

Doctoral Thesis

Assessment of trauma symptomatology in adults with intellectual disabilities:

Validation of the Lancaster and Northgate Trauma Scales

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Submission date: 1st June 2012

Word count: 32, 967

Doctoral Programme in Clinical Psychology

University of East Anglia

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Acknowledgements

I would firstly like to thank Dr Peter Langdon, my supervisor, for his continual guidance, support and feedback. I would also like to thank Dr Laura Jobson for her advice and valued suggestions at various points throughout this process. I am indebted to both for the idea that formed the basis of this thesis.

I would like to express my gratitude to all of the people who agreed to participate in this research, without whom this thesis would not have been possible. Particular thanks goes to those services and people who went out of their way to ensure that this project could take place. This effort and time is all the more admirable considering the nature of the study, and the many changes and demands some services are currently subject to.

Thanks to Katherine and Jo for reading over various drafts of this thesis, which has been vastly improved by your comments and input. I also want to acknowledge the essential contribution of my parents who instilled in me an interest and care for people that led to this project and career path, and have provided immeasurable practical and emotional support throughout.

Finally, I wish to give very special thanks to Vicky who not only provided the wonderful drawings for the Trauma Information Form, but has also put up with my absences and my occasional bouts of misery and stress throughout the long process of writing this thesis. Your tolerance, unwavering support and emotional backing have been invaluable.

Abstract

Background and Aims

There is evidence that people with intellectual disabilities experience a higher rate of traumatic life events. However, attempts to research the presence of posttraumatic stress disorder (PTSD) symptomatology have been hampered by the absence of a validated and suitable assessment tool. The aim of this study, therefore, was to further examine the psychometric properties of a recently developed measure, the Lancaster and Northgate Trauma Scales (LANTS; Wigham, Hatton & Taylor, 2011b).

Method

Using a correlational design, 40 individuals (23 female, 17 male) with a mild intellectual disability (Mean FSIQ = 60.68; SD = 6.13) completed the LANTS and measures of anxiety and depression, along with a measure of general intellectual functioning. Two assessment tools developed for this study were also administered: the Impact of Events Scale – Intellectual Disabilities (IES-ID), a version of the Impact of Events Scale Revised (IES-R; Weiss & Marmar, 1997) adapted specifically for people with intellectual disabilities; and the Trauma Information Form (TIF) which is a self-report assessment of trauma experiences in line with current DSM-IV-TR criteria (2000).

Results

Both trauma scales had high internal and test-retest reliability, although the IES-ID subscales were less reliable than the total severity score. Convergent validity was also good with the LANTS and IES-ID both positively correlated with each other, and

measures of anxiety and depression. However, unlike the IES-ID, the LANTS failed to correlate with the number of traumas. No differences on trauma or demographic factors were found between a high and low PTSD group. Intellectual functioning was not related to the extent of trauma symptomatology.

Conclusions

The LANTS and IES-ID are promising trauma assessment tools, and therefore both may have clinical utility for the identification of PTSD symptomatology in people with intellectual disabilities. While the findings should be extended to a larger sample, they clearly provide a basis for more research into this under-researched but burgeoning area.

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1. Introduction

1.1. General Introduction

There is evidence to suggest that people with intellectual disabilities may exhibit higher rates of mental health problems than found in the general population (Bouras & Drummond, 1993; Cooper, Smiley, Morrison, Williamson & Allen, 2007; Emerson & Baines, 2010; Osman, 2000; Reiss, 1990; Taylor, Hatton, Dixon, & Douglas, 2004). A contributory factor to this increased prevalence is that those in this population experience more adverse life events, many of which could be considered traumatic (Hatton & Taylor, 2010). Despite this, there has been very little research into the presence of posttraumatic stress disorder (PTSD) symptomatology. Moreover, the few studies that have investigated this area have been hampered by an absence of a validated screening measure. This lack of research is significant considering that theories of PTSD indicate that people with intellectual disabilities may have an increased vulnerability to developing trauma symptomatology, and exhibit differences in the manifestation of the disorder (see Section 1.4.4.).

Therefore, the purpose of this study is to further examine the psychometric properties of a recently developed and promising assessment tool, the Lancaster and Northgate Trauma Scales (LANTS; Wigham, Hatton & Taylor, 2011b). An important element of this investigation is the evaluation of its validity as a measure of trauma. In order to do this, the LANTS is compared to a well-established measure of trauma symptomatology in the general population, modified as part of this research so that it is suitable for people with intellectual disabilities. The study has the additional aims of investigating the impact of intellectual functioning and particular demographic or trauma factors on trauma symptomatology.

This introductory chapter provides the background to the study. It begins by presenting a brief description of intellectual disability and a review of issues

surrounding mental health in this population. Next, the relationship between PTSD and intellectual disability will be discussed. Here a description of the clinical and diagnostic features of PTSD is provided, prior to a discussion of traumatic life events in this population. The section then examines how PTSD symptomatology may be exhibited in people with intellectual disabilities by first reviewing and drawing implications from existing theories of trauma, before then outlining previous research into this area through the use of a systematic literature review. The chapter then moves onto a discussion of the difficulties involved in developing mental health assessments for people with intellectual disabilities. Finally, the chapter concludes by describing the rationale and aims for this study, followed by the research questions and hypotheses to be tested.

1.2 Intellectual Disabilities and Mental Health

1.2.2 Intellectual disability.

1.2.2.1 Definition. There have been many changes to the classification and terminology used when describing intellectual disability. Some terms previously considered acceptable in the scientific literature are now seen as highly pejorative and stigmatising (Parmenter, 2011). Such changes in terminology are inevitable when considering the socially constructed nature of the concept of disability (Braddock & Parrish, 2002). Thus, as with terminology, varying definitions of intellectual disability exist. For example, the International Classification of Diseases (ICD-10; WHO, 1996) defines intellectual disability as:

A condition of arrested or incomplete development of the mind which is especially characterised by impairment of skills manifest during the developmental period (pp. 259).

In the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV-TR; American Psychiatric Association [APA], 2000), intellectual disability is characterised by:

Significantly sub average intellectual functioning (an IQ of approximately 70 or below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning.

However, the American Association of Intellectual and Developmental Disabilities (AAIDD; 2010) states that intellectual disability is characterised by:

significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18.

Despite some ostensible differences between these definitions, it is possible to delineate three core criteria for an intellectual disability. These are: significant impairment of intellectual functioning; significant impairment of adaptive/social functioning and age of onset before adulthood (British Psychological Society [BPS], 2000). Significant impairment in intellectual functioning is taken to be a score on a valid intelligence test that falls two standard deviations below the mean. This then allows a further classification of intellectual disability into mild, moderate, severe and profound using ranges of intelligence quotient (IQ). This is based on the widely used system within ICD-10 (WHO, 1996) and is outlined below in Table 1. Each category boundary has a bandwidth of 5 points based on the standard error of measurement of most widely used IQ tests (Carr, O'Reilly, Walsh, & McEvoy, 2007).

Table 1. Classifications of intellectual disability.

Classification	IQ Range
Mild	50-69
Moderate	35-49
Severe	20-34
Profound	<20

1.2.2.2 Prevalence. Estimating the prevalence of intellectual disability is fraught with difficulties due to a number of methodological problems such as varying classification criteria and methods of assessment (Hatton et al., 2001). Consequently, caution should be taken when interpreting the results of prevalence studies.

Nevertheless, it is estimated that the overall prevalence for severe intellectual disability is between 3 and 4 per 1000 (McLaren & Bryson, 1987; Richardson & Koller 1985). A mild intellectual disability is more common with an incidence of 30 per 1000 found in a systematic review of 43 prevalence studies (Emerson, 2003). Overall there are believed to be approximately 795,000 adults (defined as over 20 and under 65) with intellectual disabilities in the United Kingdom (UK). This number is predicted to increase by 14% to 908,000 by 2021 (Emerson & Hatton, 2004) due to factors such as increased life expectancy, improved healthcare, greater prevalence amongst some minority ethnic populations, and a rise in the reported numbers of children diagnosed with Autism Spectrum Disorder (DOH, 2001).

1.2.3. Mental health needs and prevalence.

While intellectual disability has been of interest since the inception of the mental health field, for many years professionals and researchers did not believe that psychopathology and intellectual disability could co-occur (Matson & Shoemaker, 2011). However, the last four decades have seen a rapid increase in research and

development in this area, and it is now recognised that those with intellectual disabilities can experience the full range of psychopathology (Matson & Shoemaker, 2011). Despite this advance, mental health symptoms are often under-reported and under-recognised in this population (Charlot, Doucette & Hezzacappa, 1993; Patel, Goldberg & Moss, 1993). One recent meta-analysis found that 1.2–27% of individuals with intellectual disabilities have unmet mental health needs (Balogh, Ouellette-Kuntz, Bourne, Lunskey, & Colantonio, 2008). Moreover, 6.2% are on waiting lists for mental health services, compared to 2.9% of the general population (Larson, Anderson, & Doljanac, 2005).

There are a number of explanations as to why these needs have been inadequately provided for (Hatton & Taylor, 2010). However, a significant factor pertains to the complexity involved in the diagnosis and assessment of psychopathology. For example, historically, mental health symptoms have been incorrectly attributed to the person's intellectual disability. This is known as “diagnostic overshadowing” and has meant that mental health problems are often under-recognised (Reiss, Levitan & McNally, 1982; Spengler, Strohmer & Prout, 1990). Individuals with intellectual disabilities may also have difficulty verbally expressing or communicating their needs (Campbell & Malone, 1991; Moss, 1999). Moreover, as mental health needs may present differently in this population, the standard criteria used for assessment may need to be modified (Sturmey, 1993; Sturmey, Reed & Corbett, 1991). These problems have had inevitable consequences for the assessment of mental health in this population, with the assessment tools available to detect cases reliably often lacking and marked by deficiencies (Caine & Hatton 1998; Hatton & Taylor, 2010). It is therefore vital that such issues are addressed in future research to ensure that mental health problems in this population are better understood and identified. Problems of assessment are discussed in more detail in Section 1.5.

Due to the reasons outlined above, estimating prevalence rates for mental health problems in individuals with intellectual disabilities is complex (Cooper et al, 2007; Rojahn & Meier, 2010). Furthermore, studies have often been hampered by methodological weaknesses including contrasting definitions of mental health and inconsistent sample definition (Hatton, 2012). It is therefore not surprising that prevalence rates vary greatly, with one review noting estimates in the range of 10% and 80% (Borthwick-Duffy, 1994). However, notwithstanding these problems, it is likely that the prevalence is high and between 20 to 40% (Bouras & Drummond, 1993; Cooper, et al., 2007; Emerson & Baines, 2010; Osman, 2000; Reiss, 1990; Taylor et al., 2004). It is therefore probable that people with intellectual disabilities experience equivalent if not higher rates of mental health problems than the general population (Holden & Gitlesen, 2003; Maughan, Collishaw, & Pickles, 1999; Rymill, 2001; Simpson, 1998), where prevalence is estimated at about 10-25% (Mental Health Foundation, 1999).

There are a number of distinct but overlapping reasons for this increased vulnerability (Hatton & Taylor, 2010). These include predisposing biological and genetic factors (O'Dwyer, 1997) and limited psychological coping resources associated with different forms of intellectual disability (Quigley, Murray, McKenzie & Elliot, 2001; Reiss & Benson, 1984; Szymanski, 1994). However, a significant contributor is increased exposure to a range of psychosocial stressors and adverse life experiences including events such as birth trauma (Collacott, Cooper & McGrother, 1992), institutionalisation, separations (Hatton & Taylor, 2010), lack of intimate relationships and social acceptance (Reid, 1994) and traumatising abuse (Hatton & Taylor, 2010). This will be discussed further in Section 1.4.1. With this consideration in mind, the phenomenon of posttraumatic stress disorder (PTSD) in intellectual disabilities will now be discussed.

1.3. Posttraumatic Stress Disorder

1.3.1. Clinical features and diagnosis. PTSD is an anxiety disorder that can develop following exposure to any event that causes psychological trauma (2000). The DSM-IV-TR (2000) details that for a diagnosis seven criteria must be met (Criteria A to F). These are outlined in Table 2. The key feature of a diagnosis is the development of characteristic symptoms following exposure to an extreme traumatic stressor (2000). For this specification to be satisfied the person needs to have experienced, witnessed, or been confronted with an event (or events) involving actual or threatened death or serious injury, or a threat to the physical integrity of self or others, and their response needs to have involved intense fear, helplessness or horror. Following this exposure, PTSD manifests as persistent re-experiencing of the event (e.g., nightmares and ‘flashbacks’) (Criterion B); persistent avoidance of stimuli associated with the trauma, such as effortful avoidance of thoughts and feelings, and numbing of general responsiveness (Criterion C); and persistent symptoms of increased arousal, for example sleep or concentration difficulties (Criterion D). These symptoms must be present for more than one month (Criterion E), and cause clinically significant distress or impairment (Criterion F).

The subjective nature of what is considered traumatic makes it difficult to establish an exhaustive list of traumatic events that would qualify as a traumatic stressor. However, the DSM-IV-TR (2000) has identified a range of potential events. Events experienced directly include military combat, kidnapping, violent personal assault (e.g. sexual assault, physical attack), terrorist attack, torture, natural disasters, severe automobile accidents, or being diagnosed with a life-threatening illness. Witnessed events include observing the serious injury or unnatural death of another person due to violent assault, accident, war or disaster, or unexpectedly witnessing a

dead body. Events experienced by others include violent personal assault, serious accident or serious injury experienced by a family member or a close friend, and learning about the sudden or unexpected death of a family member or a close friend.

Table 2. Diagnostic criteria for posttraumatic stress disorder (DSM-IV-TR, 2000).

Criterion	Description
A	The person experienced, witnessed, or has been confronted with an event involving actual or threatened death or serious injury, or a threat to the physical integrity of self or others. The person's response needs to of involved intense fear, helplessness or horror.
B	The traumatic event is persistently re-experienced in one or more of the following ways: 1) recurrent and intrusive recollections of the event including thoughts or images; 2) recurrent distressing dreams; 3) acting or feeling as if the event was reoccurring. 4) and 5) intense psychological distress or reactivity to exposure to internal or external cues that symbolise the event.
C	Persistent avoidance of stimuli associated with the trauma, such as effortful avoidance of thoughts and feelings, and numbing of general responsiveness indicated by three of the following: 1) avoidance of thoughts, feelings or conversations associated with the trauma; 2) avoidance of activities, places or people that arouse recollection 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; 7) sense of foreshortened future.
D	Persistent symptoms of increased arousal as indicated by two of the following: 1) sleep difficulties; 2) irritability or anger; 3) concentration difficulties; 4) hypervigilance; 5) exaggerated startle response.
E	Duration of disturbance longer than 1 month.
F	The disturbance causes clinical significant distress and impairment of social or academic function.

1.3.2. Epidemiology. Most people are thought to experience a traumatic event at some point in their lives (Resick, 2001) with 69% of the general population found to have experienced a trauma (Norris, 1992). Higher rates have been found in other populations, with one study observing that 84% of a sample of university students

reported experiencing at least one event that could elicit PTSD (Vrana & Lauterbach, 1994). However, not all individuals go on to develop PTSD. A National Comorbidity Survey (Kessler et al., 2005) identified lifetime prevalence for PTSD of 6.8% in adults, with a higher rate in women than men (9.7% versus 3.6% respectively). The risk of developing PTSD in those who have experienced trauma is thought to vary depending on trauma severity, with estimated prevalence rates of 30% for rape (Breslau, 2001) and up to 50% amongst torture survivors (Yehuda, McFarlane, & Shalev, 1998). A more detailed examination of such findings can be found in a recent article that reviewed the epidemiology of PTSD (Johnson, Maxwell, & Galea, 2009).

1.3.3. Course. A number of factors are considered important in determining the course and severity of PTSD. It is known that demographic characteristics, such as gender and race are associated with varying rates of PTSD (Brewin, Andrews, & Valentine, 2000). Other risk factors include previous exposure to trauma such as child abuse (e.g. Andrews, Brewin, Rose, & Kirk, 2000), age at trauma (Brewin et al., 2000), and trauma event type, with the highest risk associated with assault and violence (Breslau et al., 1998). Interpersonal factors, such as perceived social support are also important mediators in the development of PTSD (e.g. Boscarino, 1995; Brewin et al., 2000).

Notably, a consistent finding in the literature is the impact of low IQ, with a negative correlation identified between IQ and PTSD symptomatology (McNally & Shin, 1995; Vasterling, Brailey, Constans, Borges, & Sutker, 1997). There is some debate on whether low IQ is a cause or effect of trauma symptoms, with some arguing that trauma symptomatology affects mental processes, such as concentration and attention, that are important to perform effectively on IQ tests (Kira, Lewandowski, Somers, Yoon & Choido, 2012). However, while it is likely that there is some truth to

this assertion, higher trauma symptomatology has been linked to premorbid IQ levels (Macklin et al. 1998). Furthermore, associations have been found between PTSD diagnosis and fewer intellectual resources as measured by indirect, pre-exposure measures of intellectual functioning, such as arithmetic and verbal reasoning tasks (Centers for Disease Control Vietnam Experiences Study, 1988; Pitman, Orr, Lowenhagen, Macklin, & Altman, 1991), educational achievement (Green, Grace, Lindy, Gleser, & Leonard, 1990; Harel, Kahana, & Kahana, 1988), and military rank (Sutker, Bugg, & Allain, 1990). It is therefore likely that intellectual functioning prior to trauma exposure has some impact on whether an individual subsequently develops PTSD symptomatology.

1.4. Intellectual Disabilities and Posttraumatic Stress Disorder

1.4.1. Traumatic life events. There is evidence to suggest that individuals with intellectual disabilities are more likely to experience traumatic life events than those without a disability (Hatton & Emerson, 2004; Focht-New, Clements, Barol, Faulkner, & Pekala, 2008; Mansell, Sobsey, & Moskal, 1998; Ryan, 1994). In particular, those in this population have been found to be at higher risk of sexual and emotional abuse (e.g. Ammerman, Van-Hasselt, Herson, McGonigle, & Lubetsky, 1989; Anderson, 1982; Beail & Warden, 1995; Hogg, Campbell, Cullen, & Hudson, 2001; Sobsey, Gray, Pyper, & Reimer-Heck, 1991; Turk & Brown 1993) and to be victims of crimes including physical assault, robbery and forms of hate crime (Kebbell, Hatton, Johnson, & Caitriona, 2001; Department of Health [DOH], 2009). Moreover, events that would not normally be considered as traumatic such as bullying have been linked to a trauma reaction in this population (Young, Ne'eman, & Gelsner, 2012). Additionally, research demonstrates an association between life events and psychiatric problems in individuals with intellectual disabilities (Hastings, Hatton, Taylor, & Maddison, 2004; Hubert-

Williams & Hastings 2008; Tsakanikos, Bouras, Costello, & Holt, 2007) with evidence that life events precede psychological problems (Esbensen & Benson 2006; Monaghan & Soni 1992).

Despite this the events and their impact, particularly in terms of PTSD symptomatology, are often under-identified with a paucity of research in this area (Hollins & Sinason, 2007; Lunskey & Elseraf, 2011). For example, in a recent service evaluation in Rampton Prison, clinical files were reviewed for evidence of trauma (Brackenridge & Morrissey, 2010). This found that file records of potentially traumatic events, including abuse, were often lacking in detail, and there was no information to suggest that any trauma-specific assessments had been used to measure trauma exposure or symptoms. Equally, PTSD as a diagnosis was rarely considered, and there was little consideration of trauma-specific interventions. While this is only one study and therefore offers only a snapshot of the clinical picture, the finding that the impact of traumatic events are not typically identified is noteworthy.

