the United Kingdom and parts of Ireland,

the term learning disability or mental handicap is used (Carr, 2006). Intellectual disability is currently the preferred term within the field and will be the term used throughout this thesis.

### **2.1.1. Shifts in the social, clinical and theoretical conceptualisations of ID**

Historically there have been a number of derogatory terms used to describe people with ID, for example idiocy, imbecility, feeble mindedness and mental deficiency, all of which have been argued to imply a lack of respect and dignity and contribute to social marginalisation (Bernal & Hollins, 1995). In addition, retardation, a term central to the DSM-IV-TR (APA, 2000) definition, suggests a fixed course rather than a dynamic and changeable one (Meservy, 2008). This can result in practitioners and mental health providers classifying problems in functioning as being due to the individual's disability rather than exploring the aetiology of such changes in functioning (Meservy, 2008). As will be elucidated in later sections of this review, this is particularly pertinent in the context of the response to sexual trauma in people with ID.

The term ID falls under the umbrella of disability, a construct which is “socially and culturally defined as referring to an individual's impairment of functioning within a societal context and leading to a substantial disadvantage to the individual” (Meservy, 2008, p. 6). As such, even though ID implies an underlying, persistent brain dysfunction which affects the individual's ability to participate actively in their environment, it is no longer thought to be an invariable trait of the person, as the medical model would hold, but is based rather on the dynamic interaction between the individual and their environment (Meservy, 2008).

In the United Kingdom in the 1970's, the social model movement first began a vigorous critique of social responses to disability that were discriminating, excluding, oppressive and disabling (Swartz & Watermeyer, 2006). These attitudes can be understood from a social constructionist perspective which holds that the perceptions we create of ourselves, are often informed by the differences we perceive as existing between ourselves and others. “By constructing and regarding disabled people as broken, damaged, defective and dysfunctional, members of the broader non-disabled

society are able to reaffirm and reinforce an identity of being the opposite of these unwanted characteristics” (Watermeyer, 2006, pp. 33-34). Stereotypes about people with ID can thus be seen to benefit people in broader society as they assure them of their own ‘normality’ (Marks, 1999 as cited in Watermeyer 2006, p. 34). From a psychoanalytical perspective, the predicament of people with ID is that they become the ‘dustbins for disavowal’ (Shakespeare, 1994, as cited in Watermeyer, 2006, p. 34), into which the non-disabled project their unwanted and unacknowledged characteristics.

Until Penrose’s publication of *Better services for the mentally handicapped* (Department of Health and Social Security, 1971) people with ID, “did not generally seem worth it” (Fraser, 2000, p. 10). Although it has been recognised that people with ID can suffer from mental illness and in fact have a significantly higher lifetime prevalence of psychiatric disorders (Hollins, 2000; Matson & Sevin, 1994) there has been an imbalance in research and clinical services for the ID population. Beneath the marginalisation and implied devaluation of individuals with ID lay unfounded myths, such as the dehumanising perception that because people with ID seemed not to comprehend what had happened to them, they did not experience emotional pain (Sobsey & Mansell, 1990). It was also assumed that people with ID did not suffer after trauma as they ‘forget’ and are incapable of emotional insight (Ryan, 1994).

#### *Aetiological factors*

Aetiological factors in ID are mainly genetic, developmental, acquired, or a combination thereof (Sadock & Sadock, 2007). Examples of genetic causes include chromosomal and inherited conditions (e.g. Down Syndrome and Fragile X Syndrome); developmental factors comprise prenatal exposure to infections and toxins (e.g. Rubella); acquired syndromes involve perinatal trauma (e.g. prematurity) and sociocultural factors (e.g. deprivation of nurturance, nutrition and social stimulation). Generally the more severe the ID, the more evident an organic cause is. Current research indicates that genetic, environmental, biological, and psychosocial factors work augmentively in ID (Sadock & Sadock, 2007).

## 2.2. Sexual trauma

Sexual trauma refers to “one or multiple sexual violations that invoke significant distress” (Yuan, et al., 2006, p. 2). It is the main term used in this study as it is recommended and used by many clinicians and advocates who have observed that not all survivors describe what they experienced as rape or sexual assault. Furthermore, according to Yuan et al. (2006), the term sexual trauma is seen to encapsulate the act of violence with the survivor’s response. In this study the term sexual trauma is used when presenting a clinical viewpoint, and terms related to specific types of violations, (e.g. sexual assault, rape) are used when presenting particular findings in the literature.

Although the exact rape statistics for South Africa are elusive, it is clear from research findings that the country has an especially high prevalence of rape (Jewkes & Abrahams, 2002; Jewkes, Dunkle, Koss, Levin & Nduna, 2006). There are conflicting statistics in the context of ID and sexual trauma, with prevalence rates varying from 8 – 58% (Brown & Turk, 1995). Sobsey’s (1994) seminal review estimates that people with disability are at least twice and possibly five or more times more likely to be abused than people without disability. Cognisance should be taken of the fact that most estimates in the ID literature are subject to a lack of disclosure, under-reporting and variation in the definitions used by researchers (Balogh, Bretherton, Whibley, Berney, Graham, Richold, Worsley & Firth, 2001). Estimated prevalence rates are based mainly on convenience samples and are thus also not generalisable (Horner-Johnson & Drum, 2006).

This is particularly relevant in South Africa where the statistics for sexual offences in the general public are at best an estimate that does not disaggregate for able and disabled survivors. Thus, there are no reliable statistics on the rape and sexual assault of people with ID despite the problem being purportedly pervasive. The only survey conducted in Africa on sexual abuse of people with disability comes from Handicap International in Ethiopia (as cited in Hannas-Hancock, 2009), the results of which indicated that 46% of the disabled participants had experienced sexual violence. A survey of local service organizations highlighted high rates of physical, financial, sexual and emotional abuse of women with disabilities (Naidu, Haffejee, Vetten & Hargreaves, 2005). A recent study conducted by Vetten, Jewkes, Sigsworth,

Christophides, Loots and Dunseith (2008) in which a total of 11 926 rape cases reported in one year at 128 police stations in Gauteng Province, found that in the sample of 2 068 cases drawn for the study, approximately 1.9% of victims had some form of disability. A disability was recorded in 1.1% of adult victims, 1.3% of girls and 3.4% of teenagers. These figures fall below the prevalence of disability in Gauteng. According to Vetten et al. (2008), the low rates found in their study suggest three possibilities: under-recording of disability on medical and police documents; under-reporting of rape of disabled victims; or a decreased vulnerability to rape in disabled people. The latter explanation seems unlikely, given that international research suggests that people with ID are at a higher risk of sexual abuse than the general population (Peckham, 2007; Horner-Johnson & Drum, 2006; McCarthy & Thompson, 1997; Sobsey, 1994; Brown et al., 1995; Turk & Brown, 1993).

### **2.2.1. Vulnerability to sexual trauma in people with intellectual disabilities**

The vulnerability of individuals with ID is predicated upon various attitudes and myths, some of which were referred to earlier in this chapter. Society can be seen to reflect the range of emotional reactions that carers of individuals with ID display, from extreme overprotection, through equanimity to rejection (Allington-Smith, Ball & Haytor, 2002). Attitudes that are pitying, patronising, ridiculing, or openly despising are internalised by individuals with ID, contributing to low self-esteem. If people with ID perceive themselves as “damaged or unlovable” (Peckham, 2007, p. 133), it may be that they are more vulnerable to the attention of perpetrators, even if the attention shown to them involves acts of sexual violation. Compounding this is that with children (disabled or not), and adults with ID, “there is an inbuilt inequality of power” (Sinason, 2002, p. 426) which can contribute to compliance. Many individuals with ID are taught to acquiesce to caregivers’ requirements to the detriment of becoming assertive and independent. As McCarthy (2001) notes, treating adults with ID as if they are asexual and child-like, encourages compliance and facilitates abuse.

As the above implies, individuals with ID are considered easy victims (Beail & Warden, 1995). Moreover, the stigmatised, low status of people with ID, together with the assumption that they do not suffer emotional consequences can contribute to a

belief that abusing someone with ID is less serious than abusing someone who is not disabled (Brown & Craft, 1989). A 30 year old adult man convicted of twice raping a 13 year old girl with ID was granted an application to the Supreme Court of Appeal to challenge his conviction “because his rape of the child was ‘not the worst kind imaginable’” (Maughan, 2008). The lack of appropriate legal redress for perpetrators often leads to further victimisation (Sobsey, 1994). This is borne out by the frequent occurrence of multiple, rather than single incidents of abuse in the ID population (Mitchell & Clegg, 2005).

There are a number of factors that act as barriers to disclosure for individuals with ID. In cases where the perpetrator is a family member, fear of abandonment and intimidation can make it difficult for individuals to speak out (Sinason, 2002). Communication difficulties can also not only inhibit disclosure, but also render survivors dependent on others for reporting cases to the police, thus necessitating being believed and supported by caregivers. People with ID may have a history of loss of attachments and frequent failures, contributing to a diminished trust in themselves and others (Peckham, 2007). A 10 year review of a psycho-legal project in Cape Town found that of 100 cases studied, in only 50 instances was disclosure made to “a family member, friend or trusted adult, in one case using gestures. In 43 cases the abuse was discovered through witnesses, injury, pregnancy, infection, disarranged clothing or unusual behaviour” (Dickman & Roux, 2005, p. 141). Even after disclosure or discovery of sexual trauma, cases are frequently not reported as caregivers believe that reporting will “do more harm than good” (Dickman, Roux, Manson, Douglas & Shabalala, 2006, p. 116). This alludes not only to the emotional distress caused by having to act as a sole witness against the accused and be often hostilely cross examined, but also to the potential loss of income in cases in which the perpetrator is the sole provider in the victim’s family.

In addition to communication difficulties, cognitive limitations contribute to the vulnerability of individuals with ID. People with moderate to profound levels of ID, may not know the difference between appropriate and inappropriate sexual behaviour thus making competency to consent to sexual activity absent or highly questionable (Brown et al., 1995). A lack of sexual knowledge is often exacerbated by people with ID being excluded from sex education classes because educators and carers do not



want to “wake sleeping dogs” (Hanass-Hancock, 2009, p. 40). This paradoxical view that people with ID are either asexual or have an inherent “rampant sexuality” (Dickman et al., 2006, p. 116) exacerbates their vulnerability.

A final risk factor is, ironically, that sexual trauma in people with ID often goes unnoticed because clinicians and caregivers “misread the signs of psychological distress as simply being part of being intellectually disabled” (Mason, 2007, p. 248).

### **2.3. The psychological and psychiatric impact of sexual trauma**

Whilst a large body of literature suggests that sexual trauma in the general population is pathogenic (Foa & Rothbaum, 1998; Yuan et al., 2006; Koss, 2005), there is a dearth of literature on its impact on people with ID. Sequeira et al.’s (2003) critical literature review indicates that several studies suggest that the ID population may experience a range of psychopathology following rape that is similar to that experienced by adults and children without ID (e.g. PTSD, Major Depression, Generalised Anxiety Disorders) but with stronger behavioural reactions (Mitchell & Clegg, 2005; McCarthy, 2001). With this premise of commonality in mind, a summary of trauma theories that underpin clinical research in the general population is provided, before referring to the literature on sexual trauma and ID per se.

Burgess and Holstromm (1974) were the first to undertake a study which sought to account fully for “the immediate and long-term effects of rape as described by the victim” (p. 981). They coined the term Rape Trauma Syndrome (RTS) to define a two-phase reaction: an acute phase occurring in the first week post rape and a long-term re-organisation process following the rape. Because RTS was not recognised as a psychiatric disorder, it was difficult to substantiate the effects of rape within mainstream trauma discourse, as well as give reliable and valid evidence of the pathogenic impact of gender based violence in the legal sphere (Maw et al., 2008). Hence, the research which followed was mainly within the medical model, a paradigm within which impact is measured according to the presence or absence of symptoms, the identification of particular disorders and/or behavioural disturbances which affect the person’s daily life (Maw et al., 2008).

### **2.3.1. Post Traumatic Stress Disorder (PTSD)**

Since the 1980's, the psychological sequelae of sexual trauma has become increasingly conceptualised as PTSD [(see Appendix A for the DSM-IV-TR-TM's diagnostic criteria (American Psychiatric Association, 2000)]. Although fear and anxiety, the most frequently observed symptoms following rape, are integral to a diagnosis of PTSD, the diagnosis cannot be made in the absence of the victim's exceeding the threshold on three criteria: persistent re-experiencing of the event, persistently avoiding stimuli or numbing of responses, and increased arousal (Resick, 1993). A psychological perspective sees PTSD as representing an inability to process the experience of fear, which indicates either a prior vulnerability to fear, or exposure to extreme states of fear (Foa & Kozak, 1986). Cognitive behavioural theorists postulate that there are "two basic dysfunctional cognitions which mediate the development of PTSD: "the world is completely dangerous, and one's self is totally incompetent" (Foa, Ehlers, Clark, Tolin & Orsillo, 1998, p. 303). From a biological perspective, PTSD is considered to be a neurophysiological disorder with effects on the hypothalamic-pituitary-adrenal (HPA) axis, hippocampal volume and endogenous opioid functions (McCarthy, 2001).

It is important to bear in mind that not all people who experience trauma develop PTSD (Foa et al., 1998). A study by Foa, Rothbaum, Riggs and Murdock (1991) found that shortly after the assault, 94% of rape victims met the criteria for PTSD; and three months after the assault, 47% of victims still suffered from the disorder. Statistics on the prevalence of PTSD post sexual trauma in South Africa are sparse for the general population and unknown in the field of ID. Kaminer, Grimsrud, Myer, Stein and Williams' (2008) study used nationally representative data from 4 351 South African adults and investigated the relative risk of PTSD associated with different forms of assault. For women, rape was the most pathogenic trauma, bearing the highest risk for the development of PTSD.

### **2.3.2. PTSD in the ID population**

McCarthy (2001) questions whether the sparseness of literature on PTSD in people with ID is due to PTSD only having been recognised as a concept in the last 30 years, the same period in which there has been an acceptance that people with ID can also

experience serious mental illness. McCarthy (2001) postulates that “disorders that are more recently described in the general population, will take time to be delineated and explained in people with learning disability” (p. 163). Most research using the concept of PTSD with ID assumes that individuals with ID understand and respond to traumatic events in a similar way to the general population but present with additional behavioural symptoms (Sequeira et al., 2003). One way of understanding this difference in presentation is through adopting a developmental approach.

#### *A Developmental perspective of PTSD*

The developmental approach encompasses a biological, social and psychological understanding of behaviour and development (Dosen, 2005). According to this perspective people with ID pass through the stages of cognitive development in the same order as people without ID, but at a slower pace and they reach a lower level of development (Zigler, 1999). The chronological age of an individual with ID often does not serve as a reliable indicator of their developmental level, and is therefore frequently operationalised as a mental age equivalent. It is postulated that some of the ways in which children respond to trauma are relevant to an understanding of PTSD in adults with ID (McCarthy, 2001). In particular, Mitchell et al. (2005) suggest that child research may help to elucidate how people with communication problems experience and convey distress. For example, pre-school children who have experienced trauma, exhibit more behavioural symptoms such as regressive, antisocial, aggressive and destructive behaviour (McCarthy, 2001). According to Yule (1992) child and adolescent trauma survivors develop a wide range of symptoms that “tend to cluster around signs of re-experiencing the traumatic event, trying to avoid dealing with the emotions that this gives rise to and a range of signs of increased arousal” (as cited in McCarthy, 2001, p. 165).

According to Turk, Robbins and Woodhead (2005), the presentation of PTSD is mediated by the level and cause of an individual’s ID, as well as their social circumstances and communication skills. As in the general population, cognisance needs to be taken of other factors: a history of childhood abuse, early childhood adversity, the personality and resilience of the individual and exposure to other significant life events.

*A brief overview of the literature on PTSD in the ID population*

As already stated, there is very little literature documenting the psychological reactions of people with ID to sexual trauma. Furthermore, as Sequeira et al., (2003) point out, most are case studies which provide a lot of detailed information, but generally do not employ a systematic approach (e.g. few studies provide details about how reported psychological responses were assessed).

Ryan (1994) was one of the first clinicians to urge awareness of the fact that people with ID are just as likely to experience PTSD after a trauma as people without ID. Her preliminary study examined 310 people who all presented with violent and disruptive behaviour at a clinic for ID in the United States. The average level of ID was moderate and half of the sample was non-verbal. History and symptoms were thus elicited through drawings and gestures. Ryan stressed the importance of having gained the collateral from persons who knew the individuals' style of communication. She reported that almost all of the 310 referrals had confirmed experiences of significant abuse or trauma, most being sexual abuse by multiple perpetrators in childhood and/or rape. Although in half of them the abuse was known to someone working with the client, in none of the cases was a diagnosis of PTSD considered. Ryan diagnosed 51 of the 310 individuals (16.5%) with PTSD (DSM-III-R). Although Ryan did not report on the criteria on which each diagnosis was made, symptoms included: hypervigilance, exaggerated startle response, extreme fear, re-experiencing of the event, repetitive behaviours, dissociation, hypersensitivity to touch and sleep disturbance.

Firth, Balogh, Berney, Bretherton, Graham and Whibley's (2001) retrospective case analysis of 21 victims of sexual abuse contrasts with Ryan's in that only one case in their sample met the DSM-IV-TR criteria for PTSD. Firth et al. (2001) report the same reasons that many other clinicians give for not diagnosing PTSD in individuals with ID, that is, that the individuals did not meet the criteria for increased arousal or numbing, despite presenting with avoidance of places associated with the abuse and having nightmares. This highlights the precautions given by other authors, for example Sinason (2002), that symptoms of increased arousal are often difficult to perceive and require very careful observation. It could be argued that in the absence of observable autonomic arousal, symptoms such as excessive activity, as noted by

Sequeira et al. (2003) and distractibility and agitation (McCarthy, 2001) still provide evidence of increased arousal. In the avoidance cluster, symptoms of social withdrawal (i.e. seeking isolation from others, pre-occupation, resisting physical contact, and listlessness or inactivity) have been reported by Sequeira et al. (2003); Mansell, Sobsey and Calder (1992); Sobsey and Mansell (1994); Murphy, O'Callaghan and Clare (2007) and Allington-Smith et al. (2002).

Sequeira et al. (2003) reported that 19 of the 54 (35%) abused individuals with ID in their case control study presented with symptoms consistent with a DSM-IV diagnosis of PTSD. Jasson's (2009) case control study, which explored the prevalence of PTSD in sexual trauma survivors with ID living in the Western Cape also found sexual trauma to be associated with higher DSM-IV-TR PTSD diagnoses and higher levels of PTSD symptoms. In Jasson's study, 29.6% (8 of the 27 participants) met a diagnosis for PTSD compared to 3.7% in the control group. In Shabalala and Manson's (2008) study symptoms of PTSD and depression were the most common. Avoidance, intrusive thoughts and flashbacks were the least reported PTSD symptoms with none being noted in the profound range.

### **2.3.3. Critique of PTSD as a primary diagnosis for sexual trauma survivors**

The measuring of the effects of rape with standardised scales, as usually used to measure psychopathology in clinical populations pathologises women's responses to sexual trauma (Maw et al., 2008). Feminist discourse argues that the medical model, which still persists in informing our understanding of post-sexual trauma, can obscure broader social contextual factors (i.e. the intersection of oppression based on gender, together with class, race and ethnicity).

The application of categories that are structured using western psychological discourse are also questioned, with theorists arguing that non-westernised cultures may have different understandings of post-traumatic distress (Maw et al., 2008). Current research on the psychological impact of rape is chiefly American or from other 'developed' countries. It is argued by Wasco (2003) that although concepts of post-traumatic stress may provide a useful framework for understanding the sequelae of rape, contextual factors that affect actions and reactions of rape survivors from

oppressed groups should also be examined. Such factors may include low socio-economic status, racism as well as sexism. In the South African context, although literature from 'developed' countries is helpful, life experiences due to the legacy of apartheid, are different from the United States. Womersley and Maw (2009) cite Artz and Kunisaki's (1999) argument that according to available statistics the rape of women in South Africa is akin to rape during war. Living perpetually in such an abnormal situation renders women vulnerable to pervasive traumatic experiences (economically, physically and psychologically) and this will inform the psycho-social impact of rape. It can be argued that being raped is in fact not "outside the range of usual human experience," as the DSM-IV-TR defines it, but rather so common as to be normative (Brown, 2004).

Within the medical paradigm, clinicians have expressed the need for a diagnostic formulation that captures more than PTSD. Given the prevalence of individuals with ID experiencing multiple and/or ongoing sexual trauma, Herman's (1992) concept of Complex Post-traumatic Stress Disorder (CPTSD) could be considered. CPTSD describes the persisting intra- and interpersonal sequelae of the betrayal and violation that survivors of sexual abuse experience.

PTSD also does not account for multiple exposures to trauma over critical developmental periods. There is a growing body of literature (Van Der Kolk, 2005; Schore, 2001; Ford, 2009) which describes the consequences of chronic trauma as having pervasive effects on the development of the mind and brain. The experience of repeated trauma "interferes with neurobiological development and the capacity to integrate sensory, emotional and cognitive information into a cohesive whole" (Ford, p. 410). Developmental Trauma Disorder (DTD), as it has been termed, impacts on many different areas of functioning and leads to developmental delays. There is a lack of research in this field with infants and children with ID. Some literature suggests that because individuals with ID are already compromised neurobiologically, the compounding impact of repeated trauma can exacerbate developmental delays (Turk & Brown, 1993; Sinason, 1986).

Van Der Kolk argues that PTSD furthermore

does not capture the developmental effects of childhood trauma: the complex disruptions of affect regulation; the disturbed attachment patterns; the rapid behavioural regressions and shifts in emotional states; the aggressive behaviour against self and others; the failure to achieve developmental competencies; the loss of bodily regulation in the areas of sleep, food, and self-care; the altered schemas of the world; the anticipatory behaviour of traumatic expectations; the multiple somatic problems, from gastrointestinal distress to headaches; the apparent lack of awareness of danger, resulting in self-endangering behaviours; the self-hatred and self-blame; and the chronic feelings of ineffectiveness (Van Der Kolk, 2005, p. 406).

#### **2.4. Behavioural problems and other psychiatric symptoms associated with sexual trauma in the ID population**

Sequeira et al.'s (2003) seminal case-control study indicated that sexual abuse was associated with increased rates of psychiatric symptoms, behavioural problems, as well as symptoms of post-traumatic stress. A slowly growing body of literature confirms these findings. The following section describes the range of symptoms, psychopathology and behavioural difficulties that people with ID present with subsequent to sexual trauma. It should be borne in mind that because most of the reviewed studies did not provide clear descriptions of symptoms, or how they were assessed, there is a lack of firm evidence for an association between specific behaviours and diagnoses and the experience of sexual trauma.

##### **2.4.1. Behavioural problems**

Aggression, self-injurious behaviour and inappropriate sexual behaviour have been reported to be associated with sexual trauma in people with ID (Sobsey & Mansell, 1994; Allington-Smith et al., 2002; Balogh et al., 2001; Beail & Warden, 1995; Bernal & Hollins, 1995; Dunne & Power, 1990; Sobsey & Doe, 1991; Mansell, Sobsey & Calder, 1992; McCarthy, 2001; McCreary & Thompson, 1999; Murphy et al., 2007; Mitchell & Clegg, 2005; Ryan, 1994; Sequeira et al., 2003; Sinason, 1992;



Turk et al., 2005). Other documented behavioural responses include: stereotypical behaviour (Murphy et al., 2007) and social withdrawal (Mansell et al., 1992).

#### *Aggressive or challenging behaviour*

In Sequeira et al.'s (2003) study, consisting of two groups of 54 adults with ID, one of which had experienced sexual trauma, differences in disturbed behaviour between the groups were measured using the Aberrant Behaviour Checklist – Community (ABC-C). The largest differences between the two groups were for aggressive and agitated behaviours, including aggression to others, self-injury, temper outbursts and sudden changes of mood. Match-Maroney (2003), in her study of 18 adult victims of sexual trauma did not note any increased aggression. These conflicting results are possibly attributable to differing samples and methodological factors. Match-Maroney's (2003) study had a smaller sample, was non-randomised and included only borderline, mild and mild/moderate levels of ID, while 26 % of Sequeira et al.'s (2003) participants were in the moderate category and 30 % were severely or profoundly disabled. Mansell et al.'s (1992) study of 119 victims of sexual trauma found that 19.6 % of the group with mild and moderate ID and 31.1% with profound ID showed aggressive and/or other behavioural problems. Turk et al. (2005) noted the evidence of new challenging behaviours and exacerbations of existing ones in their two cases of moderate ID. Sobsey and Mansell (1994) in their study of 130 sexually abused children, reported specific problems of tantrums, non-compliance and aggressive acting out. Dunne and Power's (1990) findings of a three-year study of 13 adult victims of sexual abuse with ID reported behaviour problems and acting out to be possible indicators of sexual abuse having occurred in people with poor expressive language skills. In Sobsey and Doe's (1991) study of 162 adult survivors of sexual trauma with ID, 24.7% exhibited aggression and non-compliance.

#### *Sexual behaviour problems*

Findings from Balogh et al.'s (2001) study of behavioural symptomatology in 41 sexual trauma victims aged between 9 and 21 years concur with Sequeira et al.'s (2003) regarding verbal and physical aggression and self harm, but the authors note sexualised behaviour as being more frequent with the ID patients. Inappropriate sexual behaviour, for example, public masturbation, sexualised play and permissive sexuality, has also been reported by a number of other authors (Beail & Warden, 1995;



Mansell et al., 2002; Murphy et al., 2007; Allington-Smith et al., 2002; Sinason, 1992).

#### *Self injurious behaviours*

Self-harming behaviour in the general population has come to be understood by some clinicians as a means of coping with post-traumatic effects. As such, self-harm is seen to serve a number of functions: “re-enactment of the original trauma, expression of feelings and needs, re-organisation of the self and management of dissociative process” (Connors, 1996, p. 197). Self-harming behaviour by ID sexual trauma survivors has been reported by: Balogh et al. (2001); Beail et al. (1995); Cruz, Price-Williams & Andron, (1988); Murphy et al. (2007); Allington-Smith et al. (2002); Sequeira et al. (2003).

#### *Stereotypical behaviour*

The chief difference in symptoms between Sequeira et al.'s (2003) two groups was the presence of stereotypical behaviour, which was also reported by Murphy et al. (2007) and Allington-Smith et al. (2002). Although stereotypy has not been reported as a sequelae sexual trauma in many other studies, increases in stereotyped behaviour have been reported in studies of individuals with ID who have been bereaved (Hollins & Esterhuyzen, 1997). Sequeira et al. (2003) postulate that the increase may therefore not be specific to people who have been abused. They suggest that “cognitive, emotional and developmental factors related to ID may affect the presentation of psychological disorders in people with ID and may mediate responses to both sexual trauma and bereavement” (Sequeira et al., 2003, p. 454).

Other behavioural symptoms reported in the literature include: regression of abilities, elective mutism, running away, encopresis and enuresis (Allington-Smith et al., 2002); behavioural re-enactment (Mitchell & Clegg, 2005) and developmental and psychological regressions (Turk et al., 2005; Sinason, 1992), changes in self care, skills and communication (McCarthy, 2001).

#### **2.4.2. Perceptions of challenging behaviour**

In people with ID who often struggle to understand or be understood, behaviour can become a form of communication of their frustration or distress. Indeed the term

challenging behaviour, (i.e. aggression to others, or the self) was initially coined to indicate its interactive nature (Hollins, 2000). There are a number of factors that may underlie challenging behaviour: a history of inappropriately learned behaviour, an over or under-stimulating environment, a psychiatric disorder, neurological or endocrine abnormalities (Moss, Emerson, Kiernan, Turner, Hatton & Alborz, 2000). Sexual trauma as an aetiological factor is, however, rarely considered. It is important to recognise potential behavioural communications of trauma, as in the ID population disturbed and disturbing behaviour are often misconstrued. Sinason (2002) gives the example of how excessive masturbating or inappropriate sexual behaviour are frequently attributed to the individual's ID, rather than being seen as suggestive of a trauma response. Hence the need for caregivers and clinicians to be able to recognise the importance of non-verbal communication in expressing distress (Hollins, 2000).

#### **2.4.3. Other psychiatric symptoms associated with sexual trauma in the ID population**

Symptoms of depression as a sequelae to sexual trauma in people with ID have been reported by Cruz et al. (1988); Dunne and Power (1990); Matich-Maroney (2003); McCarthy (2001); Sinason (1992); Sequeira et al. (2003).

Anxiety symptoms have been reported by Dunne and Power (1990); Matich-Maroney (2003); Allington-Smith, et al. (2002) as well as in the aforementioned literature on PTSD. Balogh et al.'s study (2001) differed from Sequeira et al.'s (2003) in that anxiety symptoms were picked up less frequently. This may be attributable to the fact that information in Balogh et al.'s (2001) study was gathered through third parties, generally caregivers. Third party limitations were also evident in Mansell et al.'s (1992) study where the questionnaire was often filled in by clients' caregivers, some of whom noted "no problems". Because symptoms are not always observed by informants, they would thus not have been identified in participants from informant interviews alone. Differences, between self-reports and caregivers' reports, although not statistically significant, were also found by Jasson (2009). This lack of insight into the impact of the trauma on the part of the caregiver is highlighted by Ryan (1994) and points to the likelihood of obtaining more valid information regarding a person's psychological state when elicited directly from the person and not via a third party

(Arthur, 2003). As Sequeira et al. (2003) assert, an informant cannot be “completely aware of the internal subjective experience of a client or of non-visible autonomic symptoms that could be crucial to making a correct diagnosis” (p. 17). Both clinicians and caregivers can thus have difficulty assessing the impact of trauma, as highlighted by the comment “unable to describe how the assault affected her” in Shabalala and Manson’s (2008) pilot study.

Varley (1984) and Martorana (1985) both report cases of schizophreniform psychosis being precipitated by sexual assault. Sinason (2002), citing Varley’s (1984) case study report of three adolescent girls, asserts that young women with ID who are not believed when they disclose their abuse, are vulnerable to a psychotic breakdown.

## **2.5. Variables affecting the impact of sexual trauma and recovery**

The sequelae of sexual trauma are diverse, complex and highly individualised. This is apparent in the levels of severity (mild to extreme), timing (from instant to delayed reaction), duration (short-term to chronic), and the types of consequences (i.e. psychiatric symptoms, maladaptive behaviours) (Yuan et al., 2006). The reason for such a range of reactions and patterns of recovery can be attributed to pre-assault, assault, and post-assault variables (Resick, 1993).

Pre-assault variables like the demographics of age, race and socio-economic status (SES), are still unclear. Some researchers cite little impact, whilst others maintain that lower SES impacts negatively on survivors’ recovery (Wasco, 2003). Research on the influence of prior psychological functioning and life stressors is less equivocal. One of the most significant variables affecting the level of distress in the acute post-rape phase, as well as the propensity for later development of psychiatric disorders, is the pre-existence of mental health problems (Resick, 1993). In the context of this study this bears significance considering the already existent mental health problems of the ID population. There may be some differences in presentation between mild, severe and profound levels of ID. For example, someone in the mild level who has good communication skills will possibly describe ‘flashbacks’, recurring nightmares or clear memories (McCarthy, 2001) whereas someone in the profound level, unable to verbally communicate, will not.

There is support for findings that childhood sexual and/or physical assault has a direct influence on the development of PTSD in later life and that this can be complicated by the experience of sexual trauma in adulthood (Maw et al., 2008). The purported prevalence of both childhood sexual trauma and life stressors in people with ID suggests a possible increased susceptibility for the development of PTSD in this population.

In terms of assault variables, there are conflicting reports regarding the influence of the acquaintanceship status between the perpetrator and the survivor. Findings are also contradictory regarding the level of violence employed during the assault and resultant trauma (Resick, 1993). What has been found to be more significant is not the actual violence used, but rather the felt threat, or subjective distress experienced by the survivor (Resick, 1993). In Sequeira et al.'s (2003) study there was a significant positive correlation between the severity of the abuse and the severity of symptoms of depression and behavioural disturbance, but not of PTSD.