1.4.2. Diagnostic criteria. There are currently two diagnostic manuals specifically designed for use with people with intellectual disabilities: the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities (DC-LD; RCP, 2001) and the Diagnostic Manual-Intellectual Disability (DM-ID; Fletcher, Loschen, Stavrakaki, & First, 2007). The DC-LD does not have a PTSD section and no explanation is provided for this exclusion. However in contrast the DM-ID affords PTSD its own chapter in recognition that it is so frequently under-diagnosed in this population. The authors outline minimal adaptation to the DSM-IV-TR criteria, describing that those with a mild intellectual disability are likely to have a similar symptom experience to that of the general population (Razza & Tomasulo, 2007). However, some modifications are included. For example, it is suggested that in some

individuals symptoms may be expressed in overt behavioural patterns. Thus, flashbacks or re-experiencing phenomena may be experienced as self-injury and avoidance behaviour may manifest as non-compliance. It is also noted that dreams about the trauma may be represented in people with an intellectual disability as frightening dreams without recognisable content. The chapter also specifies that some events not considered traumatic for those in the general population may be traumatic for people with intellectual disabilities, and therefore recommends a broader range of events may need to be considered to meet Criterion A.

While attempts to classify PTSD in this population should be welcomed, there is lack of empirical evidence to support these adaptations. Indeed, the authors of the PTSD chapter acknowledge that “at this point hard data is lacking with respect to the association between specific intellectual levels...and the particular ways in which PTSD can manifest” (Razza & Tomasulo, 2007, pp. 371). Others have noted that the empirical literature connecting adverse life events and PTSD in people with intellectual disabilities is not substantial (Doyle & Mitchell, 2003; Martorell & Tsakanikos, 2008; Wigham, Hatton & Taylor, 2011a). It is therefore clear that little is known about how, or if, PTSD manifests in this population, which would likely have a predictable impact on the recognition and treatment of such symptoms. The following sections aim to address this by first examining psychological theories of PTSD and their implications for people with intellectual disabilities, before reporting findings of a literature review of previous research in this area.

1.4.3. Psychological theories of PTSD. Psychological adjustment to traumatic experiences has long been the subject of theoretical interest. Although many accounts exist to explain the characteristic features that define this disorder (e.g. Lifton, 1988; Ulman & Brothers, 1988), only the primary cognitive theories will be considered here.

Such approaches are considered as the most influential theories of PTSD in terms of generating testable hypotheses and directing current treatments (Creamer, Burgess, & Patison, 1992; Foa, Steketee, & Rothbaum, 1989; Litz & Keane, 1989). They therefore offer the most developed framework for understanding psychological responses to trauma. Furthermore, a core element of cognitive theories is the way information about the event is processed. Considering the difficulties many people with intellectual disabilities may have in processing threatening information (Finzi-Dottan, Dekel, Lavi, & Su'ali, 2007; McCarthy, 2001; Weiler, Harris, Marcus, & Bellinger, 2000), such theories are of particular relevance for the present discussion. This review will begin with two early cognitive theories: the stress response theory (Horowitz, 1976; 1986; 1997) and the fear network account (Foa et al., 1989). This will be followed by a discussion of three current cognitive theories: emotional processing theory (Foa & Riggs, 1993; Foa & Rothbaum, 1998), dual representation theory (Brewin, Dalgleish, & Joseph, 1996) and Ehlers and Clark's (2000) cognitive appraisal model.

1.4.3.1. Stress response (Horowitz, 1976, 1986, 1997). As the earliest cognitive model of the aetiology of reaction to trauma (Dalgleish, 2004), this model proposes that individuals hold schemata about the world and themselves against which new information is interpreted and integrated into existing, longer-term representations. Horowitz argued that the main impetus within the cognitive system for the processing of trauma-related information is to match new information with these existing schemas, termed the "completion tendency". Trauma symptoms are said to occur when, following the initial outcry at the realisation of the trauma, individuals fail to assimilate this new trauma information within these structures. This failure to "complete" activates psychological defence mechanisms to avoid memories of the trauma and to prevent this

information from entering consciousness. This is experienced as denial, numbing and avoidance of trauma reminders.

Due to the completion tendency, Horowitz proposes that trauma-related information is maintained in what he terms “active memory”. This is a type of memory that has a tendency to repeat its contents into conscious awareness until successful completion has been achieved. Active memory of the trauma thereby causes traumatic information to break through psychological defences in the form of flashbacks, nightmares and unwanted thoughts (the re-experiencing symptoms of PTSD). According to Horowitz, this tension between the need to complete and the psychological defence mechanisms causes oscillation between phases of intrusion and denial and numbing as the traumatic material is gradually assimilated into long-term schematic representations and therefore cleared from active memory storage. Persistent posttraumatic symptoms are thought to arise from a failure to process and integrate the new information within the oscillation process (Horowitz, 1976).

This theory accounts for far more of the core data of the disorder than it fails to and therefore has considerable explanatory power (Dalgliesh, 2004). The model also provides a good account of how factors that are associated with a greater mismatch between trauma-related information and pre-existing schemas, such as personal injury, threat to life, bereavement, and negative cognitions would lead to more severe PTSD. However, the nature of emotions is less well explained by this theory. It is not explicit how, for example, shame might arise following a traumatic experience (Dalgliesh, 2004). Moreover, the notion of active memory is underspecified (Dalgliesh, 2004). It is not clear whether this is a schema, or a part of memory previously outlined in cognitive theories of memory such as working memory (Baddeley, 2000; Baddeley & Hitch, 1974). Another criticism of the model is how certain elements known to be important in PTSD are held. Although PTSD is associated with negative thoughts, interpretations

and attributions about the trauma, this theory does not explain where these thoughts or beliefs are represented, or how they are examined, manipulated and changed (Dalglish, 2004). Finally, the theory does not address peritraumatic reactions, or the role of environmental factors such as trauma cues and social support (Brewin & Holmes, 2003). Consequently, there is little discussion of the individual differences in responses to traumatic events.

1.4.3.2. Fear network account (Foa, et al., 1989). In contrast to the schema theory outlined by Horowitz which attempts to account for organisation of abstracted knowledge, Foa and colleagues put forward a network theory where the focus is on the connectivity between different representations. It is proposed that anxiety disorders occur when a “fear network” is activated. This network is conceptualised as an associative network within long-term memory consisting of three key parts: information about the feared object; information about cognitive, behavioural, and physiological responses to the feared object; and information linking these parts together. Dalglish (2004) describes how the fear network essentially acts as a “memory record of the trauma” (pp. 19), and PTSD symptoms such as re-experiencing are produced when one or more of the elements in the network are encountered. However, avoidance and numbing symptoms are viewed as mechanisms that reduce the risk of activation of the network by trauma stimuli. They therefore diminish the frequency of re-experiencing symptoms. The theory also outlines that the network for a traumatic event would be bigger than that for a feared object in the other anxiety disorders (e.g. specific phobias). It is proposed that traumatic experiences violate basic concepts of safety to such a degree that previously safe aspects of the environment are included in the fear network. Consequently, a large number of environmental cues could trigger activation of the network.

This theory provides a good account of the central symptoms of PTSD (APA, 2000). Specifically, the model provides a clear framework for how information about a traumatic event is processed (Brewin & Holmes, 2003). The effect of this can be seen in how the model has led to the development of highly successful, theoretically grounded treatment interventions in terms of exposure therapy (Foa, Ehlers, Clark, Tolin, & Orsillo, 1991; Foa, Rothbaum, Riggs, & Murdock, 1999). Similarly, the model accounts for individual differences in post-trauma response, with pre-trauma psychiatric history, previous experience of trauma and trauma severity all serving to potentiate the fear network that is established. However, the theory does not distinguish between flashbacks and ordinary trauma memories and cannot explain how memory can produce rapid responses such as flashbacks and physiological arousal, but at the same time be disorganised and contain gaps (Brewin & Holmes, 2003). Furthermore, the theory is relatively traumacentric in that it is primarily a representation of the trauma and related stimuli. Therefore, unlike stress response theory, it is not explicit about how the content of such abstracted representations of the world and the self can be modified in the original fear network approach (Foa et al., 1989). While there is some account of higher order meaning in the assertion that traumatic events violate basic “rules of safety”, the theory does not address how such rules might be represented. Consequently, in theoretical terms, it is not clear how an individual’s sense of meaning is transformed following a trauma, nor how it might be restored following successful exposure therapy (Brewin & Holmes, 2003).

1.4.3.3. Dual Representation Theory (DRT; Brewin, Dalgleish, & Joseph, 1996). In contrast to the previous two theories, DRT offers a multi-representational approach to understanding PTSD symptomatology by incorporating both network and schema approaches. The principle underlying this theory is that trauma memories are

represented in fundamentally different ways to that of ordinary, day-to-day memories (Brewin & Holmes, 2003). Specifically, DRT conceptualises that trauma information is stored in two separate memory systems: the “situationally accessible memory” (SAM) system and the “verbally accessible memory” (VAM) system. VAMs can be deliberately retrieved and edited by the traumatised individual and are fully contextualised within the person’s autobiographical memory. SAMs, however, contain information that cannot be deliberately accessed or edited by the individual in the same way as VAMs. SAMs are not seen as being contextualised within the autobiographical database and are accessed only when cued by exposure to stimuli redolent of the original traumatic situation. According to this theory, VAM and SAM representations are encoded in parallel at the time of the trauma and between them account for the range of PTSD symptomatology. For example, dissociative memories or ‘flashbacks’, result from the activation of SAM representations (via cueing), whereas a person’s ability to recount the trauma, their intrusive memories, and the cognitions regarding the event would be a function of accessing the VAM system.

According to this theory, in order to successfully recover from PTSD, emotional processing needs to proceed via both the VAM and SAM representations (Brewin et al., 1996). That is, individuals are required to consciously integrate the verbally accessible information in VAMs with their pre-existing beliefs and models of the world, and activate information in SAMs through exposure to cues concerning the event. To explain why some people develop PTSD and others do not, it is proposed that for some individuals the discrepancies between the trauma event and prior assumptions are too great. Consequently, emotional processing of the trauma information either becomes chronic or does not occur due to individuals avoiding the reactivation of the highly distressing information stored in VAM and SAM (Brewin & Holmes, 2003; Rachman, 1980).

With its conceptualisation of SAMs, DRT has been described as a de facto network theory of the PTSD (Dalgleish, 2004), and therefore has good explanatory power in terms of accounting for much of the core data of PTSD. However, with the addition of VAMs, DRT has improved utility for explaining the transformation of meaning, appraisal and cognition following trauma. The theory also has some empirical support. In one study, participants viewed a trauma film under different encoding conditions. Participants were asked to carry out either a concurrent visuospatial or verbal task, following which researchers recorded the number of intrusive memories of the film. As predicted by DRT, the visuospatial task, which would require resources from the SAM system, resulted in poorer encoding of perceptual information and fewer intrusive memories compared with controls. Conversely, the verbal task, which was predicted to draw upon the VAM system resources thereby interrupting encoding and leading to a less detailed conscious representation of the film due, resulted in more intrusions compared with controls (Holmes, Brewin & Hennessy, 2004).

While this research is promising, the study took place under controlled conditions and employed an analogue design. It is therefore unclear how much the results can be extrapolated to “real life” situations. Moreover, Dalgleish (2004) observes that the data are equally consistent with associative network theory where it may be expected that a relative lack of stimulus elements (in the visuospatial condition) would lead to fewer intrusions, whereas the lack of (verbal) response and meaning elements would reduce the contact between the network and the existing autobiographical database, thereby leading to more persistent intrusive experiences. The theory also struggles to account for pre-trauma factors and the transformation of meaning as it does not explicitly include representations of abstracted knowledge such as schemas. It is therefore not known how assumptions about the world and the self might actually be represented in the theory, and whether they form part of the VAM system (Dalgleish,

2004). Finally, there is little discussion of how VAMs and SAMs might interact with each other. There is therefore the need for further research to confirm some of the tenets of this theory (Brewin & Holmes, 2003).

1.4.3.4. Cognitive appraisal model (Ehlers & Clark, 2000). Ehlers and Clark (2000) have proposed a cognitive model that focuses on the maintenance of PTSD. The central component of the model is the notion of “current threat” which is said to occur as a direct result of two processes: individual differences in the appraisal of the trauma event and its sequelae, and individual differences in the nature of the trauma memory itself. In terms of appraisals, several types are implicated including overgeneralisation of threat across a range of normal activities (e.g. “Nowhere is safe”), overestimation of the likelihood of further traumatic events occurring (e.g. “I attract disaster”), and negative appraisals of one’s own actions during the trauma (e.g. “I cannot cope with stress”). Other appraisals are thought to focus more on the trauma sequelae, such as PTSD symptoms following the trauma (e.g. “I’ll never get over this”), the reactions of others (e.g. “I cannot rely on other people”), and on the wider consequences of the trauma, such as physical consequences (e.g. “I will never be able to lead a normal life again”).

In terms of the second process, it is proposed that PTSD symptoms arise as a result of incomplete integration of trauma memories into the autobiographical memory. According to this theory, this action is mediated by the way the traumatic experience is processed at the time. The use of data-driven processing (processing of sensory and perceptual information) is hypothesised to lead to poor elaboration in memory, whereas conceptually-driven processing (processing the meaning of the situation) provides a context to the information during the trauma, leading to better elaboration and fewer PTSD symptoms. As well as providing an account of the processes underlying this

sense of threat, Ehlers and Clark go on to propose the emergence of behavioural and cognitive responses as a reaction to the threat, which consist of the avoidance symptoms seen in PTSD. Similar to the role of safety behaviours in other anxiety disorders, these responses serve to alleviate distress in the short term by removing or controlling the sense of threat. However, as is also the case in anxiety, they actually play a maintaining role in PTSD by preventing the individual from making any cognitive change.

As with DRT the cognitive appraisal theory harnesses the explanatory power exhibited by traditional network approaches (e.g. Foa et al., 1989) and supplies a comprehensive account for the core symptoms of PTSD. Furthermore, the focus on appraisals provides a framework for understanding the transformation of meaning following trauma and the mechanism of action of some pre-trauma risk factors. By utilising appraisals the theory also accounts for how different types of cognition impact on the disorder and recovery from it. This theory therefore provides a good context for treatment, forming the basis of cognitive therapy techniques. There is also good evidence in support of various aspects of the model. This includes evidence of a relationship between a number of factors and persistent PTSD symptoms such as: negative interpretations of the trauma (Dunmore, Clark, & Ehlers, 1997; Dunmore, Clark, & Ehlers, 1999); negative interpretations of initial PTSD symptoms (Clohessy & Ehlers, 1999; Dunmore et al., 1997, 1999; Ehlers, Mayou, & Bryant, 1998; Ehlers & Steil, 1995; Mayou, Bryant, & Ehlers, 2001; Steil & Ehlers, 2000); negative interpretations of other people's responses (Dunmore et al., 1997, 1999); and safety behaviours and avoidance (Dunmore et al., 1999; Dunmore, Clark, & Ehlers, 2001).

Nonetheless, the theory does have some limitations. Dalgelish (2004) points out that there is no representational space that specifically codes referential meaning as is the role of VAMs in DRT (Brewin et al., 1996). This role is incorporated within the memory records as it is in traditional network theory. However because of this the

theory struggles to explain how an individual can talk about their verbal memories of the trauma in the form of appraisals without activating any of the stimulus and response elements that are associated in the same network or memory record (Daggleish, 2004). Moreover, Ehlers and Clark's assertions regarding the impact of cognitive processing during trauma are less well supported (Brewin & Holmes, 2003). While a relationship between data-driven processing and later distress and avoidance has been identified, evidence that data-driven processing is linked to intrusive memories is lacking (Halligan, Clark, & Ehlers, 2002; Holmes, Brewin, & Hennessy, 2004; Murray, Ehlers, & Mayou, 2002). The reason for this may be that attempts to instruct participants to process material in a particular way tend to be ineffective, and that assessment of cognitive processing or memory disorganisation is complex (Brewin & Holmes, 2003). Nevertheless this is an important point that will need to be addressed by further research.

1.4.3.5. Emotional processing theory (Foa & Riggs, 1993; Foa & Rothbaum, 1998). Building upon the earlier fear network account, the emotional processing theory is underpinned by three core components: pre and post-trauma memory records, schemas and the posttraumatic reactions of self and others. According to this theory the type and extent of post-trauma symptomatology is determined by the nature of, and interaction between, these components. Memory records in this model include all of the elements of fear networks but with some extensions. Firstly, there is a greater emphasis on the disorganised nature of the memory records of traumatic experiences (Foa & Riggs, 1993), which are described as impoverished partly due to disrupted and biased information processing at the time of trauma (Thrasher & Daggleish, 1999; Williams, Watts, MacLeod & Mathews, 1997). Secondly, trauma memories are proposed to be characterised by large numbers of stimulus-danger associations (Foa & Rothbaum,

1998). Consequently, stimuli only tangentially related to the trauma can become associated with danger. The final extension put forward is that trauma memories differ from other fear-related representations due to the diversity of the response elements that they contain, such as physiological responses and a wide range of behavioural responses that may have proved adaptive at the time of the trauma (e.g. dissociation, screaming, numbing). In addition to trauma records, Foa and colleagues place importance on the impact of schemas in that in line with previous accounts, traumatic experiences can violate existing schematic knowledge thus leading to PTSD symptomatology. Finally, Foa and colleagues placed increased emphasis on negative appraisals of trauma symptomatology, which may relate to events that took place at the time of the trauma, to symptoms that developed afterwards, to disruption in daily activities, and to the responses of others.

By incorporating the strengths of both schema and network accounts, this model has robust explanatory power in accounting for most of the core data of the disorder (Dalgleish, 2004). Moreover, unlike DRT and Ehlers and Clark's (2000) theory it elaborates an explicit schematic level of representation, and is therefore in some way more beneficial (Dalgleish, 2004). The model also seeks to explain the interaction between pre-trauma schemas, memory records and post-trauma factors, suggesting that schemas regarding the world being a dangerous place are seen as resulting from a range of stimuli-danger connections in the memory records (Foa & Jaycox, 1999). The theory has also received some empirical support. Through analysing the therapy narratives of rape victims at the beginning and end of successful therapy, one study found signs of disorganisation in the narratives (such as unfinished thoughts and repetitions) decreased from the first to last narrative which was correlated with symptom improvement of trauma-related anxiety (Foa, Molnar & Cashman, 1995). Furthermore, the increased emphasis on pre-trauma risk factors and on appraisal processes has been strongly

supported by recent research reviewed above in the cognitive appraisal section (Clohessy & Ehlers, 1999; Dunmore et al., 1997, 1999; Ehlers et al., 1998; Ehlers & Steil, 1995; Mayou et al., 2001; Steil & Ehlers, 2000). Despite these strengths, the theory does not provide an explicit mental conceptualisation of referential meaning. This is especially true of the third component (post trauma reactions) which is represented under the broader umbrella of memory records. This is problematic because, as with Ehlers and Clark's model (2000), the model struggles to explain discrepancies between verbal accounts of the trauma and re-experiencing of the trauma in other ways (Dalglish, 2004). The status of other aspects of the theory is less well-established, particularly the hypothesised mechanisms of change (Brewin & Holmes, 2003).

1.4.4. Theoretical implications for intellectual disabilities

1.4.4.1. *Developmental context.* Longitudinal studies have shown that developmental processes have a different trajectory for people with intellectual disabilities compared to those in the general population (Mahaney & Stephens, 1974; Moore & Stephens, 1974; Stephens & McLaughlin, 1974). Such differences in developmental level affect the presentation of psychopathology in intellectual disability (Cooper, 2003; Fletcher et al., 2007; Hove & Havik, 2010; Matson & Smioldo, 1998). While considerable controversy exists on the quality and quantity of this relationship (Matson & Smioldo, 1998), this pathoplastic effect is typically greater the more severe the intellectual disability (Cooper, 2003). Research from childhood PTSD has shown that developmental factors, such as level of cognitive and language development, are considered highly important in trauma symptomatology (McCarthy, 2001; Meiser-Steadman, 2002; Pynoos, 1994; Salmon & Bryant, 2002; Yule, 1992). For example, pre-school children are more likely to show regressive and destructive behaviours in

response to traumatic events, whereas school age children are able to give accounts of their experiences and to report how distressing the re-experiencing was in thoughts and images (McCarthy, 2001). While people with intellectual disabilities are not necessarily comparable to children, it follows that those in this population may be similarly affected by developmental differences (Finizi-Dottan et al., 2007; McCarthy, 2001; Mevisson & De Jongh, 2010; Wigham et al., 2011b). Hence developmental factors will be considered in the following section which, using the theories already outlined, will attempt to understand the impact of trauma on those with intellectual disabilities. It is important to note however that this process is difficult. Very few theories explicitly discuss, or have been tested using people with intellectual disabilities or low IQs. Moreover, people with intellectual disabilities are a heterogeneous group, so there is likely to be a great deal of variations between individuals. However it is possible for some tentative interpretations to be made.

1.4.4.2. Information processing theories. Implications here are discussed in relation to three processes considered to be of theoretical importance: memory, appraisals and coping strategies.

1.4.4.2.1. *Memory and information processing.* Theories posit that memory and information processing are vital processes in the development of PTSD. Variations in cognitive development mean that such faculties are often impaired or reduced in people with intellectual disabilities (Clare & Gudjonsson 1993; McCarthy, 2001; Weiler et al., 2000). These difficulties may be further confounded during and following a traumatic experience due to the large amount of threatening information required to be processed (Weiler et al., 2000). It is therefore essential to consider how this impacts upon the extent and presentation of trauma symptomatology. For example, such deficits may lead

to a greater vulnerability to PTSD in this population. It has been suggested that those at a lower developmental level lay down less coherent memories (Salmon & Bryant, 2002), which according to theoretical accounts would then lead to an increased level of symptoms. Symptoms might also be more prevalent or persistent as individuals may be less effective at engaging in operations conceptualised to reduce symptomatology. For example, according to DRT, to recover from PTSD it is important to transform SAM representations of the trauma into VAMs. This process is predicted by DRT to be more problematic for those with deficits in verbal memory (Brewin, Kleiner, Vasterling & Field, 2007). Indeed such difficulties have been linked, albeit not causally, to greater PTSD symptoms (Johnsen & Asbjørnsen, 2008). Considering the verbal memory problems often typical of people with intellectual disabilities, trauma symptomatology may be increased. Interestingly, as the VAM system inhibits the SAM system, it is also possible that deficits in verbal memory may also mean that symptoms representative of the SAM system such as flashbacks and nightmares may be more prevalent in this population. Differences in peritraumatic processing could also lead to more symptoms according to some theories. Ehlers and Clark (2000) predict that lower intelligence may mean individuals are more likely to process information using data-driven processing, which would in turn lead to increased PTSD symptoms. However, assumptions regarding data-driven processing remain contentious (Brewin & Holmes, 2003), and would need to be empirically tested using an intellectual disability sample.

Memory and information processing difficulties could also mean that PTSD symptomatology is expressed differently in those with intellectual disabilities. For example, re-experiencing phenomena are a consequence of a number of higher cognitive processes. This includes the recognition of, and the attempt to reconcile, a disparity between trauma-related information and existing cognitive schemata, in addition to the memory and language ability to retrieve and describe these intrusive

episodes (Salmon & Bryant, 2002). It is possible that due to developmental differences some people with intellectual disabilities may have difficulties with performing some or all of these operations. It is known from research on child and adolescent trauma reactions that development can impact on whether - and the ways in which - such symptoms are expressed. For example, most school age children and adolescents are found to experience the full range of re-experiencing symptomatology (Fletcher, 1996). However, the same is not true of younger (pre-school) children who, rather than experiencing flashbacks (Meiser-Steadman, 2002), tend to exhibit symptoms such as distress at reminders of the trauma, bad dreams and engagement in posttraumatic play (Fletcher, 1996). It is conceivable that a similar distinction would be found in intellectual disability. Those with severe intellectual disabilities may be less likely than those in the mild range to exhibit typical re-experiencing symptomatology. Rather, they may exhibit symptoms of challenging behaviour such as self-injury or physical health complaints (McCarthy, 2001; Mitchell & Clegg, 2005; Mitchell, Clegg, & Furniss, 2006).

1.4.4.2.2. Appraisals. The theories outlined above place an important role on the appraisal and meaning given to a traumatic event, where at the encoding stage a judgment is made regarding whether the event is dangerous or relates to existing schema. One recent review identified how there are developmental differences between people with and without intellectual disabilities that can impact on moral judgments (Langdon, Clare, & Murphy, 2010). It is possible, therefore, that there are also differences in the way that people with intellectual disabilities appraise traumatic events or their subsequent symptoms. For example, interpreting an event as dangerous is influenced by knowledge of the world and the reactions of others (Salmon & Bryant, 2002). As people with intellectual disabilities may have less knowledge about the

world, there could be either a failure to appraise unusual events as traumatic, or the appraisal of some situations as very dangerous when they are not (Salmon & Bryant, 2002). Furthermore, those with intellectual disabilities may be more reliant on or influenced by external sources - such as staff or parents – when judging the nature of an event. The importance of parental reactions in mediating appraisals has been found in childhood PTSD (Franks, 2011; Salmon & Bryant, 2002; Winston, Kassam-Adams, Garcia-Espana, Ittenbach, & Cnaan, 2003). Key-workers and care staff may operate in a similar way for people with intellectual disabilities. These factors may also impact in a similar way on how an individual interprets the posttraumatic symptoms, an important element of the cognitive appraisal model (Ehlers & Clark, 2000). For example, the extent to which a symptom such as flashbacks are seen as signs of “going mad” or being “out of control” may be mediated by the reactions of others. There may also be developmental differences with such metacognitive thoughts only possible for those operating at a higher cognitive level. However, the impact of development on metacognition still needs to be established (Meiser-Steadman, 2002).

1.4.4.2.3. *Coping strategies.* Theoretical accounts, especially the cognitive appraisal model (Ehlers & Clark, 2000), conceptualise an important role for how an individual responds to PTSD symptomatology, with maladaptive coping responses hypothesised to lead to persistent symptoms. It is recognised that the strategies employed by children following a traumatic event vary according to age, and that this can affect PTSD symptomatology (Franks, 2011). There may be also differences in the ways that people with intellectual disability are able to manage trauma symptomatology that could impact on how such symptoms manifest or persist. For example, intellectual disability is characterised by an absence of adaptive skills including lack of planning or verbal mediation (Ashworth, Hirdes, & Martin, 2009; Soenen, VanBerckelaer-Onnes, &

Scholte, 2009). As a consequence of such deficits, those in this population may engage in less effective coping methods. Difficulties in planning abilities may mean that individuals would be less successful at avoiding reminders of the event. Symptoms would therefore be constantly triggered, thus leading to an increase in their prevalence and persistence.

It is also possible however, that people with intellectual disabilities may be less likely to engage in some maladaptive cognitive strategies. Salmon and Bryant (2002) suggest that those operating at a lower developmental level may lack the abstract cognitive abilities to employ cognitive strategies such as avoidance, thought suppression, rumination or worry. It is known, for example, that pre-school children engage less in the avoidance or suppression of thoughts or feelings (Fletcher, 1996). A similar finding may be found for some individuals with intellectual disabilities. Moreover, if this was the case, because cognitive strategies impair the processing of traumatic memories, those in this population would develop a more detailed record of the event and therefore experience reduced symptomatology. However, it is important that this assertion is tested using an intellectual disability sample. Whatever the impact of these potentially different coping strategies, it is likely that there would be some variations in approaches adopted by people with intellectual disabilities. This would need to be a consideration for assessment.

1.4.4.3. Summary. In this section the way that cognitive theories of PTSD might relate to trauma symptomatology in people with intellectual disabilities was discussed. Although tentative, two specific implications were highlighted. Firstly, those with intellectual disabilities may be more vulnerable to developing PTSD symptomatology. Secondly, due to developmental factors, there may be some differences in how or whether certain symptoms are exhibited. For example, it has been found that very young

children do not exhibit some re-experiencing phenomena. It is possible that a similar pattern will be found for some individuals with intellectual disabilities. The next section is a systematic review of previous research in this area and aims to examine some of these predictions.

1.4.5. Do people with Intellectual Disabilities exhibit symptoms of PTSD?

1.4.5.1. Aim. A systematic review was carried out to evaluate previous research into intellectual disability and PTSD symptomatology. The purpose was to examine whether the literature supported some of the theoretical implications outlined above.

1.4.5.2. Search Method. The following databases were searched on the 26th November 2011 to identify relevant articles: PsychInfo (1980-2010), Medline (1980-2010), and EMBASE (1980-2010). Key search terms used were “PTSD”, “Post traumatic stress disorder”, “assess*”, “symptoms”, "intellectual disabilit*", "learning disabilit*", "mental retard*", "mental handicap", "developmental disabilit*", and “subnormal”. All searches were combined and duplicates removed. The reference sections of each identified article were also analysed and relevant papers were recovered via hand searching.

1.4.5.3. Inclusion and exclusion criteria. The review sought articles that were written in English and published in peer-reviewed journals between 1980 (the point at which PTSD became a formal diagnostic entity) and 2010. No limits were placed in relation to the age of the participants. The initial search elicited 148 papers. Studies were included if they measured or set out to investigate PTSD symptoms in those with intellectual disabilities. Case studies were excluded due to difficulties with

generalisability. Initially criteria were set to exclude those studies that did not include participants who had an intellectual disability defined by an IQ of below 70. However, on review of articles gathered from the search, it was clear that very few satisfied this specification. Therefore, the criteria were expanded to include studies where the participants were described as having an intellectual disability. Review articles were also excluded.

Following the application of the above inclusion and exclusion criteria, eight papers that addressed the topic of this review were selected. The reference lists of these articles were also investigated to identify other suitable studies. This elicited a further two papers.

1.4.5.4. Results. The search resulted in ten studies. The studies varied in terms of sample selection, research questions, type of assessment measures used and what they were assessing.

1.4.5.5. Evaluation of studies. One of the earliest pieces of research into symptoms of trauma in this population described individuals who had attended a consultation service (Ryan, 1994). Most of these individuals were originally referred for exhibiting complex behaviours. Of the 310 people seen, 51 (16.5%) were said to meet DSM-III-R criteria for PTSD (APA, 1987). Each member of the sample had experienced more than one type of trauma. The most common trauma was abuse (physical and sexual), but also included witnessing harm or death to others. While this study benefited from a large clinical sample, no information on the cause of intellectual disability is provided, and there was no measure of IQ or adaptive ability. This makes comparisons with other studies difficult. However, another descriptive study involved

only those individuals with an IQ of below 70 measured using a standardised measure (Harden & Sahl, 1997). Using a large sample of 233 children and adolescents assessed in a specialised programme during a one-year period, they found 1.7% had PTSD. This was diagnosed by a team based on information in the case notes. The use of a defined sample was positive, and allowed the sample to be grouped according to IQ (borderline, mild, moderate and severe), so that symptom levels could be compared across these groups. Interestingly, of those found to have PTSD all were in the borderline and mild group. Frith et al. (2001) also used case note analysis of a sample of 43 victims and perpetrators of sexual abuse, finding that 2.5% met all the criteria for PTSD, although another five participants showed symptomatology.

These studies offer useful and interesting results, adding to the literature of a sparse field of research. However, an overriding problem appears to be the use of retrospective analysis of case notes to identify symptoms of PTSD. This method is problematic for a number of reasons. Firstly, the findings may be subject to researcher bias. With the exception of Harden and Sahl (1997) where a team derived a diagnosis based on medical records, no details are given about who analysed the notes, and no checks on reliability (such as inter-rater reliability) were carried out. Secondly, it is possible that not all symptoms observed would have been documented in the case notes, and the reporting of symptoms is likely to have varied between clinicians. Thirdly, as some symptoms of PTSD (such as flashbacks and dreams) require verbal expression (Finzi-Dottan et al., 2007), this method may be more sensitive to the detection of PTSD symptoms in those more able to express their internal states. The impact of such bias may have been observed in Harden and Sahl's study (1997). It is conceivable that people with mild intellectual disabilities were found to experience higher rates of PTSD because symptoms would be more likely to be documented for such individuals due to

superior verbal skills, rather than an increased vulnerability. Consequently, this method may lead to unreliable results and an underestimation of PTSD symptoms.

An alternative method used to assess for symptoms of PTSD was to employ measures validated in the general population. For example, one study used the Schedule for Affective Disorders and Schizophrenia for School Age Children (K-SADS-PL; Kaufman et al., 1997) to assess PTSD in children with autism (Mehtar & Mukaddes, 2010). They found that 26% had experienced trauma, while 17.4% of this 26% met the criteria for PTSD. Of those with a trauma history, 12 (66%) were diagnosed with PTSD. Finzi-Dottan et al. (2007) investigated symptoms of PTSD in both an intellectual disability group and a non-intellectual disability group following a terrorist attack. Using the Child Posttraumatic Stress Reaction Index (CPTS-RI; Fredrick, Pynoos, & Nader, 1991), they found that those with intellectual disabilities exhibited more symptoms of PTSD than those without. This finding has been supported in a study that used a clinical interview to assess symptoms (Hayes, 2009), where an intellectual disability group was found to exhibit significantly more PTSD symptoms ($p < .001$) than in a non-intellectual disability group. An IQ cut-off score of below 70 used to define the ID group was a positive step. In another study, Sequeira and Howlin (2003) used an informant measure (The PTSD checklist for child parent report [PCL-C/R; Ford et al., 1999]), and the Psychiatric Assessment Schedule for Adults with Developmental Disability total score (PAS-ADD; Moss et al., 1993) to investigate for symptoms of PTSD. They used a sample of 108 and compared symptoms between those with, and without, a history of been abused. They found that 19 (35%) of the abused group had PTSD, which was significantly more than the control group ($p < .001$). The use of a standardised measure of challenging behaviour identified that those in the abused group were more likely to exhibit challenging behaviour such as self-injury. Although it is

positive that this study recruited a large sample, this was poorly defined with data on the intellectual functioning of the group absent.

The administration of general population measures allows the use of standardised criteria to assess for symptoms of PTSD. However, it is unclear whether these measures can be used with people with intellectual disabilities, with psychometric data on the use of these measures in an intellectually disabled population lacking. Furthermore, in some cases no references or details are provided regarding the clinical interview used to assess for symptoms (i.e., Hayes, 2009). In light of the communication problems often characteristic of individuals with intellectual disabilities, it is important that assessment methods are tailored to meet these communication needs (Mevisson & De Jongh, 2010). Thus the use of un-modified measures that have been validated in a non-intellectual disability population may not be suitable. Presence of symptoms could easily be attributed to other factors such as comprehension difficulties and social desirability (Stenfert-Kroese, 1997). This point is discussed in more detail in Section 1.5.

Three studies have attempted to address this concern either through developing, or modifying an existing PTSD assessment tool (Callaghan, Clare & Murphy, 2003; Mitchell et al., 2006; Wigham et al., 2011b). Mitchell et al. (2006) used an adapted version of the Posttraumatic Diagnostic Scale (PDS; Foa, Cashman, Jaycox & Perry, 1997) along with interpretative phenomenological analysis to assess for PTSD symptoms. Modifications to the PDS concerned unscripted changes to its language when required. The study found similarities between how participants with mild intellectual disabilities responded to trauma and DSM-IV-TR criteria (2000), although participants did also report changes in their physical health as a result of trauma. In addition, participants gave examples of mental images of the trauma, avoidance of reminders, and threat-related appraisals of what may happen in the future. In their study,

Callaghan, et al. (2003) used an informant interview developed for the study to assess PTSD symptoms in a group of individuals with severe and profound intellectual disabilities, reporting that three participants met DSM-IV criteria for PTSD (1994). While the use of measures specifically developed for individuals with an intellectual disability in these two studies is welcomed, neither provides data on the reliability or validity of the measures used. Also, the basis for the changes are not clear or, as in the case of Mitchell et al. (2006), were carried out in an unstructured and ad hoc basis. The absence of psychometric data inhibits the conclusions that can be drawn. It is for this reason that the need for a measure of trauma for people with intellectual disabilities has been widely acknowledged by other researchers (Brackenridge & Morrissey, 2010; Mevissen & De Jongh, 2010; Mevissen, Lievegoed, & De Jongh, 2010; Wigham et al., 2011a, 2011b).

In an effort to address some of these problems Wigham et al. (2011b) developed the Lancaster and Northgate Trauma Scales (LANTS), a measure of trauma psychopathology in people with intellectual disabilities. This is a novel measure which was constructed by generating a pool of 48 items pertaining to possible effects of traumatic experiences on people with intellectual disabilities. This item pool was gathered from three sources: (1) a systematic literature review of the empirical evidence linking life events and trauma effects in people with intellectual disabilities (Wigham et al., 2011a); (2) the general population trauma literature; and (3) the views of service users, carers, advocates and staff. These themes and interviews were then pooled and analysed via content analysis producing both a self-report and informant version.

Using a sample of 99 adults, both the self-report and informant LANTS were found to have good internal consistency ($\alpha = .84$ and $.89$, respectively) and test-retest reliability (self-report: $r = .72$; behavioural changes: $r = .58$; frequency: $r = .57$; and severity: $r = .59$). There was also some evidence for its validity, with relationships

found with other measures of general mental health. This includes a significantly positive correlation found between all sections of the informant LANTS (behavioural changes: $r = .24$; frequency: $r = .32$; severity: $r = .33$) and the PAS-ADD (Moss et al., 1993). While this was not found for the self-report scales ($r = .04$), this version was found to be associated with The Brief Symptom Inventory (BSI) (Derogatis, 1993) ($r = .62$). Both versions were associated with the amount of life events experienced. Specifically, the self report LANTS was found to significantly correlate ($p < .01$) with both the self-report ($r = .45$) and informant versions ($r = .36$) of the Bangor Life Events Schedule for Intellectual Disabilities (BLESID; Hulbert Williams et al., submitted for publication). A highly significant relationship was also found between the informant LANTS and the self report BLESID (behavioural changes: $r = .28$; frequency: $r = .25$; severity: $r = .27$ and informant BLESID (behavioural changes: $r = .64$; frequency: $r = .54$; severity: $r = .62$).

In terms of validity, both versions of the LANTS were found to be associated with an informant measure of trauma in children (Pediatric Emotional Distress Scale [PEDS]; Saylor, Swenson, Reynolds, & Taylor, 1999). Moreover, the self-report version was correlated with a well-established self-report measure of trauma in the general population, the Impact of Events Scale (IES; Horowitz et al., 1979) (self-report: $r = .62$; informant: $r = .58$). However, as neither measure was developed for use in this population, the validity of using such scales is therefore suspect (Esbensen, Rojahn, Aman, & Ruedrich, 2003). This was particularly problematic as the IES which was, as a “gold standard” measure of PTSD symptomatology (Creamer, Bell, & Failla, 2003), the primary method of establishing whether the LANTS was measuring trauma symptomatology. Only a small sample was used, and it had not been modified for use in this population. Although the internal consistency is reported (intrusion scale: $\alpha = .87$; avoidance scale: $\alpha = .71$), no validity data are provided. Consequently it is not known if

this is an appropriate or psychometrically sound measure of trauma symptomatology in people with intellectual disabilities. Therefore, despite some promising early data, it is clear more work is necessary to establish the validity of the LANTS.

1.4.5.6. Summary of review findings. The studies reviewed offer some tentative indications as to the presentation of PTSD in individuals with intellectual disabilities. For example, there is evidence that it is possible to identify symptoms of PTSD in this population. There is also some indication that there may be an increase in challenging behaviour following trauma (Mehtar & Mukaddes, 2010; Mitchell et al., 2006; Sequeira & Howlin, 2003), and one study implicated physical health problems as a reaction to trauma (Mitchell et al., 2006). Moreover, while only two included a comparison between those with and without intellectual disabilities, significantly more symptoms were found in individuals with intellectual disabilities. This supports some of the theoretical implications outlined above. However, further research will be needed to support these results. This is especially true as this review demonstrates the paucity of research in this area. Furthermore, the few studies that are reported are hindered by methodological weaknesses.

Overall, these papers can be criticised on three accounts. Firstly, theoretical implications were made more difficult due to the paucity of theory-driven research. Secondly, the participants are rarely defined in any of the papers. Very few specified inclusion criteria to ensure that all had intellectual disabilities, thus comparison of the studies is difficult. With the exception of one study (Mektar & Mukaddes, 2010), there was also a general assumption that people with intellectual disabilities are a homogeneous group, which is not the case. There is the possibility that PTSD symptoms may vary with intellectual and developmental disabilities of different aetiologies. For example, those with autism spectrum disorders (ASD) may have

specific difficulties accessing social support, a significant risk factor in the development of PTSD (Brewin et al., 2000).