In terms of post-assault variables and the time elapsed since the trauma the scant literature in the ID field yields conflicting reports. In a study conducted by Murphy et al. (2007) in which they assessed PTSD symptoms in ID individuals using a standardised measure of skills and behaviour at three different points in time after the trauma, they found that changes in adaptive functioning, challenging behaviours, as well as symptoms of PTSD, were worse immediately after the event, but had subsided somewhat 3 months following the event. These findings concur with earlier cited references in the general population (e.g. Foa et al., 1991). In Sequeira et al.'s (2003) study, however, there was no significant correlation between the time elapsed since the abuse and any of the results on the measures used. The authors suggested that this may have been attributable to the disparity in the availability of psychotherapy and psychological services for people with ID and the general population. The majority of participants in the abused sample had not received any psychological or psychotherapeutic intervention following their sexual trauma.

Other post-assault variables concern the support a survivor receives as well as the survivor's own reactions and attempts to cope with the trauma. It is unclear whether

having a supportive family will necessarily mediate the impact of sexual trauma, but unsupportive responses from a survivor's social network do seem to worsen symptoms (Resick, 1993; Sinason, 1992). Post-rape cognitive appraisals and attributions inform a survivor's reactions to the assault. Maw et al. (2008) refer to a growing body of literature that suggests that the way in which survivors make meaning of the trauma is more important than the level of support they receive. Persons with ID are thus arguably doubly compromised in that they frequently lack both the cognitive ability to process their traumatic experiences, as well as the requisite support, not only from their families, but in terms of psychotherapeutic intervention.

## **2.6. Summary**

The paucity of research does not allow for conclusions, but a slowly developing body of literature suggests that the sequelae of sexual trauma for people with severe or profound ID includes changes in adaptive and challenging behaviours, as well as the typical symptoms of PTSD (Murphy et al., 2007; Sequeira et al., 2003). Further systematic and rigorous research is required, before the tentative hypothesis of Sequeira et al. (2003) can be proved, that the difference in reactions between the ID and general population are mediated by a person with ID's cognitive impairment. Cognisance should also be taken of the understanding that just as in people without ID, the consequences of sexual trauma are diverse, complex and highly individualised. Without this acknowledgement there is a risk of perpetuating what has historically often been the case in research on the impact of rape in the general population, which is to pathologise survivors, obscure broader social contextual factors, as well as steer research away from the more complex psychological effects of sexual trauma.

## **2.7. Aims of this study**

The main aim of this study was to delineate the most frequently occurring sexual trauma response symptoms in individuals with ID within a South African context. There are no standardised diagnostic tools to assess the effects of trauma in the ID population. Outcomes of this study may contribute to the creation of an instrument for use with the ID population group, adapted and standardized for use in South Africa.

## **CHAPTER 3: METHODOLOGY**

This chapter begins with a contextualisation of the study, followed by an explanation of the research design that was used. The sample is then described in terms of gender, race and socio-economic status. The procedures in gaining access to the sample, the data capturing instrument and the method of data collecting are outlined. Thereafter follows a discussion of how the data was analysed and a consideration of the ethical implications of the study.

### **3.1. Context of the research**

There is a paucity of literature on the effects of sexual trauma in the ID population which contributes to difficulty in recognising symptoms, both by caregivers and clinicians. This study is part of a larger research project investigating the impact of sexual trauma on people with ID. The project is a collaboration between the University of Cape Town and the Sexual Abuse Victim Empowerment (SAVE) project run by Cape Mental Health Society (CMHS).

CMHS is a non-governmental organization that offers mental health services to indigent people with psychiatric disorders and/or ID in the Western Cape. The SAVE project was established in 1990 to assist complainants with ID in rape cases in response to a request from the SAPS and prosecutors in the Department of Justice. In the past many prosecutors withdrew rape cases involving ID complainants. It was rare for rape cases involving a complainant with ID to go to court, and for the complainant to appear, especially as sole witness against the accused, as is often required (Dickman & Roux, 2005). Clinical psychologists who consult for the SAVE project conduct psycho-legal assessments, provide court preparation and advice for investigating officers and prosecutors, as well as giving expert testimony if subpoenaed to court.

Most complainants referred to the SAVE project are from areas in greater Cape Town and its surrounds which were designated for black and coloured<sup>1</sup> residents under the apartheid regime, e.g. Langa, Khayalitsha, Gugulethu, Mannenberg, Mitchells Plain and Delft. Poor service delivery, lack of resources, high levels of unemployment, poverty and crime persist in these areas. An estimated one fifth of complainants come from rural areas including the West Coast and the Overberg. In almost all cases complainants have few resources available to them to gain access to legal redress or therapeutic interventions.

Psychological evaluation in the psycho-legal programme serves primarily to assess a complainant's levels of intellectual functioning, ability to consent to sexual activity, as well as competency to act as a witness in court. The compiled report further includes the individual's background history, current functioning, appearance and behaviour on interview, results of tests which were administered to assess ID level [Individual Scale for General Scholastic Aptitude (ISGSA) and Vinelands Adaptive Behaviour Scale (VABS)], as well as a short description of the alleged rape and the complainant's reactions.

Shabalala and Manson (2008) conducted a pilot study of 133 of the abovementioned reports which were written in 2006-2007, that focused on "the alleged rape and reactions" section of the reports. Although the most common symptoms were of PTSD and depression, other prevalent symptoms reported in the literature on sexual trauma and ID were not as commonly noted. That 31.6% of the sample were reported as having had no response to their sexual trauma suggested a need for further investigation. This study follows on the 2008 pilot study, increasing the generalisability thereof by adding the years 2005, 2008 and 2009.

### **3.2. Aims**

The main aim of this study was to describe the frequency of reported symptoms of psychological disturbance in individuals with ID who had experienced sexual trauma. A further aim was to explore whether there was a difference in the number of reported symptoms between the different ID levels. The following was hypothesised:

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<sup>1</sup> The terms "black" and "coloured" are used in this context to reflect South Africa's past history, and ongoing socio-economic divisions.



**Hypothesis 1:** In the different PTSD symptom criteria clusters there would be more symptoms of increased arousal than re-experiencing and avoidance.

**Hypothesis 2:** There would be a difference in the number of reported symptoms between different levels of ID.

**Hypothesis 3:** There would be a difference between the number of symptoms reported by the different clinical psychologists who assessed the sample.

### **3.3. Design**

This is an archival study of the SAVE project's clinical psychologists' notes and assessment reports on 295 female sexual assault/rape victims from 2005 - 2009. The advantage of using these texts as a source of data is that they are objective and non-reactive. A drawback, however, is that the information is once removed from its source and it is also not always clear how the data was processed. This is a descriptive and explorative study, using quantitative measures to identify the frequency of commonly reported post rape symptoms in people with different levels of ID. The rationale for using a quantitative method is that it is the simplest manner of establishing the prevalence of symptoms in a sample this size. It also allows for the measurement of different variables that can be mathematically manipulated in order to make inferences and comparisons.

The pilot study focused on the "reaction to the alleged assault" section of the reports. Because many survivors and/or caregivers were unable to describe the impact of the trauma it was decided to look not only at what was verbally reported by the caregivers, but at what had been observed by the psychologists. Hence the clinical psychologists' notes and descriptions of the survivors' appearance and behaviour on interview were also examined. Data from the notes will be used in the discussion to elucidate the quantitative findings. The limited scope of this thesis does not allow for an analysis of the qualitative data that has been generated by this study.

### **3.4. Sample**

The records used for this study constitute a convenient sample of psychologists' notes and psycho-legal reports written between 2005-2009 for 295 female children and



adults who were allegedly raped or sexually assaulted and referred to Cape Mental Health's SAVE project by prosecutors or investigating officers.

An inclusion criterion for this study was that the individual was diagnosed with ID by the psychologist who assessed her. The level of ID was determined in accordance with the DSM-IV-TR diagnostic criteria, using both an Intelligence Quotient (IQ) and a measure of adaptive functioning (VABS). In most cases IQ was measured with the ISGSA. Developed in 1994, the ISGSA is an adjusted, standardised version of the Old South African Individual Scale (OASIS) and is used to diagnose and classify children with ID to be referred for special education. In instances where the severity of disability impeded administration of the ISGSA, the Vinelands Adaptive Behaviour Composite Score (VABS) alone was used. The VABS is a semi-structured interview conducted with the individual's caregiver to determine performance of daily activities that are required for personal and social sufficiency.

The five clinical psychologists who conducted the assessments and wrote the reports had consulted at CMHS consistently for the period 2005-2009. All of the consulting clinical psychologists at CMHS have experience in working with people with ID although their individual level of expertise in working with ID and sexual trauma was not available to the researcher. Male victims were excluded from the sample as within dominant discourses of heterosexuality there are notable differences in how men and women experience the impact of rape (Gavey, 2005, as cited in Womersley & Maw, 2009). No racial categorization was used in the reports. However, almost all individuals referred to the SAVE project are either black or coloured, reflecting South Africa's history of apartheid and continued social-economic divisions as mentioned in the contextualization section above. Languages spoken were English, Afrikaans and isiXhosa. Of the five psychologists, only one speaks isiXhosa and an interpreter was thus frequently used in the assessments.

### **3.5. Procedures**

A research proposal and a letter requesting access to records and permission to do this study were sent to the board of directors and trustees of CMHS. Data capturing was

conducted over a period of a month at CMHS as files containing clients' reports may not leave the premises.

#### *Data capturing form*

The same data capturing form using Microsoft Excel that was used in the pilot study (Shabalala & Manson, 2008) was adapted for use in this study. Variables included: the assessing psychologist, (coded as 1, 2, 3, 4 and 5); the following categories of data about the individual intellectually disabled clients: (I) chronological age, recorded in months; (II) level of disability, (coded as 1 = mild, 2 = moderate, 3 = severe, 4 = profound); (III) mental age as derived through the ISGSA; (IV) level of adaptive functioning, measured through the VABS, with levels of disability across three different domains, i.e. communication, socialisation and daily living skills, (coded as 1 = mild, 2 = moderate, 3 = severe, 4 = profound). The following variables were added for this part of the study: number of perpetrators (1 = 1 perpetrator, 2 = multiple perpetrators); approximate time elapsed since the incident, the nature of the assault (1 = sexual assault, 2 = vaginal rape; 3 = anal rape, 4 = attempted rape); number of known sexual assault incidents (1 = once, 2 = raped more than once by a different perpetrator, 3 = ongoing abuse, sometimes over months and years, by the same perpetrator); the relationship to the perpetrator (i.e. 1 = known or 2 = stranger).

#### *Coding of reported reactions*

The same list of symptoms which had been identified in the pilot study (Shabalala & Manson, 2008) after examining 133 reports was used for this research. Instances in which the individual, caregiver or psychologist were unable to say how the sexual trauma had affected the individual, were labelled "none reported". Variables were coded with 1 = reported, 0 = not reported.

The data captured in the pilot study for the years 2006-2007 was used, in addition to reports written in 2005, 2008 and 2009. The 2006-2007 reports were re-checked so as to be able to include data for the abovementioned additional variables.

### 3.6. Data analysis

Microsoft Excel and the Statistical Package for Social Sciences, SPSS (PASW version 18 of the software) were used for the data analysis.

Symptoms were first clustered into categories of PTSD, Depression, Behavioural Disturbance and “other”. The PTSD symptoms were categorised according to the DSM-IV-TR (2000) three clusters: namely, re-experiencing of the event, avoidance of stimuli associated with the event and increased arousal. The re-experiencing cluster included nightmares, intrusive thoughts, flashbacks, guilt and dissociation. Avoidance included: avoidance (i.e. of places, people or activities associated with the trauma), withdrawal (seeking isolation from others, being pre-occupied, resisting any form of physical contact) and decreased recreation. Increased arousal included fear, sleep problems, increased startle response, agitation/restlessness, anger, irritability, temper outbursts and anxiety. The following symptoms made up the depression cluster: sadness, tearfulness, suicidality, appetite/weight changes, somatic complaints and memory problems. Behavioural disturbances included aggression, oppositional and sexualised behaviours. There is clearly an overlap of some symptom clusters. For example, irritability, sleep disturbance and decreased recreation are all symptoms of both PTSD and depression. Symptoms were clustered as described for statistical purposes so as to allow for comparison of the different PTSD criteria symptoms, ease of presentation of the descriptive statistics and because of the context of this study. That is, the development of new-onset depressive symptoms that occur subsequent to trauma, rarely precede or develop in the absence of trauma (Breslau, Davis, Peterson & Schultz, 2000).

Some symptoms were collapsed: for example, increased/decreased appetite and increased/decreased weight became “appetite disturbance”, insomnia, hypersomnia and sleep disturbance became “sleep problems”, restlessness and agitation were collapsed into one category and termed “restlessness/agitation”. A category labelled “other” included the other reported symptoms: increased washing, shame, confusion, distressed/upset, school refusal, substance use and loss of skills.

Descriptive statistics for the demographics of the group and the different variables were generated using SPSS. Descriptive statistics were calculated for the frequency and percentage of reported symptoms both according to different levels of ID and for the sample as a whole.

### **3.6.1. Statistical Analysis**

**Hypothesis 1:** *In the different PTSD symptom criteria clusters there would be more symptoms of increased arousal than re-experiencing and avoidance.*

A repeated measures analysis of variance (ANOVA) was done to test the assumption that there would be more symptoms falling in the criteria of increased arousal than re-experiencing and avoidance. To test the assumptions of ANOVA a pairwise comparison using Sidak's adjustment for multiple comparisons was done. Sidak's test was chosen as it is a more stringent test of group differences than the Least Squares Difference test.

**Hypothesis 2:** *There would be a difference in the number of reported symptoms between different levels of ID*

To compare the number of reported symptoms statistically in the four different ID levels an analysis of variance (ANOVA) was used. From reading the psychologists' reports it was speculated that the profound group would report less symptoms than the other groups. Therefore a three planned comparison to compare the mild and profound groups, the moderate and profound groups and the severe and profound groups on total number of symptoms reported were conducted.

**Hypothesis 3:** *There would be a difference between the number of symptoms reported by the different psychologists who assessed the sample.*

To compare the number of reported symptoms by the five different psychologists statistically, an analysis of variance (ANOVA) was used, followed by a post hoc Games Howell test. The Games Howell test was used because the variance between the groups was heterogeneous. An analysis of covariance was also used to ensure that any difference in the mental ages of individuals tested by the different psychologists did not affect the number of symptoms reported by the psychologists.

### **3.7. Ethical considerations**

After the submission of a research proposal, ethical clearance for the study was received from the Ethics Committee in the Department of Psychology at the University of Cape Town. Permission was sought and received from CMHS for access to the clinical psychologists' reports which were not permitted to be removed from the organisation's premises. Since this is an archival study, there is no risk of maleficence to individuals whose reports were analysed. In order to respect individuals' anonymity and confidentiality, identifying details and names have been omitted from this thesis. Psychologists were coded so as not to be identifiable. CMHS will be provided with a copy of this thesis.

University Of Cape Town

## CHAPTER 4: RESULTS

This chapter begins with descriptive statistics for the characteristics of the sample and the different sexual trauma variables. Thereafter, the prevalence of reported symptoms in response to sexual trauma for the total sample is given. The differences in the percentage of symptoms reported between the different PTSD symptom criteria clusters follows. Results of the comparison of the number of reported symptoms between different ID levels are then provided. The chapter culminates with the outcome of the comparison between the number of symptoms reported by different psychologists and a summary of results.

### 4.1. Characteristics of the sample

The source of data for this archival study consisted of the psychologists' reports and notes for 295 female intellectually disabled sexual assault and rape survivors. The average chronological age of victims assessed was 20 years, and ranged between 7 and 63 years; 32.5 % were under the age of 16 years. 33.9 % of the sample fell in the mild category (IQ 50-55 to approximately 70), 39.3% were moderate (IQ 35-40 to 50-55), 23.3% were severe (IQ 20-25 to 35-40) and 3.3 % were profound (IQ below 20-25). Table 1 illustrates the characteristics of the sample according to level of ID, chronological and mental age.