Finally, many of the studies relied on non-standardised or idiosyncratic measures of PTSD, and the assessment used varied considerably between studies. Moreover, reliability and validity data regarding the measures used were also absent and this makes the interpretation of findings, and comparisons between studies problematic. The only study that included a suitable measure was Wigham et al. (2011b), and initial psychometric data on the LANTS appears very encouraging. However, it is important that research is undertaken to establish its validity. Specifically, this should compare the LANTS with a wider range of general mental health measures, and a well-established measure of trauma that is proven to be psychometrically robust for use with this population. This may provide more information on whether the LANTS is identifying symptoms of trauma or just those of general mental health problems. This is important as valid case identification of trauma reactions facilitates distinction from other psychiatric conditions potentially resulting from life events and consequently, trauma-focused interventions (Bisson & Andrew, 2007; Mevissen & de Jongh, 2010; Mevissen et al., 2010; Stenfert-Kroese & Thomas, 2006). The development of a validated measure will not only be useful clinically, but will also have implications for research into the disorder and intellectual disability. It is notable that a more detailed understanding of PTSD in children was greatly facilitated by the development and use of specifically designed assessment measures (Meiser-Steadman, 2002).

1.4.6. Interim summary. In summary, there is evidence to suggest that individuals with intellectual disabilities are more likely to develop mental health problems. One of the causes of this may be an increased rate of adverse life events affecting this population. However, very little is known about how traumatic life events

may impact on those with intellectual disabilities in terms of PTSD symptomatology. Psychological theories of PTSD indicate that, due in part developmental differences, individuals in this population may be more vulnerable to developing PTSD and that there may be variations in the presentation of some PTSD symptoms. Research into this area demonstrates that PTSD can be measured and found in people with intellectual disabilities, and provides some tentative support for some of these theoretical implications. However, these studies have been impeded by the lack of a valid measure of trauma symptomatology. While the LANTS (Wigham et al., 2011b) has been developed to address this clinical and research gap, this tool requires further validation particularly in terms of its utility as a measure of trauma. The next section will consider some of the difficulties faced by researchers and respondents when developing scales for use with people with intellectual disabilities.

1.5. Assessment of Mental Health in Intellectual Disability

1.5.1. Introduction/Section overview. Accurate assessment of mental health is vital for effective intervention and research. In the general population, an important part of this process is the use of standardised screening measures. However, the development and use of such measures for people with intellectual disabilities is complex (Mohr & Costello, 2007). The communication deficits (Campbell & Malone, 1991; Moss, 1999) and memory problems (Clare & Gudjonsson 1993) often characteristic of those in this population mean that individuals may be increasingly susceptible to a number of response biases which can in turn impact on the validity or reliability assessment tools. These include acquiescence (saying yes to a question), suggestibility (saying what the person thinks the interviewer wants to hear) and confabulation (making up a response to fill gaps in memory or uncertainty) (Hatton & Taylor, 2010). Due to this, there has been a lack of suitable assessment measures

designed for use with this population (Einfeld & Tonge, 1996), and the impact of this on mental health provision and identification has already been outlined (Section 1.2.3.). In this section, the difficulties involved when developing measures for this population are discussed, along with how these problems can be remedied. To do this, four factors delineated as important by Finlay and Lyons (2001) are addressed. These are: question content, question phrasing, response format and psychometric properties.

1.5.2. Question Content. How an individual responds to a question is affected by a number of factors pertaining to its content. Firstly, it is widely acknowledged that vocabulary and meaning should be clear and simple, and devoid of technical language (e.g., Lowe & de Paiva, 1988; Prosser & Bromley, 1998). Acquiescence is more common when the question is not understood (Prosser & Bromley, 1998), so use of clear language prevents confusion and improves the reliability of responses. For example, Lindsay and Michie (1988) found higher reliability scores for a version of the Zung Self-Rating Anxiety Scale and Self-Rating Depression Scale (Zung, 1965, 1971) that was modified so the language and concepts were simplified, than when it was administered in its standard form. Moreover, another study found a high degree of convergent validity for various assessments of anxiety and depression that were revised so that they were easily understood and suitable for people with intellectual disabilities (Lindsay, Michie, Baty, Smith, & Miller, 1994).

Similarly, items that include abstract concepts are also likely to be difficult for this population. This includes questions regarding emotions, which have been found to be harder to answer than questions about concrete situations for some people with intellectual disabilities (Booth & Booth, 1994b; Lowe & de Paiva, 1988; Malik, Ashton-Schaeffer, & Kleiber, 1991; McVilly, 1995; Sigelman, Winer, & Schoenrock, 1982). Finlay and Lyons (2001) also outline that question content should also be

relevant. This is an especially pertinent issue for the assessment of psychiatric disorders where there is some debate regarding whether those with intellectual disabilities exhibit the same symptoms of psychopathology as those in the general population (e.g., Aman, 1991; Moss et al., 1993; Moss, Prosser, & Goldberg, 1996; Sovner & Hurley, 1986). This problem in relation to PTSD was outlined above. If symptoms are not experienced by the respondent and therefore not relevant, it is likely that the individual will have difficulty answering that question which in turn increases the chance of response biases. For example, in the development of the PAS-ADD (Moss et al., 1993), although auditory hallucinations were the most easily recorded, few of the participants diagnosed with schizophrenia were able to give a clear enough account of thought disorder to allow scoring. It is for these reasons that care should be exercised when modifying questionnaires developed for the general population by simplifying the language but otherwise leaving the content intact (e.g., Jiranek & Kirby, 1990; Kazdin, Matson, & Senatore, 1983; Lindsay & Michie, 1988; Lindsay et al., 1994; Prout & Schaeffer, 1985; Reynolds & Miller, 1985). However, individuals in PAS-ADD study would be classified as having a severe intellectual disability (mean IQ = 37.6, SD = 9.4), and it may be that those with mild intellectual disabilities could reflect better on their internal emotional experience. Moreover, these problems can be addressed to some extent by including questions that refer to specific activities or events (e.g., Booth & Booth, 1994; Smyley & Elsworth, 1997). Use of follow-up questions to check comprehension are also recommended (Finlay & Lyons, 2001). Therefore, this difficulty should not conclusively prevent the application of diagnostic criteria developed for the general population to people with intellectual disabilities; rather, caution should be taken when doing so.

Questions with sensitive or taboo content may also be liable to bias. Such effects have also been observed in the general population (Barnett, 1998), but this may be

accentuated in people with intellectual disabilities who often use services in which professionals exert a large degree of control over their lives (Finlay & Lyons, 2001). Individuals may therefore be more concerned with the possible consequences of their responses, particularly as service use is characterised by the sharing of information among professionals (Biklen & Moseley, 1988; Prosser & Bromley, 1998). Experimental evidence for this assertion comes from one study which found that, using a sample of individuals with mild intellectual disabilities, significantly more participants reported engagement in risky behaviours (e.g., drug use, carrying weapons) when an anonymous survey was used compared with a confidential interview (M = 23.8% and 13%, respectively) (Pack, Wallander, & Browne, 1998). In order to counter this problem, it is therefore important that measures include explicit statements that information will not be shared with caregivers or service workers (Barnett, 1998). The use of open-ended questions and a conversational style is also recommended to ensure respondents feel at ease (Finlay & Lyons, 2001).

1.5.3. Question Phrasing. The way that questions are phrased can also lead to response biases. For example, the use of complex sentence structures creates difficulties for many people with intellectual disability (Kabzems, 1985; McConkey, Morris, & Purcell, 1999; Prosser & Bromley, 1998; Wyngaarden, 1981). As outlined above (Section 1.5.2), it is therefore important that questions are clear and simple to avoid acquiescence (Finlay & Lyons, 2002). Negatively phrased items (i.e., when “no” or “not” are added to positive phrasings) have been shown experimentally in the general population to be more difficult to respond to than affirmative items (Gough, 1965; Slobin, 1966). It is likely the same will hold for those with intellectual disabilities (Lowe & de Paiva, 1988; Wehmeyer, 1994). Similarly, there is a problem with the use of modifiers - single words or clauses that change the sense of a question. In these

cases, the person may respond to the simple form of the item as if the modifier were not present. For example, Finlay and Lyons (2001) describe how the question, "What things would you like to change about yourself?" might be responded to as if it were, "What things would you like to change?". Because of these difficulties, it is better when developing measures to use affirmative statements such as "I cause trouble/I give up easily/I am slow at work/I make a mess of things I try/I forget things" (Szivos-Bach, 1993).

Another consideration in regards to question phrasing includes subject-object confusion. Reversible items, in which the subject and object can be confused although the sentence still makes sense (e.g., the man chases the dog), have been found to be harder for the general population than non-reversible items (e.g., the man waters the flowers) (Slobin, 1966). This may also be a particular problem for people with intellectual disabilities, particularly if they attend to only a few words per question (Flynn, et al., 1985). Finally, sentences using the passive tense are more difficult for those in the general population than those using the active tense (Slobin, 1966). Thus these phrasings should be avoided during measure development in people with intellectual disabilities.

1.5.4. Response Format. There is some evidence to suggest that the response format used can significantly affect how those with intellectual disabilities respond. Self-report questionnaires often involve yes-no or multiple choice response formats. However, although a matter of some debate, such methods may lead to increased acquiescence in this population. In a series of studies Sigelman and colleagues found that yes-no questions were subject to a systematic acquiescence bias, even when the answer was absurd (e.g., "Does it usually snow in the summer here?") (Sigelman, Budd, Spanhel, & Schoenrock, 1981a, 1981b; Sigelman, Budd, Winer, Schoenrock, & Martin,

1982; Sigelman et al., 1981; Sigelman et al., 1982). However, some have contested the findings of such studies, noting that differences in methodology may account for these results (Rapley & Antaki, 1996). Moreover, acquiescence may not be as common in people with intellectual disabilities as suggested by Sigelman and colleagues (e.g., Booth & Booth, 1994a; Conroy & Bradley, 1985; Matikka & Vesala, 1997; Rapley & Antaki, 1996; Wehmeyer, 1994). Therefore, yes-no response formats may not be that detrimental to the integrity of assessment tools, particularly when used in certain circumstances such as to judge frequency or as screening questions concerning concrete activities (Finlay & Lyons, 2001). Indeed, Lindsay and Michie (1988) found that yes-no questions yielded greater split-half reliability than the standard response format of the Zung Self-Rating Anxiety Scale in a sample of 29 people with mild and moderate intellectual disabilities ($r = .69$).

Multiple-choice formats may lead to difficulties if presented orally (Finlay & Lyons, 2001). This may be particularly complex for people with intellectual disabilities due to the length of the question, the high memory load required of the respondent (Kabzems, 1985; Reynolds, 1979), and the difficulties in fitting the response given into one of the categories (Malik et al., 1991; Zetlin et al., 1985). Furthermore, these formats also often involve judgments of degree or frequency, which can be problematic (Biklen & Moseley, 1988; Booth & Booth, 1994a, 1994b, 1996; Flynn, 1986; Lindsay & Michie, 1988; Malik et al., 1991; Matson & Frame, 1986; Moss et al., 1997; Wyngaarden, 1981). Finlay and Lyons (2001) suggest that this calls into question the use of Likert-type questions to assess degree or frequency, such as in the modified versions of the Zung Self-Rating Depression Scale (ZDS; Zung, 1965) and the Beck Depression Inventory (BDI; Helsel & Matson, 1988; Kazdin et al., 1983; Matson, Kazdin, & Senatore, 1984; Senatore, Matson, & Kazdin, 1985).

However, research shows that adaptations can enable multiple-choice items to

be used in this population. For example, in a recent review of 51 studies that used Likert scales, it was concluded they were a useful way of configuring self-report questionnaires for use with individuals with mild to borderline intellectual disabilities (Hartley & Maclean, 2006). This and other studies have also found that specific changes can lead to increased response rates and decreased bias. For instance, the provision of pictorial or visual aids provides a greater differentiation between options, aids memory and increases understanding (Foxx, Faw, Taylor, Davis, & Fulia, 1993; Hartley & Maclean, 2006; March, 1992; Sigelman & Budd, 1986; Wadsworth & Harper, 1991). Paraphrasing or expanding on the questions is also recommended (Clare & Gudjonsson, 1995; Smith & McCarthy, 1996; Fogarty, Bramston & Cummins, 1997; Kober & Eggleton, 2002), although such prompts should always be scripted to ensure consistency across participants (Antaki, 1998). It is also vital that the scale does not have too many points (Fang et al., 2011), with a number of studies showing that people with intellectual disabilities cannot respond as effectively to a five-point scale (Chachamovich et al., 2009; Fang et al., 2011; Hartley & Maclean, 2006; Levine, 1985). It is for this reason that a three or four-point scale may be more preferable.

1.5.5. Psychometric Properties. Finlay and Lyons (2001) describe how an important obstacle in the development of measures for this population is establishing good psychometric properties. Historically, studies frequently used tools developed for the general population to assess people with intellectual disabilities (Aman, 1991). However, due to the difficulties outlined above, such instruments are unlikely to be appropriate (Gowans & Hulbert, 1983; Schurr, Joiner, & Towne, 1970). Psychometric properties may differ and cannot be assumed (Esbenson et al., 2003). For example, when the Perceived Competence Scale (Harter, 1982) was used with a sample of

children with intellectual disabilities the factor structure changed from four to two (Silon & Harter, 1985).

It is therefore important to develop new, or modify existing, assessment tools, and there has been a proliferation of such measures in recent years (Davis, Atezaz Saeed, & Antonacci, 2008). However, establishing good psychometric properties for these questionnaires continues to be difficult. While some recently developed psychiatric assessments exhibit especially promising psychometric properties (Cuthill, Espie & Cooper, 2003; Mindham & Espie, 2003; Esbensen et al., 2003), many of the statistics reported for new measures mainly refer to reliability rather than to validity (Finlay & Lyons, 2001; Perez-Achiaga, Nelson, & Hassiotis, 2009; Reed, 2007). Because of the difficulties outlined above, it is wrong to assume that reliable questionnaires are also valid. For instance, adequate test-retest reliabilities could just be due to consistencies in response biases (Sigelman et al., 1981).

It is for this reason that Finlay & Lyons (2001) advocate a more rigorous approach to questionnaire development, where both convergent and criterion validity are addressed. However, this process typically relies on comparing the questionnaire under construction to a “gold standard” measure in form of a universally accepted assessment instrument (Rojahn, Rowe, Kasdan, Moore, & van Ingen, 2011). No such gold standard exists in intellectual disability research (Aman, 1991; Sturmey, 2007). Consequently, researchers may need to explore alternative methods of assessing validity. One approach may be to make comparisons with gold standard measures used in the general population. For the reasons outlined above, it would be important that such instruments are adapted so that they are suitable for people with intellectual disabilities, and that efforts are made to ensure they are psychometrically sound. Nevertheless, this approach has a number of advantages. Firstly, it provides a framework based on an existing research and clinical foundation, although it is accepted

that some standardisation may be lost in the process of modifying extant measures (Lindsay & Michie, 1988). Secondly, it would allow an assessment of whether the standard diagnostic criteria are applicable to individuals with intellectual disabilities. It is for this reason that other researchers have recommended the examination of unmodified criteria in this way (Sturmeay, 1995a, 1995b). Hence, in addition to clarifying the utility of assessment tools in people with intellectual disabilities, employing general population gold standard measures would also enable a better understanding of mental health symptoms in this population.

1.5.6. Summary. This review highlighted a number of issues pertaining to the development of assessment instruments for people with intellectual disabilities. Firstly, it is questionable to use measures that have not been adapted for, or examined for use with, those in this population. Factors such as response format and question content and phrasing can all affect how those with intellectual disabilities respond. It is therefore important that scales include adaptations to enable optimum response accuracy. Potential modifications were outlined. Secondly, these problems have contributed to the general lack of validity data on measures developed for people with intellectual disabilities. It is therefore important that this is addressed for newly developed assessment tools. To do this there may be some scope for using well-established measures from the general population, modified so they are suitable for people with this population. This approach would further establish the utility of new scales as a valid assessment of the construct they purport to measure, and potentially provide increased understanding of psychopathology in people with intellectual disabilities.

1.6. Summary of Literature and Rationale for Current Study

There is evidence to show that people with intellectual disabilities experience both a higher rate of mental health symptoms and traumatic life events. Despite this, few research studies have examined the presence of PTSD symptomatology in this population. This is surprising as theoretical accounts of the disorder indicate that people with an intellectual disability may be more vulnerable to developing PTSD symptomatology, and that some symptoms may present differently. The few studies that have investigated this area are marked by methodological issues including the lack of a validated measure. The LANTS (Wigham et al., 2011b) has recently been developed to address this. However, while initial psychometric data are encouraging, more work is necessary to further establish its validity, particularly with regard to its use as a measure of trauma. This reflects a wider problem with assessment tools developed for people with intellectual disabilities. Due to the difficulties associated with this process, many are not well validated. It is important that efforts are made to address this. One approach may be to compare newly developed measures to extant and well-established measures from the general population, modified so that they are suitable for use with people with intellectual disabilities.

This study therefore aims to further examine the psychometric properties of the LANTS. A specific focus was the investigation of validity by comparing it to a modified version of the Impact of Events Scale Revised (IES-R; Weiss & Marmar, 1997), a well-established measure of trauma symptomatology in the general population. In addition to examination of internal and test-retest reliability, a correlational design was used to compare the two trauma scales and measures of anxiety, depression and IQ. The study addresses a number of points indicated as important in this review by: (1) responding to the current need for a psychometrically sound measure of PTSD in this population, as identified by other researchers (Brackenridge & Morrissey, 2010;

Mevissen & De Jongh, 2010; Mevissen, et al., 2010; Wigham et al., 2011a, 2011b) (2) providing independent replication and extension of the findings for the LANTS; (3) contributing to research need for more theoretically based research into this area; and (4) adding to the research base on how symptoms of PTSD manifest in people with an intellectual disability. This has obvious clinical implications for case identification and the understanding of the disorder generally.

1.7. Research Questions and Hypotheses

1. Are the LANTS and the IES-ID reliable measures?

Hypothesis 1: - The IES-ID will show good internal consistency (above $r = .80$; Cicchetti & Sparrow, 1990) for the total score, and the three symptom clusters (intrusion, avoidance, and hyperarousal).

Hypothesis 2: - The LANTS will show high internal consistency across both the self-report and informant versions.

Hypothesis 3: - The IES-ID will show high test-retest reliability (above $ICC = .70$; Cicchetti & Sparrow, 1981) for the total severity score, and the symptom clusters.

Hypothesis 4: - The LANTS will show high test-retest reliability across both the self-report and informant versions.

2. Are the LANTS and the IES-ID and valid measures of trauma symptomatology in adults with mild intellectual disabilities?

Hypothesis 5: - The IES-ID and the LANTS will be positively correlated.

Hypothesis 6: - Scores on the IES-ID and the LANTS will positively correlate with a measure of anxiety.

Hypothesis 7: - Scores on the IES-ID and the LANTS will positively correlate with a measure of depression.

Hypothesis 8: - There will be a positive correlation between number of traumatic events experienced and scores on the LANTS and IES-ID.

3. What is the relationship between PTSD symptoms and IQ?

Hypothesis 9: - There will be a negative correlation between IQ and the IES-ID and the LANTS.

Additional Research Question

4. Are there any differences between those with a high and low level of trauma symptoms on demographic and trauma factors?

2. Method

2.1. Overview

This chapter describes the methodology used in the study. It begins by explaining the study design and provides information on the participants, including the recruitment procedure and the inclusion and exclusion criteria. The measures used, together with an overview of their psychometric properties are then discussed. This is followed by an account of the study procedure, ethical considerations and plans for data analysis.

2.2. Design

The main aim of the study was to explore the psychometric properties of the LANTS, with a specific focus on its convergent validity. To investigate this, a correlational, cross-sectional design using a sample of participants with mild intellectual disabilities was employed. Performance on the LANTS was compared with the IES-ID, a version of the IES-R (Weiss & Marmar, 1997) modified as part of this study so that it was appropriate for use in people with intellectual disabilities. These measures were also compared with assessments of anxiety and depression. Data were collected at two time points (approximately two weeks apart) to allow for measurement of test-retest reliability. In order to address the additional research question, a between-groups approach was utilised. To achieve this, a post-hoc median split was performed using the IES-ID total severity score. This then allowed a comparison between the two groups on a number of demographic factors.

2.3 Participants

2.3.1. Sample Size. Two statistical procedures were planned for the analysis: correlations (to test hypotheses one to nine) and t-tests (additional research question). To calculate the sample size needed to address hypothesis one to nine a procedure based on that described by Kraemer and Thiemann (1987) was adopted whereby the expected correlation coefficient is employed as the effect size. Wigham et al. (2011b) found a correlation coefficient of .64 and .58 between scores on the self-report LANTS and the IES intrusion and avoidance symptom clusters, respectively. Therefore a correlation coefficient of $r = .60$ was adopted as the expected correlation, along with a lower bound confidence interval (CI) of $r = .40$. Using a z score of 1.645 for a one-sided prediction, a sample size of 40 would be needed (lower bound CI $r = .40$).

A sample size calculation was also conducted to ensure that the study would have enough power to find a distinction between a PTSD and non-PTSD group for the additional research question. This was calculated using the computer software G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007). As the only study (to the author's knowledge) to compare demographic factors in this way, it was necessary to use data from the general population. Therefore, based on the means and standard deviations reported for differences in age in McFarlane (1988; PTSD - $M = 39.4$, $SD = 6.5$; Non-PTSD - $M = 32.8$, $SD = 8.5$) a Cohen's d of 0.87 was calculated. Using this as the effect size, an α error probability of .05 and a power of 0.8, a sample size of 36 was estimated. Therefore, the larger sample size of 40 was adopted for the present study.

2.3.2. Sample. Participants were recruited between October 2011 and April 2012. Overall, 52 individuals initially agreed to take part in the study following an approach from their key-worker. However, seven were excluded for not meeting the study inclusion criteria, with four found to have IQ scores below 55 and another three

reporting to have not experienced a traumatic event. A further four participants decided not to take part following a meeting with the researcher and a further discussion of the content of research, while another participant's data were removed after they became upset during the assessment.

Thus, 40 participants were recruited, although informant data could only be collected for 36 individuals and an additional four informants failed to complete the measure at Time 2. The sample consisted of 23 females (57.5%) and 17 males (42.5%), with a mean age of 36.95 (SD = 14.84; range = 20 - 70). Twenty-six participants were recruited from day centres (65%), with ten coming from residential services (25%) and a further four from Learning Disability Teams (10%). In terms of known intellectual disability, seven had Down's syndrome (17.5%), three were diagnosed with cerebral palsy (7.5%) and one had Rett's Syndrome (2.5%). For the remaining 29 (72.5%) individuals an identifiable cause of intellectual disability could not be established (i.e. their key-worker did not know). The majority of participants were white, barring one who classed themselves as mixed race. All participants and key-workers provided informed consent. Demographic details were not collected for the key-worker participants.

2.3.3. Inclusion Criteria. There were four inclusion criteria for this study:

- i) Participants had to be over the age of 18.
- ii) Participants were required to be able to speak English as a first language.
- iii) Participants needed to have a mild intellectual disability. This was defined by a Full Scale IQ (FSIQ) of between 50-75 as measured by the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999).

- iv) Participants were required to have the capacity to provide informed consent to take part in the study.

2.3.4. Exclusion Criteria There were four exclusion criteria:

- i) Participants were excluded if they were actively psychotic. It was expected that the assessment procedure would be too distressing and difficult for such individuals.
- ii) Participants were excluded if they were found to have not experienced a trauma as assessed by the Trauma Information Form (TIF).
- iii) Participants were excluded if they had an impairment that could confound the standardisation or presentation of one of the assessments (e.g., visually impaired, hearing impairment).
- iv) Participants were also excluded if relevant professionals felt that the participant did not fully understand the information given about the study. This was included as an extra safeguard to ensure that individuals who had agreed to take part understood what they were consenting to.

2.3.5. Recruitment Procedure. Participants were recruited from Norfolk Community Learning Disability Teams, and independent residential services and day centres across Norfolk, Cambridgeshire and Suffolk. Details of services were obtained from a contact list created by the local Adult Community Learning Disability Teams. To begin recruitment, managers of the services and teams were contacted directly and informed about the project. Depending on the preference of the individual or service, further information about the study was then provided by a meeting, phone call or email. Once consent for the research to take place had been granted, a presentation of

the research proposal was made to the clinical and staff teams. When a presentation was not possible, this information was disseminated by the team managers. Team members were then asked to identify and contact potential participants who matched the inclusion criteria, and to invite them to participate in the study. Individuals who expressed an interest were then provided with an information sheet by their key-worker (Appendix A). The key-worker was also provided with an information sheet at this stage (Appendix B). If the participant agreed to take part, they were asked to complete a “consent to share information” form (Appendix C) which was then passed on to the researcher. Following this, the researcher contacted or approached the participants in order to arrange a mutually convenient time for the first and second appointment, which took place approximately two weeks later. In the first session, the participant and key-worker were asked to provide their written consent to participate (Appendix D).

2.4. Assessment Measures

The following measures were completed by participants and can be found in Appendix E. A number of considerations were taken into account when the assessments were chosen, and these will be outlined for each measure. However, a key stipulation was that assessments had been developed for, or previously used with, people with intellectual disabilities.

2.4.1. Weschler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999).

The WASI is a short test of intelligence, designed for use with individuals aged from 6–89 years. It consists of four subtests: two on the verbal scale (Vocabulary and Similarities) and two on the performance scale (Block Design and Matrix Reasoning). These subtests examine different facets of intelligence including verbal knowledge,

visual information processing, spatial and nonverbal reasoning and crystallised and fluid intelligence (Horn & Cattell, 1966). The test provides an accurate estimate of intellectual functioning. The reliability ($r = .98$) and validity ($r = .92$) of this measure have been established, as have the normal distribution ($M = 100$; $SD = 15$) (Wechsler, 1999). The WASI also correlates highly with the FSIQ ($r = .92$) on the Wechsler Adult Intelligence Scale (WAIS-III; Wechsler, 1998).

The WASI is administered in a standardised manner by a trained professional to ensure that the comparison with normative data are justified. It takes approximately 20-30 minutes to complete and is therefore well suited to rapid assessment and screening in research settings. It was chosen for this study as it balanced the need for a reliable measure of intellectual disability, required for the inclusion/exclusion criteria, with test demand. Whilst the WASI does not provide a comprehensive analysis of an individual's cognitive functioning, it can be used to screen for intellectual disability (Axelrod, 2002).

2.4.2. Lancaster and Northgate Trauma Scales (LANTS; Wigham et al., 2011). The LANTS includes two sections: the self-report LANTS and the informant LANTS. The self-report section consists of 34 items with a four-point visual rating scale that examines the frequency of symptoms. The informant version is completed by someone who knows the respondent well. It is composed of 47 items and has three subscales: "behavioural changes", "frequency", and "severity". The LANTS also includes screening questions at the start of the questionnaire that aim to assess whether an individual is likely to acquiesce. Here respondents are asked to state their favourite and least favourite food and television programme, and are then asked whether they liked what they said they disliked. If a participant fails these questions, it is proposed that the measure should not be continued.

Both the self-report and informant LANTS have been found to have good

internal reliability ($r = 0.84$ and $r = 0.89$ respectively) and test-retest reliability (self-report: $r = 0.72$; behavioural changes: $r = 0.58$; frequency: $r = 0.57$; and severity, $r = 0.59$). These correlations were all found to be highly significant ($p < .01$). However, limited convergence was found between the two versions of the LANTS, with the self-report section only correlating with the behavioural changes subscale of the informant LANTS ($r = .204$, $p < .005$). In terms of validity, the LANTS has been found to converge with a number of measures of general mental health. This includes a significantly positive correlation found between the PAS-ADD (Moss et al., 1993) and all sections of the informant LANTS, although, no such association was found with the self-report scale ($r = 0.04$). However, the self-report LANTS was found to be correlated with the Positive Symptom Total on the Brief Symptom Inventory (BSI; Derogatis, 1993 [$r = 0.62$]), while the informant version was not.

A relationship was found between the LANTS and life events. Specifically, the LANTS was found to significantly correlate with both the self-report and informant versions of the BLESID (Hulbert Williams et al., submitted for publication). Those in a high life events group scored significantly higher on the LANTS self-report than a low life events group ($p < .001$). This was also found for all three subscales of the informant LANTS ($p < .001$). Moreover, the informant LANTS was highly correlated with both the “acting out” and “internalizing” subscales on the Pediatric Emotional Distress Scale (PEDS; Saylor et al., 1999), an informant measure of trauma in children. The informant LANTS was also found to be associated with problem behaviours, with a positive correlation found with the Behaviour Problems Inventory (BPI-01; Rojahn, Matson, Lott, Esbensen, & Smalls, 2001). However, this correlation was not found using the self-report LANTS.

2.4.3. Impact of Event Scale - Intellectual Disabilities (IES-ID). To address the aims of the present study, a measure was required to assess the convergent validity of the LANTS. However, as described in the Introduction, there is no other known measure of PTSD validated for use in this population. A measure was therefore developed for the present study by modifying an existing measure of PTSD in the general population. This approach was adopted as it has the advantage of providing a framework based on an existing research and clinical foundation, although it is accepted that some standardisation may be lost in the process of modifying extant measures (Lindsay & Michie, 1988). The measure chosen was the IES-R (Weiss & Marmar, 1997). Designed as a screening tool, the IES-R is a self-report questionnaire that assesses the subjective distress caused by traumatic events. It includes 22 items measured using a five-point scale (scored 0-4), and was adapted from the IES (Horowitz et al., 1979).

The IES-R was chosen for a number of reasons. Firstly, it corresponds directly to the DSM-IV-TR (2000) symptoms of PTSD comprising three subscales: avoidance, intrusion and hyperarousal. This allows for a comparison with existing knowledge about PTSD in the general population. The IES-R is also relatively short and easy to complete, and has been used successfully with this population previously (Wigham et al., 2011). Finally, it has well-established psychometric properties. Internal consistency has been found to be high ($r = .87$ for intrusion, $r = .84$ for avoidance and $r = .90$ for hyperarousal), as has test-retest reliability ($r = .57 - .94$ for intrusion, $r = .51$ to $.89$ for avoidance, and $r = .59$ to $.92$ for hyperarousal) (Weiss & Marmar, 1997). It has also been found to relate well to other measures of PTSD such as the PDS (Foa et al., 1993), and is considered to be the most widely used measure of traumatic stress (Creamer et al., 2003). A clinical cut-off of a total score of 33 has been suggested (Creamer et al. 2003).

2.4.3.1. Modifications to the IES-R. The IES-R was modified for the present study so that it could be used with individuals with intellectual disabilities, thus creating the IES-ID. As part of this process, professionals in an Adult Community Learning Disability Team were consulted (two clinical psychologists, a speech and language therapist, and an assistant psychologist). This influenced some of the adaptations made, particularly in terms of the response format of the IES-ID. Generally, the extent of modification was limited to item organisation, format and wording, in order to attempt to preserve the validity of the original questionnaire in relation to the spread of symptoms to be elicited. Initial changes included the adaptation of the IES-R from a self-report measure to a semi-structured interview which included an interviewer “script”. This approach was taken to ensure some standardisation in terms of the instructions given and to enable – as far as is possible – that the participant felt at ease. The use of a semi-structured interview has been found to be advantageous when working with people with intellectual disabilities, especially in relation to the assessment of life events (Nadarajah, Roy, Harris, & Corbett, 1995).

The language of the IES-R was also changed to ensure that items were comprehensible and appropriate for individuals with intellectual disabilities. Guidance was followed to ensure that the question structure was simple and avoided the use of technical vocabulary (Finlay & Lyons, 2001). Additionally, the text was made larger to increase the accessibility of the measure (Stenfert-Kroese, 1997). The order of the items was also changed. This was so that some “easier” questions (mainly those that asked directly about physical symptoms) would appear at the start and end of the questionnaire. This approach was adopted to help reduce the possibility that the respondent would become disheartened, or leave the assessment thinking they had not performed well. To examine the effectiveness of these changes, the readability of the

new and changed items was assessed using the Flesch formula (1948, cited in Ley, 1977). This formula is calculated through Microsoft Word and takes the average sentence length and number of syllables per 100 words into account to provide an index of “reading ease”, ranging from 0 (very difficult) to 100 (very easy). This demonstrated the reading ease of the IES-ID to be “very easy” (90%).

In terms of specific changes to question content, where possible the items were changed so that they referred to the specific event the respondent had previously identified. For example, the item, “I was aware that I still had a lot of feelings about it, but I didn’t deal with them” was changed to, “Have you been upset because of [event identified] but have not asked for help?”. This approach was taken as it can be difficult for people with intellectual disabilities to understand contextual implications and therefore questions that refer to specific events are more helpful (Finlay & Lyons, 2001; Hurley, Levitas, Lucavalier & Pary, 2007). Moreover, it is recommended that when asking about sensitive content it is more beneficial to ask about specifics rather than generalities (Finlay & Lyons, 2001). For most questions, further examples are also provided for certain items to aid the interviewer if the respondent does not understand the question. Allowing interviewers to paraphrase or expand upon question items or response alternatives is related to an increased response rate and decreased response bias among adolescents and adults with intellectual disabilities (Fogarty et al. 1997; Kober & Eggleton, 2002). Furthermore, the use of scripted probes has been recommended as a method to aid and check comprehension, reducing the chances of acquiescence or socially desirable answers (Finlay & Lyons, 2001).

The response format was also modified. The rating scale was changed from five to four, as five point rating scales have been found to be confusing for people with an intellectual disability (Chachamovich et al., 2009; Fang et al., 2011). Other changes included that respondents were asked whether they have experienced each symptom

(answering Yes or No), prior to rating the distress this caused. This approach was adopted to simplify the assessment, alleviate confusion and also ensure that the load was reduced for those who had not experienced those symptoms. If a reply of “no” was given, the item received a mark of zero and the researcher moved onto the next question. If the respondent had experienced the symptom, they were then asked “how much has that upset or scared you?”. Possible responses and associated scores were then: “a little bit” (for which they would score 1), “in the middle” (2) or “a lot” (3). This was augmented with a visual scale which improves the reliability and validity when using Likert scales with people with mild learning disabilities (Hartley & Maclean, 2006). A comparison of the items of the IES-R and the IES-ID can be found in Appendix F. The first three participants involved in the study were used to pilot the IES-ID and examine whether additional adaptations were necessary. This procedure revealed no significant difficulties or concerns, so further modifications were not made.

2.4.4. Trauma Information Form (TIF). In order to address the aims of the study, it was necessary to find out the traumatic experiences participants had previously been exposed to. It was important that this information was obtained via self-report for two reasons: firstly, the IES-ID necessitates the identification of a specific event and it was assumed that a participant would be better able to answer questions about an event they had identified themselves; secondly, research has shown that informants may not understand or be aware of the significance of an individual’s traumatic experiences (Nadarajah, Roy, Harris, & Corbett, 1995; Razza & Tomoloso, 2007). Another consideration was that, in keeping with the ethos of the proposed study, it was important that any assessment used should be designed for use with people with intellectual disabilities. To the author’s knowledge, no such assessment exists and this has been recognised by other researchers (Newman, Christopher, & Berry, 2000). The BLESID

(Hulbert Williams et al., submitted for publication) was discounted as certain events that are typically seen as traumatic, such as sexual assault, are only assessed in the informant version of this questionnaire. Therefore it was deemed necessary to develop a self-report assessment tool. The content and development of the devised measure will now be outlined.

As with the IES-ID, the TIF is a semi-structured interview and much of the guidance considered in the development of the IES-ID was adopted when developing this questionnaire. For example, the language was made simple and non-technical, with large text. Following an introduction, respondents were asked whether they have experienced or witnessed 13 traumatic events. These were chosen to cover those outlined in DSM-IV-TR (2000) and include: violent personal assault (e.g. sexual assault, physical attack), torture, natural disasters, severe automobile accidents or other accident (i.e., fire or explosion), being diagnosed with a life-threatening illness, being in a war zone, and the unexpected death of a family member or a close friend. Bullying was also included as it has been found to be both common and linked to the development of PTSD in this population (Young et al., 2012). Each event was accompanied by a pictorial representation of the event to aid comprehension, and the respondent asked to tick the event or events that they had experienced. There then followed a section for participants to describe if anything which had made them “very upset or very frightened?” to probe for other experiences that was not included on the original list. The respondent was then asked to pick the one event that had upset them the most. Questions on the IES-ID were then asked in reference to the selected event.

Following this, further questions were asked to assess for the symptoms outlined in the DSM-IV-TR. Firstly, participants were asked when the event occurred, and this was assessed using significant events as reference points (Finlay & Lyons, 2001; Hulbert Williams et al., submitted for publication). Hence this questionnaire asked

whether the event happened: since the participant was informed about meeting the researcher; between last Christmas and the time of the assessment; before last Christmas; when the participant was a child or teenager. This essentially established whether the event happened recently, less than a year ago, more than a year ago, or when they were a child. It was accepted that this was not exact and may change for each individual. Thus the interviewer may have needed to adapt these items or probe for more information when necessary. Finally, the respondent was asked to state whether the symptoms identified using the IES-ID had impacted on aspects of their daily living. Thus, it was outlined that this item should be asked following administration of the IES-ID. A number of domains were selected for their relevance to people with an intellectual disability including: work / day centre, relationships with friends and family, going out and having fun, school / college work, and general happiness with life.

2.4.5. Glasgow Depression Scale (GDS-LD; Cuthill et al., 2003). This scale was devised to assess for symptoms of depression in people with intellectual disabilities. It comprises a 20-item assisted self-report scale and is accompanied by a Carer Supplement (GDS-CS). The items were largely drawn from the diagnostic criteria outlined in the DC-LD (RCP, 2001). It has been found to have high internal consistency ($r = .90$) and test-retest reliability ($r = .97$). The GDS-CS was also found to be reliable (internal consistency: $r = 0.98$; test-retest: $r = .88$), and correlated highly with the GDS-LD ($r = .93$). Its construct validity is also high, correlating highly with the Beck Depression Inventory (BDI-II; $r = .88$), and successfully differentiated between depressed and non-depressed groups ascertained by scores on the Mini-PAS-ADD (Prosser et al. 1996) and clinical judgment. A cut-off score (13) yielded 96% sensitivity and 90% specificity. It was selected for use in this study as it is quick to administer (5-10 minutes), and in a recent review was recommended as the most promising self-report

measure of depression in people with intellectual disabilities (Hermans & Evenhuis, 2010).

2.4.6. Glasgow Anxiety Scale (GAS-ID; Mindham & Espie, 2003). This scale was devised to assess for symptoms of anxiety in people with intellectual disabilities. It has been found to have had excellent test–retest reliability ($r = .95$) and internal consistency ($\alpha = .95$). It was also reasonably correlated with the BAI ($r = .75$) and was found to distinguish between anxious and non-anxious participants. The correlation between the physiological subscale of the GAS-ID and changes in pulse rate was moderately significant ($r = .52$). It takes 5-10 minutes to administer. This was also selected due to its good psychometric properties, and because it is quick to administer. Furthermore, in a recent review of measures of anxiety in people with intellectual disabilities, it was considered the most promising (Hermans, van der Pas, & Evenhuis, 2011).