**Table 1:** Characteristics of the sample

	Mild	Moderate	Severe	Profound
Chronological age (years)				
<i>Mean</i>	18	20	22	28
<i>Range</i>	7 – 51	8 – 45	9 – 63	11 – 49
<i>Valid N</i>	100	116	68	10
Mental age (years : months)				
<i>Mean</i>	7:7	6:0	4:7	4:7
<i>Range</i>	3:6 – 12:7	4:0 – 10:0	3:5 – 7:7	-
<i>Valid N</i>	100	115	60	1

*Note:* Missing mental ages are due to the ISGSA not having been administered.

## 4.2. Sexual trauma variables

The majority of the sample reported having been raped vaginally. In three quarters of the cases the perpetrator was known to the individual, and in most instances the perpetrator was aware of the individual's disability. The majority reported having been raped once. A quarter of the sample was raped or abused on an ongoing basis over a period of months or years, or had been raped previously (see Table 2). The average amount of time between the sexual trauma and assessment by a psychologist at CMHS was 13 months.

**Table 2:** Sexual trauma variables

Variable	Frequency	Percent
Nature of assault		
<i>Sexual assault</i>	16	5.4
<i>Vaginal rape</i>	257	87.1
<i>Anal rape</i>	8	2.7
<i>Attempted rape</i>	3	1.0
<i>Missing*</i>	11	3.7
<i>Total</i>	284	100
No. of perpetrators		
<i>One perpetrator</i>	258	87.5
<i>Multiple perpetrators</i>	29	9.8
<i>Missing*</i>	8	2.7
<i>Total</i>	287	100
Relationship to perpetrator		
<i>Known</i>	223	75.6
<i>Stranger</i>	35	11.9
<i>Missing*</i>	37	12.5
<i>Total</i>	258	100.0
Rate of sexual abuse/rape		
<i>Once</i>	212	71.9
<i>More than once (different perpetrators)</i>	34	11.5
<i>Ongoing abuse/rape</i>	36	12.2
<i>Missing*</i>	13	4.4
<i>Total</i>	282	100

Note: \*Missing data = not reported

*Footnote:* A multiple regression was run to see whether the different sexual trauma variables significantly predicted the total number of symptoms reported. The final model, which included the number of perpetrators, nature of the assault, relationship to the victim, rate of sexual abuse and the time elapsed since the incident, was not significant ( $R^2=0.05$ ,  $F(8, 222) = 1.40$ ,  $p=.197$ ). See Appendices B, C and D for correlation matrix table and the full regression results.

### **4.3. Descriptive statistics of reported symptoms**

This section provides descriptive statistics for the prevalence of reported symptoms across all ID levels. PTSD and depressive symptoms were the most commonly reported while behavioural disturbance was the least reported. 29.8 % of the sample reported no symptoms.

#### **4.3.1. PTSD symptom**

In the increased arousal criteria category the most prevalent symptoms, for all levels of ID, were sleep disturbance, fear and anger. Anxiety was the most frequently reported symptom for the mild and moderate levels, and was also commonly reported in the severe level. There were no reports of anxiety in the profound level. Across all levels of ID nightmares were the most common in the re-experiencing cluster, with intrusive thoughts, flashbacks and dissociation the least common. In the avoidance category, symptoms of withdrawal were the most prevalent for the mild, moderate and severe levels, with avoidance and decreased recreation less reported. There were no reports of any avoidance criteria symptoms in the profound level (see Table 3).



**Table 3:** Descriptive statistics for reported symptoms of PTSD in different ID levels and the total sample

Reported Symptoms	Mild (n= 100)		Moderate (n= 116)		Severe (n= 69)		Profound (n= 10)		Total (n= 295)	
	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent
PTSD symptoms										
I. Re-experiencing										
<i>Intrusive thoughts</i>	5	5.0	5	4.3	1	1.4	0	0	11	3.7
<i>Nightmares</i>	9	9.0	17	14.7	6	8.7	2	20	34	11.5
<i>Flashbacks</i>	4	4.0	3	2.6	0	0	0	0	7	2.4
<i>Dissociation</i>	4	4.0	4	3.4	1	1.4	0	0	9	3.0
<i>Guilt</i>	2	2.0	0	0	1	1.4	0	0	3	1.0
II. Avoidance										
<i>Avoidance</i>	5	5.0	4	3.4	2	2.9	0	0	11	3.7
<i>Withdrawal</i>	8	8.0	25	21.6	11	15.9	0	0	44	14.92
<i>Decreased pleasure</i>	0	0	2	1.7	0	0	0	0	2	0.7
III. Increased arousal										
<i>Sleep disturbance</i>	19	19.2	24	21.8	9	14.1	3	30	55	18.6
<i>Anger</i>	13	13.0	20	17.2	9	13.0	1	10.0	43	14.6
<i>Irritability</i>	4	4.0	8	6.9	7	10.1	0	0	19	6.4
<i>Temper outbursts</i>	3	3.0	4	3.4	2	2.9	0	0	9	3.1
<i>Increased startle response</i>	5	5.0	3	2.6	5	7.2	0	0	13	4.4
<i>Anxiety</i>	27	27.0	28	24.1	10	14.5	0	0	65	22
<i>Fear</i>	21	21.0	26	22.4	11	15.9	2	20.0	58	19.7
<i>Restlessness/agitation</i>	2	2.0	5	4.3	1	1.4	0	0	8	2.7

#### **4.3.2. Depressive symptoms, behavioural problems and other reported symptoms**

The most prevalent depressive symptom was sadness/low mood. Somatic complaints (e.g. abdominal and chest pains, headaches, dizziness, and back ache) were most frequently reported in the moderate level, but were also common in the mild and severe levels. Appetite/weight changes were fairly common, while memory problems and suicidality were less frequently reported.

Symptoms of behavioural disturbance were not frequently reported. Aggression was the most common symptom in this cluster, with fewer symptoms of sexualised behaviour.

In terms of symptoms reported in the cluster titled “other”, there were only 13 reports of individuals having lost the ability to perform previously mastered skills. Psychologists used the term distressed/upset to describe 7.5 % of the sample’s reported response to the sexual trauma and/or behaviour on interview when having to talk about the event. There was only 1 report of substance use, and 3 of school refusal (see Table 4).

**Table 4:** Descriptive statistics for reported symptoms in different ID levels and the total sample

Reported Symptoms	Mild (n= 100)		Moderate (n=116)		Severe (n= 69)		Profound (n= 10)		Total (n= 295)	
	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent
<b>Depressive symptoms</b>										
<i>Sadness/low mood</i>	25	25.0	33	28.4	6	8.7	0	0	64	21.7
<i>Tearful</i>	8	8.0	15	12.9	5	7.2	0	0	28	9.5
<i>Appetite/weight changes</i>	6	6.0	10	8.6	6	8.7	0	0	22	7.5
<i>Memory problems</i>	1	1.0	4	3.4	3	4.3	1	10.0	9	3.1
<i>Suicidal</i>	4	4.0	2	1.7	0	0	0	0	6	2.0
<i>Somatic complaints</i>	6	6.0	19	16.4	6	8.7	0	0	31	10.5
<b>Behavioural disturbance</b>										
<i>Aggression</i>	6	6.0	6	5.2	6	8.7	0	0	18	6.1
<i>Oppositional</i>	2	2.0	7	6.0	4	5.8	0	0	13	4.4
<i>Sexualised behaviour</i>	2	2.0	4	3.4	2	2.9	2	20.0	10	3.4
<b>Other</b>										
<i>Increased washing</i>	1	1.0	0	0.0	0	0	1	10.0	2	0.7
<i>Shame</i>	6	6.0	1	0.9	0	0	0	0	7	2.4
<i>Confusion</i>	0	0	5	4.3	2	2.9	2	20.0	9	3.1
<i>Distressed/upset</i>	11	11.0	9	7.8	2	2.9	0	0	22	7.5
<i>School refusal</i>	0	0	1	0.9	2	2.9	0	0	3	1.0
<i>Substance use</i>	0	0	1	0.9	0	0	0	0	1	0.3
<i>Loss of skills</i>	4	4.0	4	3.4	4	5.8	1	10.0	13	4.4
No symptoms reported	29	29.0	26	22.4	29	42.0	6	60	90	29.8

#### 4.4. Statistical analysis

This section includes the results of the statistical analyses that were conducted to test the four hypotheses that were made.

##### 4.4.1. Hypothesis 1

*In the different PTSD symptom criteria clusters there would be more symptoms of increased arousal than re-experiencing and avoidance.*

The differences in the percentage of symptoms reported between the different PTSD symptom criteria clusters as highlighted in the descriptive statistics section were analysed in greater detail. It seemed that symptoms of increased arousal were more prevalent than symptoms of re-experiencing and avoidance (see Table 5). A repeated measures ANOVA was done to investigate this assumption.

**Table 5:** The differences in percentage of symptoms reported between the different PTSD symptoms criteria clusters

Symptoms criteria clusters	Mean	Std. Deviation	N
Re-experiencing percentage	4.20	9.96	295
Avoidance percentage	6.44	14.28	295
Increased arousal percentage	11.53	14.71	295

To test the assumptions for ANOVA Mauchly's test of Sphericity for homogeneity of covariance was done and found to be significant, ( $W [2, 294] = 0.90, p < .001$ ). As the assumption of sphericity was not upheld, the Greenhouse-Geisser test was done as this is a more reliable test when covariance between the groups is different (see Table 6).

**Table 6:** Greenhouse-Geisser test of within subjects effects

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
PTSD	8306.44	1.82	4568.69	29.06	<.001	0.09
Error (PTSD)	84038.93	534.53	157.22			

The repeated measures ANOVA showed that there was a significant difference in the number of reported symptoms for arousal, avoidance and re-experience. ( $F [1.82, 534.53] = 29.06, p < .001, \eta^2 = 0.09$ ). 9% of the variance in symptoms reported was due to the difference in symptom criteria. A pairwise comparison using Sidak's

adjustment for multiple comparisons showed significant differences between increased arousal and avoidance ( $p < 0.001$ ) and between increased arousal and re-experiencing ( $p < 0.001$ ). Sidak's test was chosen as it is a more stringent test of group differences than the Least Squares Difference test. Most reported symptoms were of increased arousal (sleep disturbance, anger, irritability, temper outbursts, increased startle response, anxiety, fear and restlessness/agitation). There was no significant difference between re-experiencing (intrusive thoughts, nightmares, flashbacks, dissociation and guilt) and avoidance (withdrawal, decreased recreation and avoidance),  $p = 0.075$ . On average, individuals reported increased arousal symptoms nearly twice as often as avoidance, and three times more often than symptoms of re-experiencing.

#### 4.4.2. Hypothesis 2

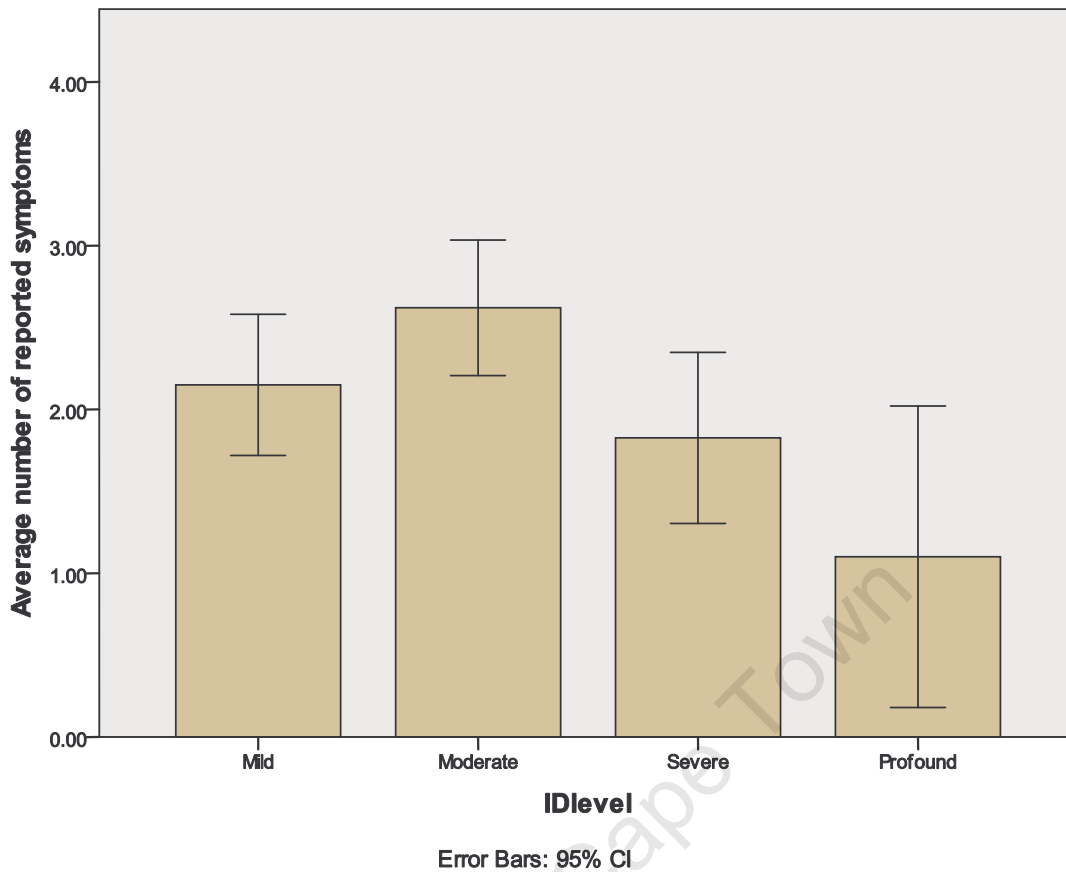
*There would be a difference in the number of reported symptoms between different levels of ID.*

Having looked at the prevalence of symptoms across all levels of ID, as discussed in the descriptive statistics section, the differences between the reported number of symptoms between ID levels was next investigated (see Table 7).

**Table 7:** Comparison of number of reported symptoms between ID levels

ID level	Mean	Std. Deviation	N
Mild	2.15	2.17	100
Moderate	2.62	2.24	116
Severe	1.82	2.17	69
Profound	1.10	1.28	10
Total	2.22	2.20	295

The above figures are represented graphically in figure 1.



**Figure 1:** Average number of reported symptoms in different ID levels.

*Note: error bars indicate 95 % confidence levels*

It appeared that the moderate group reported the most symptoms and the profound group reported the least number of symptoms. To compare the number of reported symptoms in the four different ID levels statistically, an analysis of variance (ANOVA) was used.

**Table 8:** Tests of normality

	ID level	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	Df	Sig.
Total no. of symptoms reported	Mild	.248	100	<.0001	.834	100	<.001
	Moderate	.160	116	<.0001	.903	116	<.001
	Severe	.201	69	<.0001	.804	69	<.001
	Profound	.231	10	.139	.824	10	.028

a. Lilliefors Significance Correction

Levene's test for homogeneity of variance was not significant, ( $F [3,291] = 1.49, p = 0.218$ ). The Kolmogorov-Smirnov test of normality found that the different ID levels were not normally distributed on the total number of symptoms reported:  $KS_{mild} (100) = 0.248, p < 0.0001$ ,  $KS_{mod} (116) = 0.160, p < 0.0001$ ,  $KS_{severe} (69) = 0.201, p < 0.0001$ ,

$KS_{\text{profound}}(10) = 0.231, p = 0.139$ . The data was not transformed as data transformations are ineffective for positively skewed samples such as this sample. However, because the assumption of homogeneity of variance was upheld, and ANOVA is a robust test, the results can still be reliably interpreted.

**Table 9:** Tests of Between-Subjects Effects

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
ID Level	42.36 <sup>a</sup>	3	14.12	2.96	.032	.03
Error	1384.87	291	4.75			
Corrected Total	1427.23	294				

a. R Squared = .030 (Adjusted R Squared = .020)

The analysis of variance (ANOVA) showed that there was a significant difference in the number of symptoms reported between the different levels of ID ( $F [3, 291] = 2.96, p < .032, \eta^2 = 0.03$ ). The three planned comparison (see Table 10), showed a significant difference between the moderate and profound groups ( $p = .035$ ).

**Table 10:** Simple Contrast Results

ID level	Contrast Estimate	Hypothesised value	Std. Error	Sig.
Mild vs Profound	1.05	0	.72	.148
Moderate vs Profound	1.52	0	.719	.035
Severe vs Profound	0.72	0	.738	.326

#### 4.4.3. Hypothesis 3

**There would be a difference between the number of symptoms reported by the different psychologists who assessed the sample.**

As indicated in the Methodology chapter, having read the psychologists' reports it was hypothesised that certain psychologists reported fewer symptoms than others. Table 11 illustrates the mean number of symptoms reported by each psychologist.

**Table 11:** Mean number of symptoms reported as recorded by different psychologists

Psychologist	Mean	Std. Deviation	N
1	2.50	1.90	77
2	1.32	1.53	82
3	1.65	1.94	84
4	4.17	2.77	47
5	3.80	.83	5
Total	2.22	2.20	295

Note: N = number of individuals assessed by each clinical psychologist

Psychologists 2 and 3 appear to have reported fewer symptoms on average than psychologists 1, 4 and 5 (see table 11). To compare the number of reported symptoms by the five different psychologists statistically, an analysis of variance (ANOVA) was used.

**Table 12:** Tests of normality

Psychologist	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk			
	Statistic	df	Sig.	Statistic	df	Sig.	
Total no. of symptoms reported	1	.18	77	<.001	.92	77	<.001
	2	.19	82	<.001	.80	82	<.001
	3	.21	84	<.001	.79	84	<.001
	4	.16	47	.003	.93	47	.016
	5	.23	5	.200	.88	5	.314

a. Lilliefors Significance Correction

Levene's test for homogeneity of variance was significant, ( $F [4,290] = 6.06, p < 0.001$ ). The Kolmogorov-Smirnov test of normality (see Table 12) found that the psychologists' reporting of symptoms was not normally distributed:  $KS_1 (77) = 0.18, p < 0.000$ ,  $KS_2 (82) = 0.19, p < 0.001$ ,  $KS_3 (84) = 0.21, p < 0.001$ ,  $KS_4 (47) = 0.16, p < 0.016$ ,  $KS_5 (5) = 0.23, p < 0.314$ ). However, since ANOVA is a robust test, and because the assumption of homogeneity of variance was upheld, the results can still be reliably interpreted.

**Table 13:** Tests of Between-Subject Effects

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Psychologist	289.45	4	72.36	18.44	<.001	.20
Error	1137.78	290	3.92			
Corrected Total	1427.23	294				

a. R Squared = .203 (Adjusted R Squared = .192)



As Table 13 indicates, there was a significant difference in the number of symptoms reported between the psychologists ( $F [4,290] = 18.44, p <.001, \eta^2 = .20$ ). The Games Howell post hoc test method was used because variance between the groups was heterogeneous. Psychologists 2 and 3 reported significantly fewer symptoms than psychologists 1, 4 and 5 (all  $p <0.05$ ). On average psychologists 2 and 3 reported 1 symptom while psychologist 1, 4 and 5 reported between 2 and 4 symptoms each (see Table 10). One reason for the discrepancy in the number of reported symptoms could have been that psychologists 2 and 3 assessed more individuals with severe and profound levels of ID than the other psychologists did, and that individuals in this range reported fewer symptoms. An analysis of covariance was thus done to cancel out the effects of mental age on the number of symptoms reported (see Appendix E). However it was found that there was not a difference in mental age of individuals assessed by the different psychologists ( $F [1,267] = 1.9; p = .169$ ). Even with mental age added as a covariant there was still a significant difference in the number of symptoms reported by the different psychologists ( $F [4, 267] = 18.17; p <.001$ ).

#### **4.5. Summary of results**

In summary, the most frequently reported symptoms were for PTSD and depression. Behavioural disturbance was not common and 29.8% of the sample reportedly had “no response” to the sexual trauma. As hypothesised, symptoms of increased arousal were more prevalent than symptoms of re-experiencing and avoidance in the PTSD criteria clusters. A difference was found between the number of symptoms reported: the moderate group reported the most symptoms and the profound group reported the least number of symptoms. And finally, there was a significant difference in the number of symptoms reported depending on which psychologist did the assessment.

## CHAPTER 5: DISCUSSION

This chapter provides a discussion of the results that were reported in the previous chapter. It begins with reference to the characteristics of the sample and the different sexual trauma variables. A discussion of the findings regarding reported symptoms follows. Suppositions are made as to why certain symptoms were more common in certain levels of ID and why increased arousal was more frequently reported than avoidance and re-experiencing. The chapter concludes with possible reasons for why there were so many reports of “no response” to the sexual trauma.

### 5.1. Characteristics of the sample

The sample consisted of 295 female sexual trauma survivors with ID who had been referred to the SAVE project. In terms of the age of the individuals, the developmental perspective would argue that the mental age range (3 years 6 months to 12 years 7 months) is more applicable in understanding the trauma responses of this sample than the chronological age range (7 years to 63 years). That almost a third of this sample was under the age of 16 years old is similar to what has been reported in other studies in the general population in South Africa. For example, Vetten et al. (2008) found that 14.6% of their sample of 2 064 rape docketts were for children 0 -11 years old and 25.2% were 12 – 17 years old. Most trauma literature studies children and adults separately, but in this study, they were looked at together. There are no comparative studies between adults and children with ID, but the literature suggests that at lower developmental levels the manifestation of trauma symptoms in adults appears to be similar to what is seen in children (Tomasulo & Razza, 2007).

With regard to the ID level distribution, although estimated demographics within literature for the ID population are conflictual, the ratios within this sample were different to those provided in the literature. According to Sadock and Sadock (2007) 85 % of people with ID generally fall in the mild range but in this study they made up only a third of the sample. The moderate level in this sample comprised almost 40 %, as opposed to 10 %; the severe level 23 %, as opposed to 4% and the profound level 3 %, not 1 - 2 %. These discrepancies are attributable to a number of possible factors.

Firstly, most people assessed by the SAVE programme are referred by the Sexual Offences Court and referral is dependent on the prosecutor, magistrate, or a social worker suspecting that the complainant has an intellectual disability. This may mean that not all people with mild ID are referred to the SAVE programme, as many adults with mild ID can live independently with some support (Sadock & Sadock, 2007) and their presentation is not always noticeably different from the general population (Tomasulo & Razza, 2007). This concurs with reports by Maw (2010) who found that in a sample of 62 women, who presented at Thuthuzela Care Centre, which provides forensic, clinical and counselling support for rape survivors, two had undiagnosed mild ID. It may have been that other women in the sample also had undiagnosed ID, but they were not referred for assessment due to lack of details regarding their educational histories (Maw, personal communication, 2010). Pillay and Lockhart (2003) cite evidence which suggests that in South Africa children with mild ID are often not appropriately diagnosed and managed. A further factor to consider is that levels of ID may have been depressed because scores obtained on the VABS and ISGSA which measure social competence and cognitive ability respectively, are affected by social and cultural influences as opposed to an individual's potential. As one of the assessing psychologists reported,

Sexual abuse, interrupted education, or not having any access to school, lack of care, neglect, can all impact on the ability to develop skills as well as social perceptiveness. Scores are therefore not always indicative of individuals' potential, but are rather based on circumstances/deprivations etc. and contribute to making individuals functionally impaired.

Although the number of persons in the profound level is closer to the estimated demographics of the population, there is a possibility that people who are profoundly disabled are likely to be more restricted with regards to their ability to communicate and thus report the abuse. Since referral to the SAVE programme is contingent upon there being ongoing legal proceedings, this could possibly mean that they were under represented in this study.

## 5.2. Sexual trauma variables

The sexual trauma variables included the nature of the sexual trauma, relationship to the perpetrator, frequency of trauma, and the time elapsed since the incident. Results of the multiple regressions that were run to see whether the different sexual trauma variables significantly predicted the total number of symptoms reported were not significant.

### *Nature of sexual trauma*

Completed rape, as opposed to attempted rape and sexual assault, was reported by 89.8 % of this sample. These findings are higher than in other studies. For example, in Brown et al.'s (1995) second two-year incidence report only 57 % of their sample of 119 adult survivors with ID was raped. The high percentage reported in this present study may possibly be accounted for by the statistics for the rape of women and children in South Africa which, according to Moffet (2006), are the highest in the world for a country that is not at war. A feminist perspective (Brownmiller, 1975) holds that rape should be understood in the broader context of patriarchy and female oppression. Although adopting a feminist perspective is helpful in examining the prevalence of sexual violence in a country like South Africa with its deeply entrenched social traditions of male dominance, the issue is further complicated by poverty and, according to Posel (2005) broader political and ideological anxieties concerning the "moral community of the country's fledgling democracy" (p . 239).

Results of the multiple regression showed that the nature of the assault had no correlation with the number of symptoms reported. These findings differed from Sequeira et al.'s (2003) study which found significant positive correlations between the severity of the act and the severity of behavioural and depressive symptoms, but no significant relationship was found with PTSD symptoms. The findings of this present study concur, however, with a growing body of literature which suggests that the severity of the sexual assault is not as significant in determining the manifestation of symptoms, as is the 'felt threat' or subjective distress a survivor experiences (Booley, 2002; Resick, 1993). It is theorised that a person's subjective appraisal of danger and emotional reaction to it also includes an estimate of their coping ability. A person with ID might feel more limited, helpless and overwhelmed by trauma

(Sequeira & Hollins, 2003). They may also struggle to cognitively process and find words for the trauma, both of which have been reported to alleviate distress and contribute to trauma symptom outcomes.

#### *Relationship to the perpetrator*

The perpetrator was known to the survivor in most cases, which is similar to what has been documented in other studies, (e.g. Peckham, 2007; Brown et al., 1995). These findings are also similar to what has been reported with regards to the rape of children in the general population (Vetten et al., 2008). The fact that the perpetrator was usually a family member, family friend, neighbour, boarder, staff member of a day facility, transport provider, or church elder suggests that survivors trusted them. It also points to the vulnerability of people with ID because of their proclivity to agree and obey those they deem to be in positions of authority (Zigler, 1999). The following extract from a psychologist's notes highlights the issue of compliance:

He asked her to take off her clothes. She did. He raped her. Her unassertiveness and malleability was very evident from her story. She reported how she went along with Mr. X simply on the basis that he had asked her to. Her behaviour is reflective of her level of functioning (moderate), inability to make proper decisions for herself, and her vulnerability.

The fact that most perpetrators were aware of the individuals' disability suggests that they may have been exploiting their vulnerability. This is likely in cases of ongoing abuse or when survivors were unable to disclose due to communication difficulties.

#### *Frequency of trauma*

A quarter of this sample reported ongoing or prior sexual traumas. Although comparative statistics are lacking, Mitchell and Clegg (2005) found that people with ID are reported as being more likely to have multiple, rather than single traumatic experiences. The multiple regression found no difference between the frequency of trauma and the number of reported symptoms. It is argued, however, that further research is required to compare the different types of symptoms reported by survivors of single acts of sexual violence and chronic abuse. Dependent on the potential

differences found, diagnoses other than classic PTSD (e.g. Herman's Complex PTSD or Developmental Trauma Disorder) may be found to be more pertinent.

#### *Time elapsed since the trauma*

On average individuals were assessed 13 months after the sexual trauma. The reason individuals were assessed so long after the incident is attributable to delays in the criminal justice system and a long waiting list for the SAVE programme. The considerable amount of time that had elapsed since the trauma may have contributed to both individuals and caregivers not being able to recall how the trauma had affected the individual. This present study, however, found no significant correlation between the amount of time elapsed since the trauma and the number of reported symptoms. These findings concur with Sequeira et al.'s (2003) study which attributed this to the fact that the majority of the people in the abused sample, as in this study, had not received any psychotherapeutic intervention following the abuse. Murphy et al. (2007), however, found that symptoms of behavioural disturbance in 18 adults with severe ID abated over time with the same manner of recovery that has been described in the general population (Resick, 1993).

#### *Level of ID related to the number of symptoms reported*

While none of the abovementioned trauma variables were found to significantly predict reported symptoms, the level of ID was found to be significant in terms of the number of symptoms reported. A significant difference was found between the moderate group, who reported the most symptoms, and the profound level, who reported the least. Research suggests that the prevalence of anxiety, depression and psychosis is far more prevalent in individuals with moderate ID than in people with severe and profound ID (Holden & Gitlesen, 2004). It is argued by these authors that this reflects a difference in prevalence of psychiatric symptoms, rather than problems in detecting symptoms with severe and profound ID. "There is an emerging concurrence that people with moderate ID may be more prone to psychiatric illness because they are unable to live normal lives, and are painfully aware of this" (Holden & Gitlesen, 2004, p. 560). This view may account for why individuals with moderate ID reported more symptoms of psychological distress, although no formal diagnoses were made by the clinical psychologists in this study.

### 5.3. Prevalence of reported symptoms

This study found that PTSD and depressive symptoms were most commonly reported and behavioural disturbances less so, which is contrary to other literature, (e.g. Sequeira et al., 2003; McCarthy, 2001) where symptoms of behavioural problems like aggression, self-injury and temper outbursts were reported. Although individuals assessed for this project were very rarely given diagnoses, they were described as having symptoms suggestive of PTSD as described in the DSM-IV-TR's (2000) diagnostic criteria. Thus although they had experienced trauma (Criterion A) it appears that they did not have sufficient symptoms to warrant a diagnosis of PTSD. It is possible that this was due to the difficulties people with ID may have in reporting on their psychological distress, as suggested by Mason (2007), and as was frequently indicated in this study. For example, in the case of a 41 year old with severe ID the assessing psychologist wrote that

It was difficult to assess her reactions to the alleged rape as she has not been able to describe any symptoms and her sister was not able to notice any changes in her behaviour subsequent to the alleged rape.

The absence of a diagnosis or in many cases a lack of any reported symptoms may also be attributable to the methods used to elicit information. From the reports and psychologists' notes, there was no indication that a formal or standardised method of investigation was used and it is likely that the assessors depended on caregivers' reports of what they had observed. If the latter explanation is the case, had psychologists used an instrument like the Child PTSD checklist this study may have yielded different findings, as reported by Jasson's (2009) South African study which found rape and sexual assault to be associated with higher rates of PTSD diagnosis in people with ID.

Cognisance also needs to be taken of the significant difference found in the number of reported symptoms between the different psychologists. Tomasulo and Razza (2007) assert that it is possible to use standard diagnostic criteria to diagnose PTSD in people with ID, but that the ability to understand and probe for developmentally influenced symptomatology requires a level of accuracy that may not be achieved by clinicians



less experienced with the ID population. In the absence of information regarding the different psychologists' levels of expertise in the field of ID and sexual trauma, it can only be surmised that this may have impacted on how they reported.

The types of symptoms reported in the different ID levels are discussed in the following sections according to the frequencies found in this study, beginning with increased arousal, which was the most commonly reported PTSD cluster.

### **5.3.1. PTSD**

#### *Increased arousal*

Symptoms of anxiety, sleep disturbance, fear and anger were the most common in this cluster. Fear and anxiety are the hallmarks of PTSD, and the prevalence thereof as sequelae to sexual trauma in the general population is well established (e.g. Yuan et al., 2006). These symptoms have also been noted in the literature on ID (e.g. Allington-Smith et al., 2002; Dunne & Power, 1990). In this study anxiety was highest in the mild level and no anxiety was reported in the profound level. Tomasulo and Razza (2007) assert that for individuals with mild ID, PTSD symptomatology is likely to be similar to that found in the general population. The reported absence of anxiety in the profound level may be attributable to a difficulty in giving verbal expression to physiological signs or worrying thoughts (Matson, 1997, as cited in Tomasulo & Razza, 2007). Individuals in the profound range were, however, reported as experiencing fear after the trauma. Examples of fear across all levels of ID included being afraid of going outside, being frightened of all men and being particularly fearful at night.