2.5. Assessment Procedure

At the start of each assessment the researcher went through the information sheet with the participant to ensure it was understood. Participants were given the opportunity to ask any questions and were informed that they could request a break or stop the assessment session at any time. The first assessment then proceeded in the following order for all participants: demographic information sheet (10mins) (Appendix G), WASI (20mins), TIF (15mins), LANTS (10-20mins) and IES-ID (10mins). As described above, the final section of the TIF was administered following the IES-ID. In total this session lasted approximately 75 minutes. In the second session, the LANTS, IES-ID, GDS-LD and GAS-ID (10 mins each) were administered. This took

approximately 30 minutes. At the end of both assessment sessions participants underwent a mood induction exercise which took 2 minutes (see Section 2.6.2 for more details). If the individual had asked to attend the assessment session alone, an alternative time was arranged with the key-worker for them to complete the GDS-CS and the informant version of the LANTS. If the key-worker was unable to attend, the questionnaires were posted or left at their workplace. If the key-worker was present at the assessment, they were asked to complete these forms either during or following the session.

2.6. Ethical Considerations

2.6.1. Ethical Approval. Before undertaking the research, a favourable ethical opinion was obtained from the Hertfordshire Research Ethics Committee (Appendix H). Research governance approval was obtained from the NHS Norfolk Research Governance Committee (Appendix F). Ethical considerations were reviewed in accordance with the guidelines for minimum standards of ethical approval in psychological research (BPS, 2004). The main ethical issues to consider were potential distress, consent, coercion, confidentiality and feedback.

2.6.2. Potential Distress. The study was designed to minimise the risk of distress to any participant. Participants were provided with a rationale for testing at the beginning of the tasks, and efforts were made to highlight that the questionnaires were not part of a “test”. Participants were told before the data were collected and at each session that there were no right or wrong answers and that the researcher would not inform others of their answers. They were also informed during the administration of the WASI that the questions increased in difficulty and that they were designed so that

everyone would reach questions they could not answer. It was also made clear in the information sheet and the first assessment session that the study involved asking about traumatic life events.

If distress did occur as a result of the assessment, it was planned that the assessment would be stopped immediately. The researcher would then use their clinical skills to establish why the participant had become distressed and explore this with the participant to help relieve their distress. The participant would be offered the opportunity for this information to be shared with a known staff member. This was a decision for the participant, unless it was judged to be something that could cause harm to the participant or another person, in which case the researcher would discuss this with an appropriate person. Participants were also given the name and contact details of the researcher (and the research supervisors) from the information sheet so that they could discuss any distress or withdraw from the assessment. One participant became upset during the assessment, and these procedures were used accordingly and successfully. As an additional precaution to help ensure that individuals did not leave the assessment sessions upset, participants were asked to undertake a brief mood induction exercise at the end of the assessment. This involved asking participants to visualise an event that made or makes them feel happy for 1-2 minutes (Bryan & Bryan, 1991a). This task has been used extensively and successfully with individuals with intellectual disabilities (Yasutake & Bryan, 1995).

If ongoing abuse was disclosed as part of the study, it was planned that this would be discussed with the individual's key-worker or team, as appropriate. The boundaries of confidentiality were clearly stated on the information sheet and consent form to clarify the process if such a disclosure occurred. This would also be explained at the beginning of the first assessment session.

2.6.3. Consent and Coercion. Managers and staff within each service were provided with information sheets explaining the study. They also had the opportunity to ask questions at any point during the study. It was made explicit that participation was optional and that a decision not to consent would not affect the service, staff members or the service users in any way. It was also made clear that services could withdraw from the study at any time without giving a reason.

Teams were asked to identify as potential participants only those able to consent according to the Mental Capacity Act (2005). Moreover, the participant was initially approached by their key-worker in order to protect against the possibility of acquiescence. This also meant that the individual would be able to discuss any concerns they had regarding the research with someone they know well and with whom they were comfortable. Potential participants were also provided with an information sheet and consent form, both of which were read to them by their key-worker. Participants were provided with at least 24 hours between provision of the information sheet and the request for consent to allow full consideration of whether to take part in the project. However, some participants wished to give consent immediately after the study was explained to them. This was also permitted in such cases. Participants were invited to bring their key-worker or an advocate to the assessment sessions. The information sheet and consent forms were designed to be accessible for people with a mild learning disability. However, to overcome any limitations with literacy skills, the information sheet and consent forms were read through and explained individually to each potential participant at the beginning of the first assessment session. Finally, it was made clear that participation was voluntary and each participant was made aware via the consent form of his or her right to withdraw. They were assured that deciding to withdraw would not affect their future treatment in any way.

2.6.4. Confidentiality. No information was stored in such a way that made it personally identifiable. Names and addresses of participants were stored separately from the data generated throughout the study in a locked cabinet at the University of East Anglia. Only the researcher and academic supervisor had access to this information, and it was destroyed after a period of 12 months. Participants were referred to by a code in the data set and on the questionnaires. All data were immediately transferred to a statistical software spreadsheet and saved on a password-protected computer owned by the researcher. The academic supervisors had access to this data and it was stored on their personal or work computer, where it was also password protected. The raw data were kept in a locked drawer at the researcher's residence during the data collection period under the requirements of the Data Protection Act (1998). The raw data will be destroyed after a period of five years. The author kept a record of the coding system and this was stored securely and separately to the data collected. Participants and services were made aware of the confidentiality measures.

2.6.5. Feedback. It was important that all services involved in the research were provided with appropriate feedback about the results of the study. Feedback sessions have been offered to all services who took part and managers, staff members and service users will be invited to attend.

2.7. Plan for Data Analysis

All analyses were carried out using PASW Statistics (SPSS) Version 18 (2010; SPSS Inc., Chicago, Illinois, United States of America). Data gathered from the questionnaires were entered into PASW and visually inspected for missing or inaccurate data entries. This process identified missing data for some individual items on the

informant LANTS. To ensure the use of all data available to the study, participants were removed from the analysis when data were missing pertaining to that specific analysis. However, for the calculation of internal consistency, data for the entire participant were removed. Because the missing data were found for one participant at Time 1, and seven participants at Time 2 the sample size for this measure for the analysis of internal consistency was therefore reduced (Time 1: N=35; Time 2: N = 25).

The variables were then tested for how well they met the assumptions for parametric analyses. To do this, descriptive statistics were conducted to examine the distribution of the raw data and identify any missing data. Box-plots were used to check for outliers. The raw data distribution was visually inspected using histograms. Skewness and kurtosis statistics were converted to z-scores. Given the small sample size obtained, values above 1.96 were considered to be significantly different to 0 ($p < .05$; Field, 2009) and therefore non-normally distributed. The Shapiro Wilk (S-W) test was used to check the raw data for normality.

Mid-outliers (1 SD away from the mean) were identified on Verbal IQ, IES-ID and informant LANTS. However, further analysis trimming the upper and lower 5% of the data demonstrated that their removal would not significantly affect the mean (Pallant, 2011). Therefore they were kept in the data set unchanged. Just one of the variables used in this study was normally distributed (GAS-ID), and only three variables could be successfully transformed to a normal distribution (self-report LANTS, GDS-LD, GDS-CS). The two main variables, IES-ID and self-report LANTS were non-normal, although it was possible to transform the self-report LANTS. The majority of the analyses conducted to test the hypotheses were therefore carried out using non-parametric analyses. The following analytical methods were employed to test each hypothesis.

2.7.1. Hypothesis 1, 2, 3, and 4. Cronbach's alpha coefficient (Cronbach, 1951) was calculated for both the total severity score and the three symptom clusters to examine the internal consistency of the IES-ID and the LANTS. The significance of the correlations were also examined. Intraclass correlations were used to assess the correlation between Time 1 and Time 2 for both measures to address hypotheses three and four.

2.7.2. Hypothesis 5, 6, 7, and 8. Spearman's correlation coefficient (one tailed) was used to assess the correlation between scores on the IES-ID and scores on the LANTS, with scores on the GDS-LD and the GAS-ID to address hypothesis six and seven. To test hypothesis five, the correlation between the total scores on both the self-report and informant LANTS and total severity score on the IES-ID were examined, as were the relationship between the IES-ID subscales and the LANTS.

2.7.3. Hypothesis 9. As above, Spearman's correlation coefficient (one tailed) was used to calculate the correlation between Verbal, Performance and Full Scale IQ and total scores on the IES-ID and the LANTS.

2.7.4. Additional Research Question. A median split procedure was carried out using the total score on the IES-ID to delineate a high PTSD group and a low PTSD group. If the data were normally distributed, group differences were compared using independent t-tests or Mann-Whitney U tests (Mann & Whitney, 1947) for continuous data, and Pearson Chi-square analysis and Fisher exact tests (when frequency was below five) were used for categorical data (Field, 2005). Factors that were compared included demographics such as age, gender, type of service recruited from and type of

disability, and trauma information such as multiple versus single experiences of trauma, type of trauma selected and time since the trauma occurred.

3. Results

3.1. Overview

This section will outline the results of the study. The chapter begins by describing the study participants. This is followed by an outline of the descriptive data on the measures used in the study. Each hypothesis is then tested, prior to a summary of the main research findings.

3.2. Descriptive Data

3.2.1. Trauma information. Table 3 provides frequency data for the trauma information reported by the sample. The majority of the group had encountered between one and three traumatic experiences, with a mean number of experiences found to be 2.60 (SD = 1.49). However, 10% of the sample had experienced five traumas. The most commonly reported traumatic experience was sudden bereavement. Bullying was the second most prevalent. A number of these experiences - such as natural disaster, torture, and being held hostage - had not been encountered by this sample. Only one participant selected an event that was not on the TIF as their chosen trauma, describing a time when they were followed home on an evening. However, within the range of prescribed traumas, participants reported a broad range of experiences that may not be typically considered a "Criterion A" event. For example, one participant described epileptic seizures as traumatic as they had once being told in passing that it could result in their death.

In terms of the time the trauma occurred, it is notable that only one individual reported an experience that had taken place in the last month, with the majority occurring over a year ago. Unfortunately data on the impact of trauma symptomatology on the participant' daily living were not collected for many participants. This was a

consequence of researcher error whereby because this item was administered at a separate time point from the rest of the TIF, it was often mistakenly overlooked. These data are therefore not reported or analysed here.

Table 3. Trauma frequency data for the sample.

Number of traumas experienced	N
1	10
2	12
3	11
4	1
5	4
6	1
7	1
Selected Trauma	
Car/plane crash	5
Fire explosion	0
Natural disaster	0
Physical assault	3
Assault with weapon	1
Bullied	11
Sexual assault	1
Rape	2
War Zone	0
Prison	0
Hostage	0
Torture	0
Serious illness	3
Sudden bereavement	13
Other	1
Time trauma occurred	
Child	15
Over a year ago	22
Last year	2
In last few weeks	1

3.2.2. Main measures. Table 4 presents descriptive data for each measure used in the study. This table indicates the sample to be low in depressive symptomatology. The group mean was similar to the mean found for the non-depressed intellectual

disability group in the original standardisation study ($M = 9.26$, $S.D = 2.94$; Cuthill et al., 2003), and only 10% of the present sample was found to score above the cut-off for depression applied for this measure (15). However, the sample was high in anxiety symptoms. A threshold of 13 on this scale is recommended for the possible identification of an anxiety disorder (Mindham & Espie, 2003), and the majority of the sample scored above this cut off (57.5%). A median Full Scale IQ score of 56 suggested that on average the sample was in the lower range of mild intellectual disability. It is important to note that, using the LANTS screening questions, none of the sample was found to be liable to acquiescence.

Table 4. Descriptive data for measures used in the study.

Measure	Time 1		Time 2	
	Mean (SD)	Range	Mean (SD)	Range
LANTS	57.72 (14.57)	37-94	57.58 (15.62)	35-96
IES-TS	15.85 (12.68)	0-43	16.32 (13.42)	0-56
IES-I	5.77 (6.31)	0-22	5.65 (6.62)	0-22
IES-A	5.83 (4.13)	0-17	5.35 (4.59)	0-19
IES-H	4.73 (4.22)	0-15	5.05 (4.47)	0-16
Behav	11.69 (10.48) ^a	0-43	8.75 (8.69) ^b	0-38
Freq	20.92 (19.07) ^a	0-76	16.31 (18.68) ^b	0-75
Sev	10.31 (9.00) ^a	0-36	8.28 (10.16) ^b	0-49
GDS-LD	8.60 (6.05)	0-27	-	-
GDS-CS	4.00 (3.33)	0-12	-	-
GAS-ID	15.43 (8.13)	1-36	-	-
FSIQ	60.68 (6.13)	52-75	-	-
VIQ	59.43 (6.31)	55-76	-	-
PIQ	67.40 (7.63)	56-83	-	-

Note. N=40 unless otherwise stated. Behav = behavioural changes; Freq = frequency; Sev = severity; FSIQ = Full Scale IQ; VIQ = Verbal IQ; PIQ = Performance IQ.

^a N=36; ^b N=32

3.3. Research Questions and Hypotheses

3.3.1. Research question one. This research question concerned the reliability of the two scales. Reliability coefficients are shown in Table 5.

3.3.1.1. Hypotheses one and two. It was predicted that the LANTS and IES-ID (including the subscales) would show high levels of internal consistency. This was

calculated using Cronbach's alpha which measures the extent to which an item is correlated with the remaining items of a particular subscale. Results were interpreted according to the recommendations of Cicchetti and Sparrow (1990) who outline criteria for excellent ($\alpha = > .90$), good ($\alpha = .80 - .89$), fair ($\alpha = .70 - .79$) and unacceptable ($\alpha = < .70$) levels of internal consistency. As can be seen in Table 5, these hypotheses were largely supported, with the LANTS self-report and informant versions showing high internal consistency at Time 1 and 2. In particular the behavioural changes (Time 1), frequency and severity (Time 2) subscales demonstrated excellent internal consistency.

The IES-ID total score also demonstrated excellent internal consistency at both time points with ($\alpha > .90$). However, scores for the IES subscales were less convincing, demonstrating only fair internal consistency across the two time points. Indeed, internal consistency for the avoidance subscale fell to unacceptable levels at Time 2, which suggests that the included items are not measuring the same construct. Moreover, analysis demonstrated that the inclusion of certain items actually reduces the reliability of two of the subscales. For example, if question 14 on the intrusion subscale was deleted, alpha would increase to .85. Internal consistency of the avoidance symptom cluster at time two would also increase to .72 if item seven was not included. This suggests that these items do not relate well with other items on the subscale. They may therefore have limited utility.

3.3.1.2. Hypotheses two and three. High test-retest reliability for the scales was predicted. Participants completed the measures on two occasions approximately two weeks apart. Mean test-retest response latency was 15.25 days (SD = 6.6 days). Results are shown in Table 5. On the whole, this hypothesis was supported. Use of interclass correlation coefficients identified that nearly all scales scored above ICC = .8, which is considered excellent (Cicchetti & Sparrow, 1981), with the self-report LANTS found to

have the highest consistency over time (ICC = .92). Only the avoidance subscale of the IES-ID scored less than .8 (ICC = .61), although this is still considered good (Cicchetti & Sparrow, 1981).

Table 5. Internal consistency and test-retest reliability for trauma scales.

Scale	Alpha		Retest
	Time 1	Time 2	
LANTS	.89	.89	.92
IES – TS	.90	.91	.86
IES – I	.79	.88	.85
IES - A	.72	.61	.65
IES – H	.74	.77	.82
Behav	.90 ^a	.86 ^b	.81 ^c
Freq	.89 ^a	.90 ^b	.80 ^c
Sev	.88 ^a	.92 ^b	.84 ^c

Note. N = 40 unless other wise stated
^a N=35; ^b N=25; ^c N=32

3.3.2. Research question two. This question concerned the validity of the LANTS and the IES-ID. This was assessed using one-tailed tests of correlation. Correlation coefficients between all variables can be found in Table 6. Results were interpreted according to criteria set by Hinkle, Wiersma, and Jurs (2002).

3.3.2.1. Hypothesis five. It was predicted that the IES-ID and the LANTS would be positively correlated. The results supported this part of the hypothesis, with a positive and highly significant correlation found between the self-report LANTS and the IES-ID total score, ($r = .760, p < .01$), hyperarousal ($r = .710, p < .01$), and intrusion ($r = .741, p < .01$) subscales. A moderate correlation was found between the self-report LANTS and the IES-ID avoidance subscale ($r = .626, p < .01$), although this was still

highly significant. However, the level of association between the IES-ID subscales and the informant LANTS informant were mixed. A significant but low magnitude positive correlation was observed between the IES-ID intrusion scale and all three sections of the informant LANTS (behavioural changes: $r = .384, p < .05$; frequency: $r = .409, p < .01$; severity: $r = .374, p < .05$), and between IES-ID total score and the frequency and severity subscales (frequency: $r = .367, p < .05$; severity: $r = .317, p < .05$). However, only a minimal but significant correlation was found between avoidance and the frequency subscale ($r = .287, p < .05$), although the hyperarousal symptoms cluster was not significantly associated with any section of the informant LANTS. Therefore the results only offer partial support for this hypothesis.

3.3.2.2. Hypothesis six. A positive correlation between the LANTS, IES-ID and a measure of anxiety was predicted. This hypothesis was mostly supported. A low but significant positive correlation was found between the GAS-ID and the IES-ID hyperarousal ($r = .396, p < .05$) and intrusion subscales ($r = .372, p < .05$). However, the relationship between avoidance and anxiety was not significant. The association between the self-report LANTS and the GAS-ID was a moderate one and highly significant ($r = .613, p < .01$), and was higher than that found for the IES-ID total score ($r = .368, p < .05$). The three subscales of the informant version were also correlated to a low degree with the anxiety measure (behavioural changes: $r = .388, p < .01$; frequency: $r = .394, p < .01$; severity: $r = .382, p < .05$).

3.3.2.3. Hypothesis seven. It was predicted that there would be a high correlation between the trauma scales and a measure of depression. This was well supported, with the LANTS self-report observed to have a high correlation with the GDS-LD ($r = .723, p < .01$), and a low magnitude but significant association with the

GDS-CS ($r = .356, p < .05$). Of the informant LANTS, all three subscales showed a moderate but highly significant relationship with the GDS-CS (behavioural changes: $r = .583, p < .01$; frequency: $r = .583, p < .01$; severity: $r = .586, p < .05$); although, only the frequency scale was significantly correlated with the GDS-LD ($r = .300, p < .05$). A moderate but highly significant positive relationship was also found between all subscales of the IES-ID and the GDS-LD (intrusion: $r = .525, p < .01$; hyperarousal: $r = .644, p < .01$; avoidance: $r = .499, p < .01$). However, only the intrusion scale correlated with the GDS-CS, with a low but significant positive correlation observed.

3.3.2.4. Hypothesis eight. Hypothesis eight made the predication that there would be a positive correlation between the number of traumatic events and the trauma scales. This was not supported for the LANTS, with both the informant and self-report versions showing little or no correlation with traumatic events ($r = .220, p > .05$). However, the IES total score ($r = .346, p < .05$) and hyperarousal ($r = .396, p < .01$) and avoidance subscales ($r = .314, p < .05$) all showed low but significant positive correlations with the number of traumatic events. This was not found for the intrusion scale. Therefore this hypothesis was only partially supported.

3.3.3. Research question three. It was predicted that a negative correlation would be found between IQ and both trauma scales. Correlation coefficients can be found in Table 6. On the whole this hypothesis was not supported. Despite evidence of a negative correlation between many of these variables, this was often low and did not reach significance. However, an exception was a negative correlation between the IES-ID avoidance subscale and the performance and full scale IQ ($r = -.325, p < .05$; $r = -.329, p < .05$).

Table 6. Correlations (one tailed) between traumas scales and measures of depression, anxiety and general intellectual functioning.