Sleep disturbance included insomnia, hypersomnia, frequent waking and talking or shouting out in sleep. Problems with sleep were prevalent in this study across all levels of ID. These findings concur with Mitchell and Clegg (2005); Allington-Smith et al. (2002). McCarthy (2001), however, reports that although sleep problems, including nightmares, are one of the most common post trauma symptoms in the general population, they are not as common in the ID population. A reason for this may be that sleep disturbance is acknowledged as a frequent problem in people with moderate to profound ID (attributable to a number of factors, e.g. mood disorders,



physical pain and discomfort) and hence the traumatic aetiology thereof is sometimes overlooked in this population. Sleep disturbance was the most commonly reported symptom in the profound level, suggesting that even in the absence of reported anxiety, people in the profound level experience psychological distress as a consequence of sexual trauma.

Increased startle response (noted when individuals were more “nervous” or “skrikkerig”, i.e. easily frightened) was less reported in this study. This concurs with McCarthy (2001) who asserts that increased startle response is possibly more difficult to detect in people with ID. She further explains that with close observation, an increased sensitivity to the environment and ‘jumpiness’ can be noticed. Other authors (McCreary & Thompson, 1999; Ryan, 1994) report that individuals with ID present with the same symptoms of increased startle response that people without ID do. Sinason (2002) refers to the tendency of staff to misattribute symptoms like hypervigilance to other conditions common in people with ID, e.g. Obsessive Compulsive Disorder, Attention Deficit Disorder or Autism.

The prevalence of anger as a response to sexual trauma found in this study concurs with findings in the general and ID population (Herman, 1992; Mansell, 1997; Sequeira et al., 2003).

#### *Avoidance*

Symptoms of avoidance were reported almost 50 % less frequently than symptoms of arousal. Of the three symptoms in this cluster, namely avoidance, withdrawal and decreased pleasure, the most common symptom was withdrawal, with frequencies similar to those reported by Mansell et al. (1992). Unlike Mansell’s study, however, there was no report of withdrawal in the profound level. In this study withdrawal was more common in the severe and moderate levels than in the mild range. Examples of withdrawal in these levels of ID included: “has become withdrawn, sits alone in the dark playing at home and scratching in the ground with a stick”, “withdrawn, quiet, not going out to play with friends as usual”. Withdrawal from relationships after experiencing an interpersonal trauma like rape can be seen as a consequence of shattered trust, betrayal and loss of a sense of safety in the world, as well as feelings of shame, guilt and inferiority (Herman, 1992).

In understanding withdrawal in the context of this study, it is helpful to look to the theories of positive and negative reaction tendencies of people with ID (Bennett-Gates & Zigler, 1999). “Positive-reaction tendency refers to a heightened desire for social reinforcement, generally from a supportive adult; negative-reaction tendency reflects a wariness of and reluctance to interact with strangers” (Bennett-Gates & Zigler, 1999, p. 107). These constructs are based on the attachment theory of Ainsworth (1973), as cited in Bennett-Gates and Zigler (1999). Individuals with a negative-reaction tendency are likely to have had an anxious-avoidant type of attachment with their primary caregivers. Since the early attachment patterns of individuals assessed in this sample were not available, consideration of this subject is conjectural. It has, however, been documented that people with ID have an increased risk of experiencing a disruption in mother-infant attachment and are more likely to feel unwanted and rejected by caregivers (Sinason, 1992). It is surmised that the prevalence of withdrawal in this study can possibly be attributed to a combination of an already existing negative-reaction tendency, compounded by the experience of an interpersonal trauma.

There were only 11 reports of avoidance per se, and most of these referred to children having stopped playing outside, or in some cases adults who wanted to relocate so as not to be near the perpetrator. Passive avoidance of thoughts or feelings related to the traumatic event was not as frequently reported, although in some cases evidence of numbing was suggested when individuals were described as talking in a “blunted, very flat, unemotional way” when they recounted the event. It could be argued that although not referred to as such, avoidance was present for some of the individuals who were described in the psychologists’ notes as being unwilling to talk about the sexual trauma, or having “forgotten”.

A reluctance to talk about the incident could also, however, be accounted for by a number of other factors that are noted in the literature on sexual trauma, such as a lack of trust, a sense of shame, guilt and self-blame (Herman, 1992). Both people with and without ID are likely to find it difficult to describe to a stranger how they were raped. For persons with ID, however, if there is possibly already a wariness and reluctance to interact with strangers (i.e. negative-reaction tendency), it may be that much more

difficult for them. Individuals assessed by the SAVE programme are only seen by psychologists once or twice. It is questionable whether this is adequate in terms of developing trust. Many individuals were reported as being shy on interview. For example, a 23 year old woman with moderate ID was described as being “very shy when the perpetrator’s name was mentioned. She put her head down, or leaned against the wall, mumbled and turned her head away”. It has been reported that adult survivors of childhood abuse sometimes believe that they deserved to be raped because they were disabled (Cruz et al., 1988). If this was the case for some of the individuals in this study, it may also account for a reluctance to talk about the incident. Willingness to communicate with the psychologist was also likely to have been determined by the response of other people to the rape. A number of survivors were beaten by their caregivers after it was discovered they had been raped, some were not believed, others were ostracised and teased, and in some instances individuals had to leave their homes in cases where the perpetrator was a family member.

A further probable reason for individuals reluctance to talk is attributable to the differences in race and class between the psychologists (4 white and 1 black, all middle class) and individuals and caregivers (mainly black, coloured and working class) as well as the language differentials. These differences point to a power imbalance and divide which may have informed how the interviews were conducted and experienced by both parties (Motsei, 2007 as cited in Womersley & Maw, 2009).

### *Re-experiencing*

Across all levels of ID, nightmares were the most commonly reported symptom of re-experiencing the trauma. The prevalence of nightmares in people who have PTSD in the general population and in the ID population (Mitchell & Clegg, 2005; Mansell 1997; Sinason, 1992; Dunne & Power, 1990) has been well documented. In this study, some caregivers who reported nightmares noted that individuals expressed a fear of going to sleep, and in some cases were in a state of heightened autonomic arousal after waking. For example, “she wakes up startled, saying that somebody was grabbing her or dreaming of snakes”. From a traditional behavioural perspective nightmares are considered to be conditioned stimuli which trigger a conditioned response (Kroese & Thomas, 2006). That is, individuals wake up from the nightmare so as to avoid further fear or unpleasant emotions. Going to sleep becomes something

avoided because of feelings of frustration and dread. This may account somewhat for the prevalence of sleep disturbance, fear at night, not wanting to sleep alone and difficulty falling asleep that was reported in this study. The DSM-IV-TR (2000) diagnostic criteria note that recurrent or distressing dreams of the traumatic incident may present as frightening dreams without recognisable content in children. The Diagnostic Manual-Intellectual Disability (DM-ID) (2007) lists the same adaptive criteria for individuals with a lower developmental level.

Intrusive thoughts and flashbacks were found to be less commonly reported in this study, which is contrary to reports by Mitchell and Clegg (2005), but concurs with McCarthy (2001) who notes that “good communication may be required to talk about ‘flashbacks’, vivid memories” (p.166). Although not quantitatively measured, psychologists described some individuals as not being able to speak in more than one or two word sentences. It is surmised that the reason caregivers were relied on as primary informants was because psychologists struggled to communicate with the survivors themselves. This highlights the imperative to find a better way to communicate with people with ID, especially in the severe and profound range. Examples of such an attempt are augmentative alternative communication (AAC) and individualised communication which draw on core, local and individual vocabularies and use graphic symbols, signs and photographs to supplement spoken language (Beukelman & Mirenda, 1998, as cited in Cambridge & Forrester- Jones, 2003). The authors assert that

Since the ability to communicate using a commonly understood language is fundamental to the way in which all human beings function in a society, it follows that those who are unable to do it are automatically excluded from that society. There is no simple, universal solution and any attempts to remedy the situation involve society broadening its view of acceptable ways of communicating and being prepared to learn those ways too (Cambridge & Forrester- Jones, 2003, p. 20).

Many authors (e.g. Sinason, 1992; Mc Carthy, 2002; Tomasulo & Razza, 2007) observe that it is important to keep in mind that at lower developmental levels, in children as well as in adults, the phenomenon of re-experiencing the trauma can

manifest in symptoms that are more overt and behavioural, rather than flashbacks and intrusive thoughts. Although there were few reports of re-enactment of the trauma, as described by Sinason (2002), the fact that in this present study symptoms of increased arousal were three times more prevalent than symptoms of re-experiencing, concurs with these cited authors findings.

The nine instances of dissociation that were reported in this study were in most cases first observed by the clinician during assessment. It was only with further questioning that caregivers acknowledged that symptoms of dissociation (e.g. “sat staring blankly”, “in a trance”, “in her own world”, “cut off”) were subsequent to the sexual trauma. Dissociative symptomatology in the ID population is not well established but has been reported (Johnson, 2001). Dissociative flashback episodes are included in the DSM-IV-TR and the occurrence thereof in the general population has been well documented (Herman, 1992). Janet (1889), as cited in Herman (1992), was the first to describe dissociation as occurring when one loses the ability to integrate the memory of an overwhelming event. With this in mind, there is little reason to doubt that people with ID are as likely to dissociate as non-disabled individuals. Literature in the general population has come to include distinctive symptoms of dissociation as a consequence of sexual trauma, and particularly childhood sexual abuse, as including feeling outside oneself, ‘spacing out’ watching oneself from far away, and losing touch with reality (Matich–Maroney, 2003). A possible difficulty in reporting such symptoms in people who are non-verbal or struggle to communicate suggests that careful observation of behaviour suggestive of dissociation is required. In this study it could be that symptoms of dissociation went unnoticed by caregivers. This suggests a need for further study so as to allow for a better understanding of how to identify specific manifestations of dissociation in the ID population.

Individuals were found to have significantly more symptoms of arousal than avoidance and re-experiencing, which is similar to Mitchell and Clegg’s (2002) study. One possible reason for this, as discussed above, is that arousal symptoms manifest behaviourally and are thus more observable by others. A further possibility is that many of the individuals in this study were raped more than once, or were victims of ongoing sexual abuse, which may have resulted in their remaining in a heightened state of arousal due to ongoing fear of repetition of the trauma. From a behavioural

perspective, the sexual traumas led to a conditioned fear response. And lastly, the fact that very few of the individuals in this sample had had access to counselling or any form of therapeutic intervention suggests that they may have still been, as it were, 'frozen' in trauma.

### **5.3.2. Depressive symptoms**

As stated earlier, although individuals in this study were not diagnosed with disorders, symptoms of depression subsequent to the trauma were common. These findings accord with what has been documented in the general population (Resick, 1993; Yuan et al., 2006) and ID literature (Sequeira et al., 2003; Sobsey & Mansell, 1994; Peckham, 2007; Cruz et al., 1988; Dunne & Power, 1990; McCarthy, 2001; Match-Maroney, 2003). Feelings of sadness, tearfulness, appetite disturbance, sleep problems, withdrawal and somatic complaints were the most commonly reported depressive symptoms in this study. This concurs with the trauma literature in the general population (e.g. Herman, 1992; Resick, 1993) but differs slightly from the ID literature in that somatic complaints have not been as frequently documented. A discussion of these symptoms, beginning with sadness, which was the most frequently reported symptom, follows.

There is no evidence to indicate that people with ID experience different emotional sequelae to sexual trauma than the general population does (Cruz et al., 1988; Varley, 1984). The betrayal, shame, unconscious guilt, self-blame and violation of the self that has been described in the general population (Herman, 1992) and contributes to feelings of sadness also applies to people with ID. Sinason (2002) writes that "abuse is added to whatever stigmatising or traumatic experiences the disability itself has caused, usually resulting in a compound trauma" (p. 427). Research suggests that children with ID accumulate experiences and feedback which tells them they have low ability and are likely to fail. This can lead to them feeling they have little control over events and over years, can promote an increased susceptibility to helplessness and low self-esteem (Weisz, 1999). Seligman's (1975), theory of learned helplessness, which refers to the subjective perception by individuals that they cannot exert control over important outcomes in their lives (as cited in Weisz, 1999) is possibly pertinent

in understanding the prevalence not only of sadness, but also withdrawal as sequelae to trauma in this group.

Withdrawal has already been discussed above where it was noted that symptoms thereof were highest in the moderate level. Withdrawal was twice as high in the severe level compared to the mild level. Sobsey and Doe's (1991) suggestion that withdrawal or a lack of emotional sequelae could be due to communication difficulties, rather than an actual absence of negative effects, may account for this difference, but so might learned helplessness and negative-reaction tendencies (Zigler, 1999). It behoves us to remember, however, that in the context of this study in which most individuals were raped by people known to them and often on an ongoing basis, that withdrawal was also a way of protecting themselves from what was, in reality, an unsafe environment.

Somatic complaints (e.g. abdominal and chest pains, headaches, dizziness, and back ache) were reported in 10.5 % of the sample. Somatic features, which are common in anxiety and depression, are well documented in the context of trauma in the general population (Van Der Kolk, 1996; Herman, 1992). Although it has been reported that people with ID are more likely to present with somatoform symptoms than the general population (Fink, 1995, as cited in Tonge, Brereton, Kiomall, Lourey & Taffe, 2007) somatic complaints as a response to trauma in the ID literature, is rarely reported. Shah and Mudholkar (2000, as cited in Mitchell & Clegg, 2005) describe the tendencies of traumatised children to somatise. Harper and Wadsworth (1993, as cited in Mitchell & Clegg, 2005) refer to somatic complaints being relevant to adults with ID. In the general population somatisation has been attributed to extreme arousal which can inhibit the ability to identify specific emotions and to put feelings into words (Van Der Kolk, 1996). For individuals with ID, who already struggle cognitively to process information and label their emotions, and are more predisposed to being overwhelmed by a traumatic experience due to developmental variables (Sequeira & Hollins, 2003), the prevalence of somatic complaints is possibly understandable.

Somatic complaints as symptoms of depression have frequently been reported in non-Western societies (Meys, 1998). This calls into question the applicability of the



current diagnostic system (DSM-IV-TR, 2000) and its applicability to the population groups which made up this study.

Appetite disturbance was reported by 7.5 % of the sample. Changes in appetite are symptomatic of mood disorders. Of interest, although not quantitatively measured, was that increased appetite was reported more frequently than loss of appetite.

### **5.3.3. Behavioural disturbance**

In this study symptoms of behavioural disturbance (aggressive, oppositional and sexualised behaviour) as a sequelae to sexual trauma were not as frequently reported as in other studies (e.g. Balogh et al., 2001; Dunne & Power, 1990; Murphy et al., 2007). Where for example Mansell et al. (1992) found that 19.6 % of the mild and moderate groups and 31.1% with profound disabilities showed aggressive and/or other behavioural problems, in this present study aggression was reported in only 6 % of the mild category, 5.2 % in moderate, 8.7 % in severe and none in the profound level.

Oppositional behaviour, unlike other studies (e.g. Sequeira et al., 2003) was also less frequently reported. Examples of behaviours that were coded as oppositional included: “She’s more cheeky now”, “onbeskof” (rude), “resistant to following instructions” and “stubborn and aggressive”. Oppositional behaviour was almost three times higher in the moderate and severe levels compared to the mild. It could be, as discussed in the literature review, that for people with more severe levels of ID, who often struggle to understand or be understood, such behaviour is a communication of their frustration or distress. It is also possible that some caregivers interpreted behavioural disturbance as symptomatic of the individual’s ID, rather than as a response to the sexual trauma, and thus did not report it. In the same manner, there is a persistent tendency for clinicians to misattribute behavioural problems that are possibly indicative of internal psychological difficulties, to a person’s ID (Mansell, 1997). In the context of this study, as suggested by the authors of the pilot study (Shabalala & Manson, 2008), the comparative under-reporting of behavioural disturbance as a sequelae to sexual trauma could be attributable to clinicians not probing for symptoms different to those manifested in the general population. It may also be due to the different way in which the symptoms were clustered in this study. Withdrawal was included in the



avoidance criteria for PTSD, yet is also a symptom of depression and behavioural disturbance. Irritability and temper outbursts, which were in any event not commonly reported, fell in the increased arousal cluster of PTSD. Either way, the more aggressive, challenging types of behaviour were not as prevalent in this study as reported elsewhere (Sequeira et al., 2003; Allington-Smith et al., 2002; O’Callaghan & Murphy, 2003; Mansell, Sobsey & Moskal, 1998; Sobsey & Doe, 1991). It is possible that the discrepancy in findings is also attributable to the fact that for this study a community sample was used. In most of the cited studies clinical samples were used and were thus more likely to consist of clients presenting with psychological disturbance and/or diagnosed psychiatric disorders.

Sexualised behaviour as a response to sexual trauma was also not as commonly reported in this study as it has been by other authors (Mansell et al., 1998; Murphy et al., 2007; Allington-Smith et al., 2002; Sinason, 1992). In this study it was more common in instances of ongoing abuse with children. For example, a child with severe ID who had been raped by her father over a period of years, or an 11 year old who was raped by three different men over a period of time.

Contrary to other literature (Sequeira et al., 2003; Sinason, 1992) there were no reports of stereotypical behaviours as a response to sexual trauma in this study. There were, however, descriptions of stereotypical behaviour on interview (e.g. repetitive rocking) but it was unclear as to whether this behaviour was subsequent to the sexual trauma. There was a report of a moderate ID individual who “scratched her vagina raw” after the rape. That rape can result in a feeling of having been violated and sullied and lead to increased washing is well documented in the general population (Herman, 1992). There is no reason to doubt that this individual felt the same as a consequence of the rape, but the repetitiveness and severity of her behaviour suggests that this may have been indicative of stereotypy.

#### **5.3.4. Other reported symptoms**

This section includes symptoms that were not as clearly categorisable, nor frequently reported. “Loss of skills” was less reported than it has been elsewhere (Sinason, 1992; Allington-Smith et al., 2002). In this study it referred to a deterioration or regression

in functioning. Examples thereof were that the individual was no longer able to complete tasks she had once managed or was more “clingy” than usual. Of the 13 reports of “loss of skills”, six were reports of secondary enuresis, all occurring in children and adolescents between the ages of 9 to 16 years.

There were three reports of the onset of seizures subsequent to the rape and two reports of increased seizures. Davies (1979, as cited in Sobsey, 1994) found abnormal EEG readings and active epilepsy in three to four times as many incest survivors as in a matched control group.

#### **5.4. No symptoms reported**

In this study almost 30% of the individuals assessed were reported as having no reaction to the sexual trauma. Findings indicated that 60 % of persons in the profound level, and 42 % in the severe range reported no response. These results are contrary to other studies. For example, Mansell et al. (1992) found that only 3.9 % of 119 respondents with mild and moderate disabilities reported no social or emotional problems as a consequence of sexual trauma. In a study of 162 adults with ID, Sobsey and Doe (1991) reported that 63 % presented with uncategorised emotional distress and that only 1.2% reported no emotional harm. It is not possible to compare the findings of this study directly with other cited literature because of methodological differences. Furthermore most research, including this study, was conducted without using a standardised measure. However, there are a number of key themes that emerged in the data analysis that may account for the frequency of no symptoms being reported in this project. Some of these have already been discussed above. They include the lack of a standardised instrument, reliance on caregivers’ reports, psychologists’ differing levels of expertise in the field of ID and trauma, misattribution of trauma symptoms to individuals’ ID, communication difficulties, length of time elapsed since the incident and the possibility that shame and self-blame of sexual trauma survivors inhibited engagement with psychologists. A consideration of some of these issues and other possible reasons for the frequent absence of a reported reaction to the trauma follows.

### *Caregivers' reports*

In this study, caregivers were most frequently relied on to report on the survivors' reaction to the trauma. The literature suggests that clinicians are likely to elicit more valid information regarding the psychological experiences of an individual with ID if they interview the person directly (Jasson, 2009; Tomasulo & Razza, 2007). Jasson (2009) found differences between the self-report and caregiver report on the different criteria of PTSD. In order to assess the impact of rape it makes sense that survivors themselves need to be able to express how they feel, especially in the context of discussing something as sensitive as rape. Furthermore, Allington-Smith et al. (2002) assert that caregivers often minimise the trauma or give a biased account, wanting the survivor simply to 'forget' and remain undisturbed.

### *Difficulty describing emotions*

A common explanation for why no reaction was elicited was that the individual was "unable to put feelings into words". In one instance in which an individual's father reported that he had not noticed any change in his daughter's behaviour subsequent to the rape, the psychologist wrote that this was "consistent with a lack of expressed emotion following the death of her mother, as well as her inability to describe or display feelings when interviewed". This is consistent with some theoretical understandings of ID, but is also symptomatic of trauma patients who present with alexithymia, having "no words for feelings" (Van Der Kolk, 1996, p.186). "Alexithymia is fundamentally an impairment in emotional information processing, specifically a deficit in the cognitive processing and regulation of emotions, and is manifest in PTSD" (Van der Kolk, 1996, p. 186). It is suggested that if people without ID can present with alexithymia post trauma, individuals with ID who already have difficulty identifying and describing their emotions, might struggle that much more. The following case of a 22 year old mild/moderate individual illustrates this:

She was unable to talk of the rape and unable to demonstrate it with anatomically correct dolls. When asked to tell the story she cried silently but was unable to verbalise her experience. She will not be able to give evidence in court. She has a history of language and communication difficulties and the subject of the alleged rape raised her anxiety to a level where she was unable

to talk about it, having talked quietly but readily about unrelated topics prior to this.

*Appearance and behaviour on interview*

In some instances where “no reaction” was noted in the final report, behaviour on interview suggested anxiety and withdrawal. For example,

X was a tiny, vulnerable appearing, withdrawn, shy little girl who looked about 10 years old. She spent most of the interview looking down, either biting her nails or playing with the clasp on her mother’s handbag. She wet her pants while telling of the rape.

In another instance, although the mother of an 18 year old profoundly disabled individual was “unable to report any behavioural or emotional changes that happened as a reaction to the alleged offence”, in the interview “she became progressively irritable and distressed when talking about the alleged rape. In many cases, although no reactions to the rape were noted in the reports, the psychologists’ notes indicated that victims became distressed, tearful, agitated or anxious when asked about the rape. This suggests that in the absence of reported reactions, either by the survivors or caregivers, behaviour can still be seen as a measure of psychological distress.

## CHAPTER 6: CONCLUSION

The main aim of this study was to identify the reported responses of people with ID who had experienced sexual trauma. Principal findings indicated that symptoms of PTSD and depression were the most common, whilst behavioural problems like aggression, oppositional and sexualised behaviours were less frequently reported than in other literature. That there were significantly more symptoms of increased arousal than re-experiencing and avoidance is possibly accounted for by the strong behavioural reactions people with ID have in response to trauma. It is also possibly due to most survivors not having had access to any therapeutic intervention subsequent to the rape. Individuals with moderate ID reported the most symptoms, which concurs with a growing body of literature which suggests that this is due to their painful awareness that they cannot live normal lives. The fact that individuals in the severe and profound levels reported fewer symptoms is understood to reflect, not an absence of psychological distress, but rather a difficulty in eliciting information on the part of the assessing psychologist. This highlights the need for clinicians to explore alternative forms of communicating with people with expressive language difficulties in order to be able to access their subjective experiences directly, rather than through caregivers.

Study in the field of ID and sexual trauma is in its infancy internationally, and even more so locally. Despite evidence which suggests that individuals with ID are more vulnerable to abuse than the general population, little has been done to collect comprehensive data on the prevalence and impact of sexual trauma on people with ID in South Africa. This lack of adequate and reliable research has implications for the allocation of resources towards the prevention and treatment of rape survivors with ID. That the same attention given to the rape of women and children in the general population, albeit delayed and inadequate, has not been paid to survivors with ID, suggests that although the theoretical conceptualisation of ID may have shifted, societal attitudes of exclusion and marginalisation have not.

The South African Human Rights Commission (SAHRC) has supported the need for the SAVE programme to be expanded to other provinces and for psychologists in other areas to be trained to do psychological assessments of complainants with ID (Koopman, Roux & Dickman, 2008). Outcomes of this study, which is part of a larger project on sexual trauma and ID, may contribute to the development of a standardized instrument to specifically assess the effects of trauma in the ID population in South Africa. This will in turn inform the development of appropriate therapeutic interventions.

Although this quantitative study sought primarily to identify trauma symptoms, other information gathered from the psychologists' notes and reports highlights the need to remain aware of broader social contextual factors that intersect with the experience of sexual violence. The impact of poverty on an already vulnerable and marginalised group cannot be underestimated. Social Economic Status (SES) data was not documented in the reports, but descriptions of poor living conditions and lack of access to resources was common. Most individuals did not have access to special care facilities and were left at home with different caregivers, or without supervision. In cases of familial abuse, where the perpetrator was the only source of income, survivors were sometimes ostracised by the family or encouraged not to pursue cases. In a number of instances parents were offered money, either as a form of apology for having 'damaged' or brought shame on the survivor's family or as a bribe if they did not press charges.

Although this study tentatively suggests that the differences in reactions between the ID and general population are mediated by the cognitive impairment of a person with ID, it is important to remember that behaviour and symptomatology reflect factors other than cognitive ones. Just as in the general population, where the impact of trauma is recognised as being highly individualised, so too in the context of ID will it depend on social environment, educational history, child rearing practices, attachment styles, previous traumas and personality.

#### *Limitations and implications for further studies*

Because this was an archival study of clinical psychologists' psycho-legal reports, the data gathered was not derived from its primary source (i.e. the survivors and/or

caregivers themselves). Furthermore, the reason individuals are referred to the SAVE programme is primarily to assess competence to act as witnesses in court, not to elicit trauma symptoms. A future study might interview rape survivors with ID and their caregivers directly so as to elicit more detailed descriptions of the impact of rape.

The significant difference in the number of symptoms reported by the clinical psychologists suggests that had survivors been interviewed with a standardised instrument, different results may have been obtained.

A further limitation was that most individuals were assessed more than a year after the incident. Although no correlation was found between the amount of time that had elapsed and the number of symptoms reported, it could be that other life events that occurred in the interim had effected the manifestation of trauma. A further study to assess the response to sexual trauma within three months of the event would be helpful.

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## REFERENCES

- Allington-Smith, P., Ball, R., & Haytor, R. (2002). Management of sexually abused children with learning disabilities. *Advances in Psychiatric Treatment*, 8, 66-72.
- American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4<sup>th</sup> ed., Text Revision). Washington DC: Author.
- Arthur, A.R. (2003). The emotional lives of people with Intellectual Disability. *British Journal of Learning Disabilities*, 31, 25-30.
- Balogh, R., Bretherton, K., Whibley, S., Berney, T., Graham, S., Richold, P., Worsley, C. & Firth, H. (2001). Sexual abuse in children and adolescents with intellectual disability. *Journal of Intellectual Disability Research*, 45 (3), 194-201.
- Beail, N. & Warden, S. (1995). Sexual abuse of adults with learning disabilities. *Journal of Intellectual Disability Research*, 39, 382-387.
- Bennett-Gates, D. & Zigler, E. (1999). Motivation for social reinforcement: positive and negative reaction tendency. In E. Zigler & D. Bennett-Gates (Eds.), *Personality development in individuals with mental retardation*. (pp. 107-129).
- Bernal, J. & Hollins, S. (1995). Psychiatric illness and Learning Disability: a dual diagnosis. *Advances in Psychiatric Treatment*, 1, 138-145.
- Booley, A. (2002). *Subjective accounts of post-rape adjustment amongst South African rape survivors*. Unpublished masters thesis, Univeristy of Cape Town, Cape Town.
- Breslau, N., Davis, G.C., Peterson, E.L. & Schultz, L.R. (2000). A second look at comorbidity in victims of trauma: The posttraumatic stress disorder-major depression connection. *Biological Psychiatry*, 48, 902-909.
- Brown, H. & Craft, A. (1989). *Thinking the unthinkable: Papers on sexual abuse and people with learning difficulties*. London: FPA Education Unit.
- Brown, H., Stein, J. & Turk, V. (1995). The sexual abuse of adults with learning disabilities: Report of a second two-year incidence survey. *Mental Handicap Research*, 8 (1), 3-24.



- Brown, L.S. (2004). Feminist paradigms of trauma treatment. *Psychotherapy: Theory, Research, Practice*, 41 (4), 464-471.
- Brownmiller, S. (1975). *Against our will: Men, women and rape*. New York: Random House.
- Burgess, A.W. & Holmstrom, L.L. (1974). 'Rape Trauma Syndrome'. *American Journal of Psychiatry*, 131(9) 981.
- Cambridge, P. & Forrester-Jones, R. (2003). Using individualised communication for interviewing people with intellectual disability: a case study of user-centred research. *Journal of Intellectual and Developmental Disability*, 28, 5-23.
- Carr, A. (2006). *The Handbook of Child and Adolescent Clinical Psychology: A Contextual Approach*. London: Routledge.
- Connors, R. (1996). Self-injury in trauma survivors: functions and meanings. *American Journal of Orthopsychiatry*, 66 (2) 197-207.
- Cruz, V.K., Price-Williams, D., & Andron, L. (1988). Developmentally disabled women who were molested as children. *Social Casework*, 69, 411-419.
- Dickman, B., Roux, A., Manson, S., Douglas, G., & Shabalala, N. (2006). How could she possibly manage in court? An intervention programme assisting complainants with intellectual disabilities in sexual assault cases in the Western Cape. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider & M. Priestley, M.(Eds.) *Disability and social change: a South African agenda*, (pp. 113–116). Cape Town: HSRC Press.
- Dickman, J.D., & Roux, A.J. (2005). Complainants with learning disabilities in sexual abuse cases: a 10 year review of a psycho-legal project in Cape Town, South Africa. *British Journal of Learning disabilities*, 33, 138-144.
- Dosen, A. (2005). Applying the developmental perspective in the psychiatric assessment and diagnosis of persons with intellectual disability: part 1- assessment. *Journal of intellectual Disability Research*. 49, 1 – 8.
- Dunne, T.P. & Power, A. (1990). Sexual Abuse and mental health. *Mental Handicap Research*, 3, 111-125.

- Firth, H., Balogh, R., Berney, T., Bretherton, K., Graham, S., & Whibley, S. (2001). Psychopathology of sexual abuse in young people with intellectual disability. *Journal of Intellectual Disability Research*, 45, 244-252.
- Foa, E. & Steketee, G. (1987). Rape victims: Post-traumatic stress responses and their treatment: a review of the literature. *Journal of Anxiety disorders*, 1, 69-86.
- Foa, E.B. & Rothbaum, B.O. (1998). Treating the trauma of rape: cognitive behavioural therapy for PTSD. New York: Guilford.
- Foa, E.B., Ehlers, A. Clark, D., Tolin, D. & Orsillo, S. (1998). The Posttraumatic Cognitions Inventory (PTCI): Development and validation. *Psychological Assessment*, 11, 303-314.
- Foa, E.B., & Kozak, M.J. (1986). Emotional processing of fear: Exposure to corrective information. *Psychological Bulletin*, 99, 20-35.
- Foa, E.B., Rothbaum, B.O., Riggs, D.S., & Murdock, T.M. (1991). Treatment of Posttraumatic Stress Disorder in Rape Victims: A comparison Between Cognitive-behavioural Procedures and Counselling. *Journal of Consulting and Clinical Psychology*, 5, 715-723.
- Ford, J.D. (2009). Neurobiological and Developmental Research. In C.A. Courtois & J.D. Ford (Eds.), *Treating complex traumatic stress disorder: an evidenced based guide* (pp.31-58). New York: Guildford Press.
- Fraser, W.I. (2000). Three decades after Penrose, *British Journal of Psychiatry*, 176, 10-11.
- Greenspan, S., & Switzky, H.N. (2003). Execution Exemption Should Be Based on Actual Vulnerability, Not Disability Label. *Ethics and Behaviour*, 13, 19 -26.
- Hanass-Hancock, J (2009). Interweaving Conceptualizations of Gender and Disability in the Context of Vulnerability to HIV/AIDS in KwaZulu-Natal, South Africa. *Sex Disability*, 27, 35-47.
- Herman, J (1992). *Trauma and recovery: from domestic abuse to political terror*. London: Pandora.
- Herman, J (1992). Complex PTSD: a syndrome in survivors of prolonged and repeated trauma. *Journal of Traumatic Stress*, 5, 377-391.