	No. ts	IES-I	IES-H	IES-A	IES-TS	LANTS	Behav	Freq	Sev	GAS	GDS	GDS- CS	FSIQ	VIQ	PIQ
No. ts	-	.221	.396**	.314*	.346*	.220	.162	.277	.230	.128	.293*	.058	.267*	.199	.220
IES-I	-	-	.715**	.669**	.865**	.741**	.384*	.409**	.374*	.372*	.525**	.283*	-.123	-.086	-.140
IES-H	-	-	-	.739**	.897**	.710**	.159	.270	.235	.396*	.644**	.134	-.201	-.169	-.169
IES-A	-	-	-	-	.895**	.626**	.213	.287*	.273	.296	.499**	.140	-.329*	-.146	-.325*
IES-TS	-	-	-	-	-	.760**	.278	.367*	.317*	.368*	.600**	.184	-.246	-.117	-.245
LANTS	-	-	-	-	-	-	.406**	.356*	.343*	.613**	.723**	.356*	-.096	-.078	-.087
Behav	-	-	-	-	-	-	-	.916**	.943**	.388**	.132	.583**	-.035	.140	-.101
Freq	-	-	-	-	-	-	-	-	.956**	.394**	.300*	.583**	-.118	-.012	-.128
Sev	-	-	-	-	-	-	-	-	-	.382*	.242	.586**	-.094	.004	-.115
GAS	-	-	-	-	-	-	-	-	-	-	.632**	.380*	.003	.012	.035
GDS	-	-	-	-	-	-	-	-	-	-	-	.387**	-0.74	-.185	-.023
GDS-CS	-	-	-	-	-	-	-	-	-	-	-	-	.074	.074	-.046
FSIQ	-	-	-	-	-	-	-	-	-	-	-	-	-	.659**	.955**
VIQ	-	-	-	-	-	-	-	-	-	-	-	-	-	-	.473**
PIQ	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Note. ts = Traumas; * correlation is significant at the .05 level; ** correlation is significant at the .01 level

3.3.4. Additional research question. This exploratory question aimed to investigate whether there were any differences between those in a high and low trauma group on demographic and trauma factors. A median split procedure was used to divide the group into high and low PTSD groups according to total severity scores on the IES-ID. Results are found in Table 7.

3.3.4.1. Demographic factors. No differences between the groups were found for gender ($\chi^2(df = 1, N = 40) = 0.351, p = .554$), mean age ($t(38) = .980, p = .333$), service ($\chi^2(df = 2, N = 40) = .301, p = .860$), ethnicity ($\chi^2(df = 1, N = 40) = 0.928, p = .335$), or intellectual disability of known aetiology ($\chi^2(df = 4, N = 40) = 3.528, p = .474$).

3.3.4.2. Trauma factors. There were no group differences in terms of the traumas selected by participants, nor for the time the trauma occurred ($\chi^2(df = 8, N = 40) = 7.295, p = .414$; $\chi^2(df = 3, N = 40) = 2.233, p = .526$). However, those in the high PTSD group had experienced significantly more traumatic experiences ($U=104.00, z = -2.67, p < .05, r = 0.42$) and, as expected, scored significantly higher on the LANTS self-report and informant versions ($p = < .001$ and $p = < .05$, respectively) and all IES-ID subscales ($p = < .001$). A comparison was also made between those with multiple traumas and those with a single experience. No difference was found between the groups on this factor ($\chi^2(df = 1, N = 40) = 2.707, p = .148$).

Table 7. Characteristics of high and low PTSD groups.

	Low	High
Gender (N, F:M)	10:9	13:8
Age (Yr, mean, (SD))	39.37 (17.35)	34.76 (12.16)
Service (N)		
Day centre	13	13
Residential	4	6
LD team	2	2
Known Intellectual Disability (N)		
Downs syndrome	5	2
Cerebral Palsy	1	2
Epilepsy	0	1
Rett's syndrome	1	0
None/Not known	14	14
No. Traumas (N, mean, (SD))	1.89 (.809)	3.24 (1.70)
Trauma Selected (N)		
Car/plane crash	3	2
Physical Assault	1	2
Assault with a weapon	1	0
Bullied	4	7
Sexual Assault	0	1
Serious Illness	0	2
Bereavement	8	5
Other	0	1
Time Since Trauma (N)		
Last month	0	1
Last Year	1	1
Over a year ago	9	13
When Child	9	6

3.4. Summary of Results

Analyses indicated that the trauma scales were reliable measures, with both demonstrating high internal consistency and test-retest reliability. However, the IES-ID subscales, particularly avoidance, were found to be less reliable. The LANTS and the IES-ID were also positively associated with measures of anxiety and depression and more highly associated with each other, therefore demonstrating good validity. However, unlike the IES-ID, no correlation was found between the LANTS and number of traumatic events. There was also a minimal relationship between IQ and the

measures of trauma. Finally, no significant differences were found between a high and a low group PTSD group on a range of demographic factors and some trauma information. However, those in the high PTSD group were found to have experienced a significantly higher number of traumatic events than the low PTSD group.

4. Discussion

4.1. Study Aims and Chapter Overview

Research has indicated that people with intellectual disabilities are more likely to experience events that could be considered traumatic. However, research into the impact of such events on those in this population is lacking, particularly in terms of the presence of PTSD symptomatology. Those studies that have examined this area have been hindered by the absence of a validated measure. The aim of this study was to further investigate the psychometric properties of the LANTS (Wigham et al., 2011b). A particular focus of this research was to investigate its validity by comparing it to a modified version of a well-established measure of trauma used in the general population. The study also aimed to explore the impact of IQ and demographic factors on PTSD symptomatology in people with intellectual disabilities.

This chapter begins by exploring the results of the study in detail by examining them with regards to the study hypotheses. Secondly, the strengths and limitations of the study are discussed in relation to the study recruitment, sample, procedure, design, extent of trauma and measures. Thirdly, the implications of the findings are considered, including their theoretical and clinical implications. Fourthly, suggestions for future research are outlined. This section ends with overall conclusions.

4.2. Summary of Results

4.2.1. Research question one: Are the LANTS and the IES-ID reliable measures?

Hypothesis 1: - The IES-ID will show good internal consistency (above $r = .80$; Cicchetti & Sparrow, 1990) for the total score, and the three symptom clusters

(intrusion, avoidance, and hyperarousal).

Hypothesis 2: - The LANTS will show high internal consistency across both the self-report and informant versions.

Hypothesis 3: - The IES-ID will show high test-retest reliability (above ICC = .70; Cicchetti & Sparrow, 1981) for the total severity score, and the symptom clusters.

Hypothesis 4: - The LANTS will show high test-retest reliability across both the self-report and informant versions.

Results showed that for the IES-ID total score and both versions of the LANTS these hypotheses were supported, with all of these scales showing excellent internal consistency and test-retest reliability. These findings corroborate previous evidence on the reliability of the LANTS (Wigham et al. 2011b). Furthermore, the reliability of the IES-ID total score was comparable to that found for the IES-R (Creamer et al., 2003; Weiss & Marmar, 1997). The results also demonstrate an absence of redundancy in these measures, with internal consistency of both scales falling between .80 and .90 (Streiner & Norman, 2003).

Hypotheses regarding the subscales of the IES-ID were generally less well supported. While test-retest reliability of the intrusion and hyperarousal subscales were excellent, alphas across the two time points for these symptom clusters were only found to be fair (intrusion: $\alpha = .79 - .88$; hyperarousal: $\alpha = .74 - .77$). In particular the avoidance subscale only exhibited unacceptable to fair levels of internal consistency ($\alpha = .61 - .72$). Likewise, in contrast to other scales the test-retest reliability of this subscale was only found to be good (ICC = .65). The avoidance subscale has been shown to have good reliability when used in the general population (Beck et al., 2008;

Creamer et al., 2003). There may therefore be particular difficulties with the utility of this subscale when used by people with intellectual disabilities, especially as similar levels of internal consistency were found for this symptom cluster in the original LANTS study ($\alpha = .71$; Wigham et al., 2011b). This will be discussed further in Section 4.4.1. Finally, it was found that the internal consistency of the avoidance scale and intrusion scales could be improved if certain questions were deleted. This indicates that these items may not relate well with others on the same subscale, and points to further difficulties with the reliability of the IES-ID subscales. There may be a number of reasons for this finding. It is possible that such items tap symptoms that are not relevant for this population, or that they are more complex or difficult to answer. These explanations will be explored in more detail in Sections 4.4.1 and 4.4.4.

4.2.2. Research question two: Are the LANTS and the IES-ID valid measures of trauma symptomatology in adults with mild intellectual disabilities?

Hypothesis 5: - The IES-ID and the LANTS will be positively correlated.

Hypothesis 6: - Scores on the IES-ID and the LANTS will positively correlate with a measure of anxiety.

Hypothesis 7: - Scores on the IES-ID and the LANTS will positively correlate with a measure of depression.

Hypothesis 8: - There will be a positive correlation between number of traumatic events experienced and scores on the LANTS and IES-ID.

The hypotheses for this question were predominantly supported with highly significant correlations found between both trauma scales and measures of depression

and anxiety. This endorses previous findings on the LANTS (Wigham et al., 2011b), and demonstrates that both scales have some level of validity. However, the extent of these associations differed between measures, with the self-report LANTS found to be more highly correlated with depression and anxiety ($r = .73$ and $r = .61$) than the IES-ID total score ($r = .60$ and $r = .37$). In terms of comparing the two measures, it is not clear whether this points to the increased utility of one scale over the other. On the one hand, the finding that the LANTS is more associated with other mental health measures could suggest that it is measuring a less distinct construct than the IES-ID. Thus, it may have decreased clinical utility as a trauma screen. However, it is known that PTSD has high co-morbidity with other disorders (Yule, Williams, & Joseph, 1999). Therefore, the IES-ID could be considered to have lower validity as it was not as related to other measures as was the LANTS, particularly anxiety. These issues will be discussed further in Section 4.4.1. The informant LANTS was only found to correlate with the GDS-CS, although a highly significant positive correlation was found between the informant LANTS and the measure of anxiety.

The LANTS and the IES-ID were found to be highly associated, supporting the previous relationship found between the LANTS and the IES-R (Wigham et al., 2011). A high correlation was also found between the IES-ID subscales and the LANTS, although this was less strong for the avoidance scale ($r = .63$). That the two trauma scales were more highly related with each other than with measures of anxiety and depression could suggest they were measuring a similar and separable construct. However, the relationship between the LANTS and depression was only marginally lower than that found between the LANTS and the IES-ID. Therefore, whether the LANTS is mainly tapping PTSD symptomatology may require further investigation (see Section 4.4.1). Only some subscales of the IES-ID and informant LANTS were

associated. Intrusion correlated with all three sections, while total score and avoidance symptom clusters were related to two (frequency and severity) and one (frequency) informant LANTS subscales, respectively. No relationship was found between the informant LANTS and hyperarousal.

The final hypothesis for this question, that the trauma scales would be correlated with the number of traumas experienced, was only supported for the IES-ID. This to some extent contradicts research that shows links between PTSD symptoms and psychiatric problems and life events (Hastings et al., 2004; Tsakanikos et al., 2007, Martorell & Tsakanikos, 2008; Wigham, et al., 2011a; Wigham, 2011b). This is also potentially problematic for the LANTS as a measure of trauma, considering that PTSD is defined to result from a traumatic event (APA, 2000). The implications of this finding will be discussed in further detail elsewhere in this chapter (see Section 4.4.1).

4.2.3. Research question three: What is the relationship between PTSD symptoms and IQ?

Hypothesis 9: - There will be a negative correlation between IQ and the IES-ID and the LANTS.

This hypothesis was not supported. The only exception was a small magnitude correlation between the avoidance subscale and Full Scale and Verbal IQ. These findings contrast with a wealth of research showing a link between general intellectual functioning and PTSD symptomatology (Macklin et al., 1998; McNally & Shin, 1995; Vasterling et al., 1997). However, to the author's knowledge this is the first study to investigate this relationship using individuals with intellectual disabilities. These results

may therefore suggest differences between people with intellectual disabilities and those in the general population who have a low IQ in terms of the development of PTSD symptomatology. This will be discussed in more detail in Section 4.4.4. The findings also indicate high scores on the trauma scales were not related to poorer verbal comprehension, therefore adding to the support and validity for the use of these scales. However, caution should be taken interpreting results due to lack of range in the IQ scores of participants where 65% were found to have an FSIQ of 55 or 57. This will be discussed in more detail in the strengths and weaknesses section below (Section 4.3).

4.2.4. Additional Research Question: Are there any differences between those with a high and low level of trauma symptoms on demographic and trauma factors?

No difference was found between the groups on demographic factors such as age, gender and ethnicity. This contrasts with research that shows that such variables are significant risk factors for PTSD (Brewin et al., 2000). The present study also found no difference with some factors specific to intellectual disability that had not been investigated before, such as the service participants were recruited from or known intellectual disability. The only difference between the groups on trauma factors, other than on the main trauma scales, was the number of traumas experienced which was found to be higher in the high PTSD group. This supports research from the general population which has shown that PTSD symptomatology increases with prior experiences of trauma (Andrews et al., 2000; Brewin et al., 2000). However, there was no difference between the groups in terms of the time since trauma and the type of trauma that was selected. However, this should be considered with some caution,

considering the small numbers in each group. This will be discussed further in the strengths and weaknesses section (4.3).

4.3. Strengths and Weaknesses

This section outlines the strengths and weaknesses of the study that may impact on the reliability and validity of the data. It covers the recruitment strategy, the characteristics of the eventual sample, the study design, the extent of trauma, and the reliability, validity and development of the measures used in the study.

4.3.1. Recruitment. A strength of the present study was that the recruitment strategy was designed to reduce the possibility that participants would experience distress as a consequence of taking part. It is likely that such safeguards facilitated the consent of the services and participants despite the sensitive nature of the study, thus allowing research into this data sparse area. However, whilst necessary, it is possible that these procedures introduced some bias at the different stages of recruitment. For instance, for the first step in recruitment, services and localities were approached. It is conceivable that there were differences between those services that did and did not consent that impacted on the types of participants involved in the study. Due to the requirement that key-workers were involved in the study, those that did take part could have been better resourced. Furthermore, services that consented may have been more open to new ideas and research, or more modern and flexible in their approach. This could have meant that they would be more proactive or open when addressing issues of mental health. Consequently, participants involved in this study may have been more socially able or empowered, or had been supported better in managing previous

experiences of trauma. The sample may therefore not be representative of the wider intellectual disability population.

Further bias may have been introduced at the second and third stages of recruitment. Following the agreement of the service, key-workers were asked to identify and approach suitable participants. While the inclusion and exclusion specifications were provided to guide this, it appeared that key-workers would often “screen” out certain service-users prior to making an approach based on criteria not specified for the study. For example, it was fairly typical for key-workers to state that they would not ask a particular individual as they were likely to refuse either because they would not want to meet a stranger, or because they would not want to talk about a particular event. The third phase of recruitment also led to a self-selecting sample, with identified participants asked if they would like to find out more about the study. Both the second and third stages may have ensured that the sample was biased towards those who were more emotionally robust or had reacted better to a previous trauma. Furthermore, those with more severe or recent traumas could have been missed, and it is noteworthy that only one participant involved in the study had experienced a trauma recently. Finally, due to these recruitment procedures, the sample may have consisted of more socially able individuals. Social support is an important protective factor in PTSD (Brewin et al., 2000). Therefore, this could mean that those participants who took part may have been better able to manage any previous traumatic experience. All of these issues, in addition to the fact that this was a convenience sample, could impact on the generalisability of the results to the wider intellectual disability population.

4.3.2. Sample. In contrast to previous research in this area, it is positive that the sample was clearly defined in terms of IQ level. Thus it is known that those involved in this study had an intellectual disability, and so the results can be better extrapolated to the wider intellectual disability population. Moreover, participants were recruited from a variety of services across three counties, and so included participants from a variety of different backgrounds and living arrangements. The study also included a number of participants from a community sample, therefore allowing the validation of the LANTS on a different group as suggested in the original study (Wigham et al., 2011b).

However, the sample size of the present study could be considered small. It is typically recommended the researchers recruit over 100 participants for psychometric research (Stevens, 1996). This then allows improved generalisability of the results and detailed examination of the measure in terms of specificity or sensitivity or factor structure analysis. It is therefore important that future studies aim to extend the findings of the present study using a larger sample. Nonetheless, a sample size of over 30 is deemed acceptable according to some recent reviews (Hermans & Evenhais, 2010; Hermans et al., 2011). Moreover, the study yielded medium to large effect sizes for the relationship between the trauma scales and other measures (Cohen, 1988, 1992). Therefore, as an early study into an under-researched area, the sample size is judged to be appropriate to review the first two research questions. However, it is probable that the small sample size affected the ability of the study to address the additional research question. A post hoc power calculation using G*Power (Faul et al., 2007) adopting age for the effect size indicated that the study did not have sufficient power to detect group differences (.43). Therefore, although this exploratory research question was not the main focus of this study, findings should be taken with some caution.

Another possible problem with the sample was that it was skewed towards those

in the lower end of the mild intellectual disability range, with only a few participants scoring between 60 and 70 on the IQ measure. While the lower IQ is probably illustrative of those individuals who use day services, it is likely that the sample does not represent the broader intellectual disability population. It also means that only tentative conclusions can be drawn from those analyses that used IQ. For example, the absence of a relationship between IQ and trauma could be explained by the lack of variation in IQ scores, with 65% of the sample having a FSIQ of 59 or below. It is important that future studies use alternative recruitment strategies to identify participants with higher IQs (but within the intellectual disability range). On a related point, another potential difficulty with the sample was that an IQ upper limit of 75 was included to help with recruitment. Intellectual disability is typically defined as an IQ below 70 (BPS, 2000) and so it is possible therefore the sample may not be generalisable to the general intellectual disability population. However, a bandwidth of 5 is typically applied to the boundaries (Carr et al., 2007). Furthermore, only three participants had an IQ over 70, and the IQ distribution was positively skewed. Therefore, this is unlikely to have considerably affected the results.

There are some other difficulties with the sample definition. For example, data on psychiatric diagnosis were not collected. It is recommended that this be carried out when examining the psychometric properties as a way to judge whether the studied population is representative (Hermans & Evenhuis, 2010). Moreover, the sample average was above the clinical cut-off suggested for the GAS-ID (Mindham & Espie, 2003). This may indicate that the sample was more highly anxious and therefore not typical of other people with intellectual disabilities. Finally, only limited details on the participants' intellectual disability was available. While it was collected in some cases, key-workers often did not know the individual diagnoses. Alongside this, it would have

been more beneficial in terms of demographics to have distinguished between an individual not having a known cause of intellectual disability, or it not being known. In addition to further defining the sample, these details would have further extended the conclusions with in regard to the additional research question.

4.3.3. Procedure. A strength of the study is that LANTS includes questions to screen out those who are susceptible to acquiescence, so the likelihood of this factor impacting on the results was reduced. This bolsters the conclusions that can be drawn from the study. However, the assessments were conducted on a face-to-face basis and research from the general population suggests that interview methods of data collection typically lead to less self-disclosure than paper and pencil approaches (Bradburn & Sudman, 1979; Tourangeau & Smith, 1996). Furthermore, assessment of sensitive content has been found to be more prone to error and bias (Barnett, 1998), and it is possible that in such situations individuals with intellectual disabilities may be concerned about the possible consequences of their responses (Biklen & Moseley, 1988; Prosser & Bromley, 1998). These factors may have affected the accuracy of the data in the present study as it may have led to the under-reporting of events or symptoms (Finlay & Lyons, 2001). This may have been further confounded by a lack of familiarity with the researcher. Another weakness of this study was that in some cases the key-worker would complete the informant LANTS after or during the assessment session with the participant. It is therefore possible that their responses were contaminated or influenced by the participants' responses on the self-report LANTS. This should be considered when interpreting the results.

Another possible weakness is that the assessments were conducted using a semi-structured format. Although the researcher took the utmost care to keep to the script and

wording of the questions, there was the occasional need to rephrase questions in an unscripted manner to facilitate understanding. This may have led to some inconsistency in questioning between participants which could have influenced the reliability of some results. It is likely that due to the communication problems often characteristic of this population that these procedural issues will be an ongoing difficulty with research in this area. Nevertheless, this should be considered when extrapolating the results to other populations. It is also worth noting that mean test-retest latency was probably slightly high ($M = 15.25$ days, $SD = 6.6$). The aim for Time 2 to take place 14 days following Time 1 was not always achieved for a variety of reasons. This included holidays, illness, miscommunications or key-worker time demands. However, considering the high test-retest reliability found in this study, it is unlikely that problem adversely affected results. All the same, this may be a consideration when comparing these findings with other studies. Finally, because of researcher error, data on the effect of symptoms on daily living were not collected. While this was a subsidiary element of the study, and its omission therefore did not affect the main findings of the study, it would have clearly been beneficial to have collected this information.