- Holden, B. & Gitlesen, J.P. (2004). The association between severity of intellectual disability and psychiatric symptomatology. *Journal of Intellectual Disability Research*, 48.6. pp.556 -562.
- Hollins, S (2000). Developmental psychiatry – insights from learning disability. *British Journal of Psychiatry*, 177, 201-206.
- Hollins, S. & Esterhuyzen, A. (1997). Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry*, 170, 497-501.
- Horner-Johnson, W & Drum, C.E. (2006). Prevalence of Maltreatment of people with Intellectual Disabilities: A Review of Recently Published Research. *Mental Retardation and Developmental Disabilities Research Reviews*, 12: 57-69.
- Jasson, A.E. (2009). The prevalence of PTSD in a sample of people living with Intellectual Disability who have been raped or sexually assaulted. Unpublished Masters thesis, University of Cape Town, Cape Town.
- Jewkes, R., & Abrahams, N. (2002). The epidemiology of rape and sexual coercion in South Africa: an overview. *Social Science and Medicine*, 55, 1231-1244.
- Jewkes, R., Dunkle, K., Koss, M.P., Levin, J., Nduna, M., (2006). Rape perpetration by young, rural South African men: prevalence, patterns and risk factors. *Social Science Medicine*, 63, 2949–2961.
- Johnson, D. (2001). Trauma, dissociation and learning disability. *Clinical Psychology Forum*, 147, 18-21.
- Kaminer D., Grimsrud A., Myer L., Stein D.J., & Williams D.R. (2008). Risk for post-traumatic stress disorder associated with different forms of interpersonal violence in South Africa. *Social Science & Medicine*, 67, 1589-1595.
- Koss, M. (2005). Empirically enhanced reflections on 20 years of rape research, *Journal of Interpersonal Violence*, 20, 100-109.
- Kroese, B.Z. & Thomas, G. (2006). Treating chronic nightmares of sexual assault survivors with an intellectual disability – two descriptive case studies, *Journal of applied research in intellectual disabilities*, 19, 75-80.
- Mansell, S. (1997). *Sexual abuse detection, sequelae, and therapy accommodations for people with developmental disabilities*. University of Alberta, Canada.

- Mansell, S., Sobsey, D. & Calder, P (1992). Sexual abuse treatment for persons with developmental disabilities, *Professional Psychology: Research and Practice*, 23 (5) 404-409.
- Mansell, S., Sobsey, D. & Moskal, R. (1998). Clinical findings among sexually abused children with and without developmental disabilities. *Mental Retardation*, 36, 12-22. Cambridge & Forrester- Jones, 2003
- Martorana, G.R. (1985). Schizophreniform disorder in a mentally retarded adolescent boy following sexual victimisation. *American Journal of Psychiatry*, 142, 784.
- Mason, J. (2007). The provision of psychological therapy to people with intellectual disabilities: an investigation into some of the relevant factors. *Journal of Intellectual Disability Research*, 51, 244-249.
- Match-Maroney, J. (2003). Mental health implications for sexually abused adults with mental retardation: some clinical research findings. *Mental Health Aspects of Developmental Disabilities*, 6, 11-20.
- Matson, J.L. & Sevin, J.A., (1994). Theories of dual diagnosis in Mental Retardation, *Journal of Consulting and Clinical Psychology*, 62, 6-16.
- Maughan, K. (2008, May 6). Child rapist may go free. *The Star*, p 1.
- Maw, A., Womersley, G. & O'Sullivan, M. (2008). The Psycho-social impact of rape and its implications for expert evidence in rape trials. In L. Artz & D. Smythe (Eds.), *Should we consent?* (pp121- 143). Cape Town: Juta
- McCarthy, J (2001). Post-traumatic stress disorder in people with learning disability. *Advances in Psychiatric treatment*, 7, 163-169.
- McCarthy, M. & Thompson, D. (1997). A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disability*, 10, 105-124.
- McCreary, B.D. & Thompson, J. (1999). Psychiatric Aspects of Sexual Abuse Involving Persons With Developmental Disabilities, *Canadian Journal of Psychiatry*, 44, 350-357.

- Meservy, J.Z. (2008). The new classification of mental retardation as “Intellectual Disability”. *The Brown University Child and Adolescent Behaviour Letter*, 24 (11), 1-7.
- Meys, U. (1998). The unhappy or depressed patient in Psychiatry and primary health care; a practical guide for health care workers in South Africa. (p.313). Cape Town: Juta.
- Mitchell, A. & Clegg, J. (2005). Is Post-Traumatic Stress disorder a helpful concept for adults with intellectual disability? *Journal of Intellectual Disability Research*, 49, 552-559.
- Moffet, H. (2006). ‘These women, they force us to rape them’: Rape as narrative of social control in post-apartheid South Africa. *Journal of Southern African Studies*, 32, 129-144.
- Moss, S., Emerson, E., Kiernan, C., Turner, S., Hatton, C., & Alborz, A. (2000). Psychiatric symptoms in adults with learning disabilities and challenging behaviour. *British Journal of Psychiatry*, 177, 452-456
- Murphy, G.H., O’Callaghan, A.C. & Clare, I.C.H. (2007). The impact of alleged abuse on behaviour in adults with severe intellectual disabilities, *Journal of Intellectual Disability Research*, 51 (10) 741-749.
- Naidu, E., Haffejee, S., Vetten, L. & Hargreaves, S. (2005). On the Margins: Violence against Women with Disabilities. Research report written for the Centre for the Study of Violence and Reconciliation, April 2005.
- O’Callaghan, A. & Murphy, G (2003). The impact of abuse on men and women with severe learning disabilities and their families, *British Journal of Learning Disabilities*, 31, 175-180.
- Peckham, N.G. (2007). The vulnerability and sexual abuse of people with learning disabilities, *British Journal of Learning Disabilities*, 35, 131-137.
- Pillay, A. & Lockhart, R, (2003). Models of community mental health services for children. In M. Seedat, N. Duncan & S. Lazarus (Eds.), *Community Psychology: Theory, method and practice South African and other perspectives*. (pp87-106) Cape Town: Oxford University Press.

- Posel, D. (2005). The scandal of manhood; 'Baby rape' and the politicization of sexual violence in post-apartheid South Africa, *Culture, health and sexuality*, 7, 239-252.
- Resick, P.A. (1993). The psychological impact of rape. *Journal of Interpersonal Violence*, 8 (2), 223-255.
- Ryan, R (1994). Posttraumatic Stress Disorder in persons with developmental disabilities. *Community Mental Health Journal* 30, 45 – 55.
- Sadock, B.J. & Sadock, V.A. (2007). *Kaplan & Sadock's Synopsis of Psychiatry: Behavioural Sciences/Clinical Psychiatry* (10<sup>th</sup> Ed.), Philadelphia: Lippincott Williams & Wilkins.
- Schore, A. N. (2001). The effects of early relational trauma on right brain development, affect regulation, and infant mental health. *Infant Mental Health Journal*, 22, 201-269.
- Sequeira, A. & Hollins, S. (2003). Clinical effects of sexual abuse on people with learning disability: Critical review. *British Journal of Psychiatry*, 182, 13-19.
- Sequeira, H., Howlin, P. & Hollins, S. (2003). Psychological disturbance associated with sexual abuse in people with learning disabilities: Case-control study, *British Journal of Psychiatry*, 83, 451-456.
- Shabalala, N. & Manson, S. (2008). Manifestation of sexual trauma in a sample of complainants with intellectual disabilities. Pilot study presented at IASSID World conference.
- Sinason, V. (1986). Secondary mental handicap and its relationship to trauma. *Psychoanalytic Psychotherapy*, 2, 131-54.
- Sinason, V. (1992). *Mental Handicap and the Human Condition: New approaches from the Tavistock*. London: Free Association Books.
- Sinason, V. (2002). Treating people with learning disabilities after physical or sexual abuse, *Advances in Psychiatric Treatment*, 8, 424-432.
- Sobsey, D. & Doe, T. (1991). Patterns of sexual abuse and assault. *Journal of Sexuality and Disability*, 9 (3), 243-259.

- Sobsey, D. (1994). Sexual abuse of individuals with intellectual disability, In :Sobsey, D.(1994) *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* (pp. 93-115). Baltimore, MD: Brookes.
- Sobsey,D. & Mansell, S. (1994). Sexual abuse patterns of children with disabilities. *The International Journal of Children's Rights*, 2, 96-100.
- Swartz, L. & Watermeyer, B. (2006). Introduction and overview. In Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M., Priestley, M. (Eds.) *Disability and social change: a South African agenda*, (pp. 1-6). HSRC Press, Cape Town.
- Tomasulo & Razza (2007). Posttraumatic Stress disorder. In R. Fletcher, E. Loschen, C. Stavrakaki, & M. First (Eds.), *Diagnostic Manual-Intellectual Disability: A textbook of diagnosis of mental disorders in persons with intellectual disability* (pp. 365-378). New York: National Association for the Dually Diagnosed.
- Tonge, B., Breerton,A., Kiomall, M., Lourey, E. & Taffe, J. (2007). Somatoform, Factitious, and Dissociative Disorders. In R. Fletcher, E. Loschen, C. Stavrakaki, & M. First (Eds.), *Diagnostic Manual-Intellectual Disability: A textbook of diagnosis of mental disorders in persons with intellectual disability* (pp379-409).New York: National Association for the Dually diagnosed.
- Turk, J., Robbins, I., & Woodhead, M. (2005). Post-traumatic stress disorder in young people with intellectual disability. *Journal of Intellectual Disability Research*, 49, (11), 872-875.
- Turk, V. & Brown, H. (1993). The sexual abuse of adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research*, 6(3), 193-216.
- Van Der Kolk, B. (2005). Developmental Trauma Disorder: towards a rational diagnosis for children with complex trauma histories, *Psychiatric Annals*, 35, 401-408.
- Van Der Kolk, B.E. (1996). The complexity of adaptation to trauma self-regulation, stimulus discrimination and characterological development. In B.A. Van Der Kolk, A.G. McFarlane & L. Weisaeth (Eds.), *Traumatic Stress* (pp. 182-213).



- Varley, C.K. (1984). Schizophreniform psychosis in mentally retarded adolescent girls following sexual assault. *American Journal of Psychiatry*, 141, 593-595.
- Vetten, L., Jewkes, R., Sigsworth, R., Christofides, N., Loots, L. & Dunseith, O. (2008). Tracking Justice: The Attrition of Rape Cases Through the Criminal Justice System in Gauteng. Johannesburg: Tshwaranang Legal Advocacy Centre, *The South African Medical Research Council and the Centre for the Study of Violence and Reconciliation*.
- Wasco, S. (2003). Conceptualising the harm done by rape: Applications of trauma theory to experience of sexual assault. *Trauma, violence and Abuse*, 4, 309-322.
- Watermeyer, B. (2006). Disability and psychoanalysis. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider & M. Priestley, M.(Eds.) *Disability and social change: a South African agenda*, (pp. 31-43). Cape Town: HSRC Press.
- Weisz, J.R. (1999) Cognitive performance and learned helplessness in mentally retarded persons. In: E.Zigler & D. Bennett-Gates (Eds.), *Personality development in individuals with mental retardation*, (pp.17-46). Cambridge: CambridgeUniversity Press.
- Womersley, G. & Maw, A. (2009). Contextualising the experiences of South African women in the immediate aftermath of rape. *Psychology in society*, 38, 40-60.
- Yuan, N.P., Koss, M.P., Stone, M. (2006). The psychological consequences of sexual trauma. Retrieved 4/02/2010 February 2010, from [http://new.vawnet.org/Assoc\\_Files\\_VAWnet/AR\\_PsychConsequences.pdf](http://new.vawnet.org/Assoc_Files_VAWnet/AR_PsychConsequences.pdf)
- Zigler, E. (1999). The individual with mental retardation as a whole person. In: E.Zigler & D. Bennett-Gates (Eds.), *Personality development in individuals with mental retardation*, (pp. 1- 16). Cambridge: CambridgeUniversity Press.



## APPENDICES

### APPENDIX A

DSM-IV-TR Diagnostic criteria for Posttraumatic Stress Disorder (American Psychiatric Association, 2000)

- 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 intense fear, helplessness, or horror. **Note:** In children, this may be expressed instead by disorganized or agitated behaviour.
- B. The traumatic event is persistently reexperienced in one (or more) of the following ways:
- (1) recurrent and intrusive distressing recollections of the event, including images, thoughts, or perception. **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 recognizable 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 symbolize or resemble an aspect of the traumatic event
  - (5) physiological reactivity on exposure to internal or external cues that symbolize 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 a 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 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 1 month.
- F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

## APPENDIX B

Correlation matrix table for trauma variables

	Time elapsed since incident	Relationship to victim	Number of perpetrators	Once vs. multiple	Once vs. ongoing	Vaginal rape vs. sexual assault	Vaginal rape vs. anal rape	Vaginal rape vs. attempted rape	Mild vs. moderate	Mild vs. severe	Mild vs. profound
Total no. of symptoms reported	.043	-.011	-.078	-.075	.078	-.106	.152*	.007	.206**	-.146*	-.091
Time elapsed since incident		.040	-.067	-.125*	.192*	-.020	.018	-.015	.149*	-.132*	.013
Relationship to victim			.141*	.021	-.143*	-.107	-.070	-.037	.121*	-.011	-.070
Number of perpetrators				.030	-.021	-.027	-.056	-.030	-.023	.000	.032
Once vs. multiple					-.130*	-.097	-.063	-.033	-.073	.058	.017
Once vs. ongoing						.007	.014	-.034	.002	-.045	-.064
Vaginal rape vs. sexual assault							-.048	-.025	.004	-.072	-.048
Vaginal rape vs. anal rape								-.017	-.083	.020	-.031
Vaginal rape vs. attempted rape									.026	-.052	-.017
Mild vs. moderate										-.427**	-.135*
Mild vs. severe											-.099
Mild vs. profound											

\* $p < 0.05$ ; \*\* $p < 0.01$

## APPENDIX C

### Multiple regression for the sexual trauma variables

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.043 <sup>a</sup>	.002	-.002	2.29	.002	.430	1	229	.513
2	.219 <sup>b</sup>	.048	.014	2.27	.046	1.54	7	222	.155

a. Predictors: (Constant), Time elapsed since incident

b. Predictors: (Constant), Time elapsed since incident, vaginal rape vs. attempted rape, vaginal rape vs. anal rape, vaginal rape vs. sexual assault, number of perpetrators, once vs. multiple, relationship to victim, once vs. ongoing

c. Dependent Variable: total no. of reported symptoms

APPENDIX D

Regression Coefficients<sup>a</sup>

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
	B	Std. Error	Beta			Zero-order	Partial	Part	Tolerance	VIF
2 (Constant)	2.85	.77		3.68	<.001					
Time elapsed since incident	0.00	.01	.01	.20	.84	.04	.01	.01	.94	1.06
Relationship to victim	0.05	.45	.01	.10	.92	-.01	.01	.01	.94	1.07
Number of perpetrators	-0.55	.53	-.07	-1.05	.30	-.08	-.07	-.07	.97	1.03
Once vs. multiple	-0.46	.48	-.06	-.96	.34	-.08	-.06	-.07	.96	1.05
Once vs. ongoing	0.47	.48	.07	.97	.34	.08	.07	.07	.93	1.08
Vaginal rape vs. sexual assault	-.096	.60	-.11	-1.61	.11	-.11	-.11	-.11	.97	1.03
Vaginal rape vs. anal rape	1.84	.88	.14	2.09	.04	.15	.14	.14	.99	1.02
Vaginal rape vs. attempted rape	0.13	1.62	.01	.080	.94	.01	.01	.01	.99	1.01

a. Dependent Variable: total no. of reported symptoms

## APPENDIX E

Tests of between subjects effects for psychologists' covariance

	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	291.32 <sup>a</sup>	5	58.26	14.57	<.001	.214
Intercept	61.93	1	61.93	15.48	.001	.055
MA	7.56	1	7.60	1.90	.169	.007
Psychologist	290.67	4	72.68	18.17	.001	.214
Error	1067.96	267	4.00			
Total	2827.00	273				
Corrected Total	1359.28	272				

a. R Squared = .214 (Adjusted R Squared = .200)