4.3.4. Design. To the author's knowledge this study is the first to specifically explore the relationship between DSM specified traumas and trauma symptomatology in an intellectual disability population. Previous research in this area, as outlined in the Introduction (see Section 1.3.6.), is typically characterised by exploratory or retrospective methodologies with little theoretical basis. In contrast, this study began with a comprehensive and critical review of previous research, before outlining a reasoned and justified proposal. These are relative strengths of the design. The use of a correlational design, and the development of the TIF, facilitated the recruitment of a

wide variety of participants in this difficult research area and the collection of trauma information in a sensitive and non-intrusive manner.

However, the use of a cross-sectional design, although useful for the purposes of this study, are weak in relation to causation. As such, associations between traumatic experiences and the trauma scales do not provide evidence of causal links. There could be another factor that has led, for instance, to the higher numbers of traumas in those who scored higher on the IES-ID. Another weakness of the design is the absence of a non-intellectual disability comparison group. The present study found that IQ was not related to PTSD symptomatology. In the context of a wealth of previous research showing the opposite in the general population, a comparison group would have better established whether this finding is specific to people with intellectual disabilities, or was due to a weakness in the study methodology. Moreover, it would have been useful to have compared the number of symptoms endorsed between a group of individuals with an intellectual disability and a group without. This would have allowed investigation into any differences in terms of symptom endorsement and psychometric properties, thus potentially strengthening the conclusions of the study and investigating the usefulness of the two measures. The use of a comparison group would have also enabled examination of some of the theoretical predictions outlined in the Introduction. It is important to note that this approach was not adopted in this study as the main aim was to establish the psychometric properties of the trauma scales. Moreover, to have collected data from another group in addition to 80 sessions for the intellectual disability group was considered to be beyond the scope of the present study.

Another potential weakness of the study is the absence of a measure of receptive language such as the British Picture Vocabulary Scale-II (BPVS-II; Dunn, Dunn, Whetton & Burley, 1997). It could be asserted that without such a scale, it cannot be

established whether high scores on the trauma scales are due to poor receptive language. The inclusion of the BPVS would have therefore provided an additional method of validating the trauma measures. However, this was not included to ensure that testing time was kept to a minimum and to avoid overloading participants. Furthermore, research has found a strong positive correlation between IQ and receptive language (Sams, Collins & Reynolds, 2006). As high trauma symptomatology was not related to IQ in the present study, it is therefore probable that poor receptive language does not account for scores on the LANTS and IES-ID. Nevertheless, the relationship between receptive language ability and the two trauma scales should be a focus for future research. This would also enable the specification of the receptive language necessary for completion of both measures, something that has been recommended for assessment tools developed for people with intellectual disabilities (Finlay & Lyons, 2001).

A median split was used to allocate participants to high and low trauma groups according to scores on the IES-ID. This procedure turns a continuous variable into a categorical variable by finding the median of the continuous variable and labelling values above this as high and below as low. This procedure has some limitations. Firstly, when a continuous variable is split into a categorical variable every value within each category is considered to be equal even when there may be considerable variation between category scores. This could be addressed by only using the tails of the data to dichotomise the variable, for example the top third and bottom third of the scores to minimise variability of scores. However, this is not recommended for studies with small sample sizes, such as that in this study, as the resultant reduction in sample size would lead to an unacceptable loss of statistical power. Secondly, this approach relies upon the median values of the sample to classify participants, making it susceptible to between-sample differences. For example, a value of 12 on the IES-ID in one study may result in

the participant being assigned to the high trauma group. However, it is possible that in a different study with a different sample the same participant with the same score may be placed in the low trauma group. This therefore makes generalisations about the population of a specific sample difficult since they may differ from sample to sample. Despite these criticisms median splits are routinely performed within research. Moreover, due to the small sample recruited, and the lack of research in this area, this was the preferred method to examine this exploratory question.

4.3.5. Extent of trauma. An important element of this study was the assessment of how traumatic events impact on those with intellectual disabilities. A strength of the study was the use of a prescribed list of traumas taken from DSM-IV-TR (2000). These experiences are therefore well researched and their impact on PTSD symptoms in the general population is well-established. The study also developed a self-report method of assessing this trauma that was suitable for individuals with intellectual disabilities, and related the impact of the identified trauma to a specific measure. To the author's knowledge this has not been done before, and therefore the project collected some important information on the subjective impact of certain events on this population.

There are, however, some potential difficulties in the way that the trauma information was collected and assessed that may affect the conclusions that can be extrapolated from the results. According to the DSM-IV-TR (2000), a trauma is an event that involves actual or threatened death or serious injury, or a threat to the physical integrity of self or others. The individual's response also needs to have involved intense fear, helplessness or horror. This definition clearly relies on an individual's subjective response to an event and so the same event may not be traumatic for everyone (Yule et al., 1999). However, participants' judgment of the traumatic

experiences was not fully assessed as part of the present study. Rather, the TIF required that participants describe an event that was “very frightening or upsetting”. This question may be broad and subject to interpretation, and opens up the possibility that some events identified were not in fact traumatic. The study would have therefore benefited from a method of assessing the subjective impact of the event in relation to the DSM-IV-TR criteria.

The implication of this omission is probably best exemplified by considering the inclusion of bullying on the TIF. This experience was the only addition to the original list taken from the DSM-IV-TR. It was included for two reasons. Firstly, as an early study into an under-researched area it was considered important to assess for a wide range of experiences. Secondly there is evidence of the high incidence of bullying in this population and this experience has also been linked to trauma symptomatology (Young et al., 2012). However, bullying would not typically be seen as a traumatic event, and is a term that encompasses a broad array of experiences. For example, it may vary from name-calling to sustained verbal and physical abuse, and it is unlikely that all experiences of bullying would fit the criteria for a traumatic experience set out in the DSM. It is conceivable, of course, that name-calling could lead to trauma symptomatology for some. However, without a method for further assessing the subjective impact of the experience it is difficult to ascertain if individual participants actually considered this a trauma or rather it was seen as an event from the past with which they have since come to terms. Due to this, the events assessed as part of this study can only really be described as potentially traumatic experiences. Future research should endeavour to assess in detail what types of events lead to PTSD symptomatology in this population.

4.3.6. Measures. A general strength of the measures included in this study was that they all have good psychometric properties and are suitable for use with people with intellectual disabilities. The strengths and weaknesses of each individual measure will now be discussed.

4.3.6.1. *The Wechsler Abbreviated Scale of Intelligence (WASI)*. The WASI was used as it is more suitable for research and is a recognised standardised measure. It was chosen over the Wechsler Adult Intelligence Scale (WAIS; Wechsler, 1997) as it is a shorter measure to administer and it was recognised that with the number of other tasks included in the study the WAIS would place too many demands on participants. However, the WASI is not standardised for the intellectual disability population and a floor effect operates. For example many people score 55 for the Verbal subscale and this is the lowest possible score, however there is a wide range in the raw scores for these participants. In order to obtain a T score of 20 for the Vocabulary subtests participants can score between 0 and 27. This then led to the skewed IQ distribution, and impacts on the conclusion that can be taken from the results.

4.3.6.2. *Lancaster and Northgate Trauma Scales (LANTS)*. The LANTS and its psychometric properties will be discussed in more detail in Section 4.4.1. However, it is important to note that a number of key-workers expressed concern regarding the usability of the informant LANTS. This related particularly to the response format which was described as confusing and unclear. For example, on this measure respondents are expected to leave the behavioural changes subscale blank if the behaviour has started in the last month (S. Wigham, personal communication, April 4,

2012). However, this is not stated in the instructions so informants often needed to request assistance from the researcher. It is recognised that this represents an anecdotal observation, and does not appear to have adversely affected the results. Nevertheless, this suggests that it is important that this section is administered with the individual, and could therefore demonstrate that the informant LANTS has limited utility in research in some circumstances.

4.3.6.3. Impact of Event Scale - Intellectual Disabilities (IES-ID). This section will consider the adaptation and use of the IES-ID. The psychometric properties of this measure will be discussed elsewhere (Section 4.4.1). To an extent the modifications made to the IES-ID appear to have been successful. The language is simple and easy to read, as evidenced by the high readability scores described in the Method. As outlined in the Method section, the adaptation also followed guidance from research on how to develop measures for this population.

However, there are elements that may be problematic for this measure. For example, it does not include reverse-scored items, and has a yes-no response format. Such methods have been advised against as they can lead to an increase in response bias (Finlay & Lyons, 2001; Sigelman, et al., 1981a, 1981b; Sigelman, et al., 1982). However, this format was adopted to simplify the questions. It appeared less confusing to split the question and ask whether the symptom was present prior to asking how distressing it was, than to have asked something like “How distressing has [insert symptom] been?”. The yes-no format is more acceptable when used for screening questions in this manner (Finlay & Lyons, 2001). Furthermore the IES-ID was always preceded by the acquiescence screening question included on the LANTS. Therefore, the impact of this approach may have been reduced in the present study. However, these

concerns should be considered when interpreting the results or using the IES-ID in future studies or clinical setting. There is also caution needed as the IES-ID is a modified version of a measure developed for the general population (Finlay & Lyons, 2001). Therefore the factor structure may differ when used with those with intellectual disabilities, and similar reliability and validity cannot be assumed (Riggen & Ulrich, 1993; Szivos-Bach, 1993). Moreover, the symptoms included in the IES-ID may not all be relevant as discussed in the Introduction. Therefore future research will be needed to confirm the IES-ID as an appropriate measure of this construct.

4.3.6.4. Glasgow scales. These measures were chosen as they were developed specifically for an intellectual disability population and recent reviews had recommended them as screening tools (Hermans & Evenhauis, 2010; Hermans et al., 2011). Although both require further independent validation, this section concludes that the measure is most likely adequate for the purposes of the current study.

4.4. Implications

4.4.1. LANTS and IES-ID. On the whole, both scales were found to have promising psychometric properties. The LANTS and the IES-ID total severity score all demonstrated good to excellent internal consistency in addition to excellent consistency over time. The two measures also correlated more highly with each other than with measures of other psychiatric disorders, although only marginally (see below). This could suggest that they are both able to measure a set of symptoms distinguishable from other mental health problems. Both assessment tools therefore appear to have good utility as measures of trauma symptomatology in people with intellectual disabilities.

This demonstrates the potential for both scales to be employed in clinical and research settings. However, the results of the study also highlight some important areas of consideration for both measures. Specifically, this concerns the validity of the LANTS, and difficulties with the IES-ID subscales. These issues will now be addressed in turn.

There is evidence to suggest difficulty with the utility of the LANTS as a measure of trauma symptomatology. For example, the association found between the LANTS and the IES-ID was only marginally larger than that observed with the GDS-LD ($r = .76$ to $r = .72$, respectively). In contrast a lower magnitude correlation was found between the IES-ID and depression ($r = .60$). It could be argued therefore that the LANTS is as much a measure of depressive symptomatology as it is trauma symptomatology. However, depression and PTSD have high co-morbidity (North, Smith & Spitznagel, 1994; Loughrey, Bell, Kee, Roddy & Curran, 1988) and elevated correlations are often found between established measures of both disorders. For example, the PDS and the IES-R have a correlation of .79 with the BDI (Foa et al., 1997). Moreover, the level of relationship between the LANTS and GDS-LD was not so high as to suggest they were tapping the same construct. Hence, on balance the level of association found in this study does not appear to be damaging to the integrity of the LANTS as an assessment tool.

One finding that could be problematic, however, is that unlike the IES-ID, the LANTS was not associated with the number of traumatic experiences. Considering that PTSD symptomatology increases in line with previous trauma exposure (Brewin et al., 2000), this calls into question the validity of the LANTS. This is also notable as in the development study a moderate but highly significant correlation was found between the LANTS and life events (Wigham et al., 2011b). The reasons for the discrepancy between the present study and Wigham et al (2011b) are unclear. One explanation may

be that by assessing trauma symptomatology in reference to a specific event, the IES-ID is clearly tied to traumatic events and it may follow that this measure would therefore be more closely associated than the LANTS with previous experiences of trauma.

Alternatively, the lack of relationship could be because some events identified would not be classified as traumatic (as discussed in Section 4.3.5). In such circumstances a lower level of association with a trauma measure may be expected. In any case, it is clear that this finding warrants further investigation and should be considered during future use of the LANTS.

The subscales of the IES-ID were found to be less reliable and were found to have lower internal consistency than the total score and the LANTS ($\alpha = .72 - .79$ at Time 1). However, the hyperarousal and intrusion subscales both exhibited excellent consistency over time. Furthermore, a Cronbach's alpha coefficient of .7 or above is probably acceptable for basic research purposes (Nunnally, 1978). Therefore it is likely that these two subscales retain some usefulness. In contrast, however, there appears to be specific problems with the reliability of the avoidance subscale that merits further discussion. This symptom cluster only exhibited between unacceptable and fair levels of internal consistency ($\alpha = .61 - .72$) and lower test-retest reliability than the other subscales. There are a number of possible reasons for this finding. It is of note that there was a small but significant correlation between Full Scale IQ and this subscale. This may indicate that items on this scale were more confusing or relied on a higher level of receptive language, which could have led to response inconsistencies. Moreover, it is possible that the low reliability may be because people with intellectual disabilities have less opportunity to engage in avoidance behaviours as they have less control over their lives. Alongside this, those with intellectual disabilities may have more difficulty employing cognitive strategies such as thought suppression or rumination.

An alternative explanation may come from previous research which found problems with the IES-R factor structure (Creamer et al., 2003). Specifically, the finding that certain items on the avoidance subscale also load onto the intrusion scale (Creamer et al., 2003). Although others have contested this observation (Beck et al., 2008), the findings in the present study may represent a further example of this. For instance, it is conceivable that the lower internal consistency of avoidance may be because some items would be better placed on another subscale. It has been identified that when extant measures are modified for use with people with intellectual disabilities the same factor structure cannot be assumed (Riggen & Ulrich, 1993; Szivos-Bach, 1993). There is therefore a clear need to for further investigation of the factor structure of the IES-ID.

One other consideration concerns how the IES-ID compares to the original IES, and whether the modified version represents an improvement in terms of its use with people with intellectual disabilities. The IES-ID was designed to be more user-friendly for use with this population and therefore it should be superior to the IES when used with this population. Despite this, evidence on whether this is the case is somewhat lacking due to the paucity of data on both scales. The present study does indicate that the IES-ID is a valid measure with people with intellectual disabilities. As validity has not been examined for the IES, this could indicate increased utility of the IES-ID. However, there is clearly a need for further research into the psychometric properties of both the IES and IES-ID. It would also be beneficial to collect qualitative data on the ease of use of both scales in order to establish whether the IES-ID is more user-friendly.

4.4.2. Trauma in People with intellectual disabilities. Because of the small sample size, conclusions regarding trauma and the wider intellectual disability population should be taken with some caution. The discussion surrounding whether the events identified represent a trauma should also be considered when generating implications from this study (Section 4.3.5). However, the results offer some interesting findings and areas for further investigation. Firstly, as evidenced by the promising data found for the LANTS and IES-ID, the study demonstrates that trauma can be reliably measured in this population. This is a noteworthy finding. Meiser-Steadman (2002) points out the importance of evidence showing that the IES (Horowitz et al., 1979) and other measures could be utilised with children. Such findings are credited with bringing about an acceptance of the validity of PTSD diagnosis using criteria outlined for adults. This provided the base for a more detailed understanding of PTSD in children. While further research will be needed using the LANTS and IES-ID, it is hoped that these findings may provide a similar springboard for understanding PTSD in people with intellectual disabilities. The IES-ID also allows the investigation of the three core symptoms outlined in DSM-IV-TR (2000). Therefore, the successful use of this measure indicates that the criteria outlined for use with the general population might also be applicable to this population, supporting the work of other researchers (Hurley et al., 2007; Mitchell et al., 2006). However, further work is needed to corroborate this.

This study provides some tentative data on the rates of trauma experiences and symptomatology in people with intellectual disabilities. For example, it is of note that out of 52 that initially agreed to take part in the study, only three were excluded for not having experienced a trauma. This indicates that 94% of those approached had experienced a potential trauma. While this does indicate a higher rate than found in the general population, it is of note that if bullying is excluded from this analysis this figure

drops to 71% which is similar to that found in the general population, 69% (Norris, 1992). It is therefore important that future research establish whether it is valid to include bullying on the trauma information form. However, it is possible to use the IES-ID to estimate the number in the sample that would be classed as having PTSD by applying the cut-off recommended for the IES-R (33), adjusted to account for the reduction in response points. This demonstrates that ten of the sample (25%) scored higher than this threshold. This is noteworthy considering the lifetime prevalence in the general population is 6.8% (Kessler, et al., 2005). Hence, these results may suggest that high levels of PTSD symptomatology may be common in this population. Although it is accepted that a great deal of caution should be taken due to the problems applying a cut-off established in the general population to people with intellectual disabilities. Finally, the present research also illustrates that clinicians should be open and flexible when considering what may be traumatic in this population. There is provisional evidence, albeit some of it anecdotal, that the range of traumatic experiences is greater in those with intellectual disabilities. However, there is the need for more research to confirm this finding.

At this point it also appears relevant to include some researcher observations. No formal tools were used for this process, and it is recognised that they are subjective and therefore open to bias. However they may be of some use considering the lack of research into this area. It was noted that many services and localities reported understandable concerns regarding the sensitive nature of the study. This anxiety contributed to some services and areas to not allow their service users to take part. However, many participants engaged well in the assessments, and often appeared keen to help. Participants who took part appeared able and willing to state when they did not wish to talk about something. Indeed, some participants identified events that they had

not divulged previously, and of which their key-worker was unaware. This may be relevant for two reasons. Firstly, it possibly indicates that the under-identification of trauma in people with intellectual disabilities may be due in part to attempts to protect these individuals. And secondly, that these concerns in some cases are unfounded. This may have implications for the assessment and support of people with intellectual disabilities following trauma.

4.4.3. Trauma and intellectual functioning. The study found that IQ was not related to PTSD symptomatology. This contrasts with a wealth of research in the general population (Macklin et al., 1998; McNally & Shin, 1995; Vasterling et al., 1997). However, it is likely that this finding is due to the positively skewed IQ distribution. It is therefore difficult to draw conclusions from these findings, and the relationship between IQ and PTSD in people with intellectual disabilities should be a focus of future research.

4.4.4. Theoretical implications. Some caution should be taken when extrapolating the results to theory due to the lack of theoretical research and discussion in this area. Furthermore, the focus of this study was the examination of the psychometric properties of the two trauma scales rather than the testing of specific theoretical predictions. However, it is possible to make some tentative links to theory. In the Introduction it was posited that, due to developmental factors, people with intellectual disabilities may not experience the full range of PTSD symptomatology. Symptoms that are conceptualised to rely on higher levels of cognition, particularly re-experiencing phenomena, may not be present due to many of those in this population

being at a different stage of cognitive development. Consequently, it may be predicted that questions that tap such items on the IES-ID, which is based on a widely used measure of trauma in the general population, would show less reliability. However, support for this assertion was mixed. This study demonstrates that PTSD can be measured consistently, with a high internal consistency found for the total severity score. This could illustrate that people with an intellectual disability are able to reflect upon, rate and possibly experience these complex psychological processes. This suggests that current conceptualisations, and therefore theories of PTSD may have some relevance to this population. Notably, the effective use of the IES-ID could illustrate the specific application of stress response theory to trauma in people with intellectual disabilities, as the original IES was based on tenets outlined by this account (Horowitz, 1976; 1986; 1997).

However, there was also some evidence that certain items on the subscales may have been problematic for this sample. For example, internal consistency of the intrusion and avoidance subscales improved when questions 7 and 14 were deleted, respectively. This suggests that these two items do not relate well with other items on the scale. While there may be a number of reasons for this, one explanation may be that these items are not experienced by individuals with intellectual disabilities because they require a higher level of cognitive functioning. For example, question 7 asks, “Have you felt that ____ hadn’t really happened? (e.g., has it felt like you had dreamt it).” This relies on participants having undergone some level of dissociation which may be considered a higher cognitive skill (Johnson, 2001). Moreover, question 14 asks, “Have you felt like ____ was happening again?”. This requires individuals to have experienced flashbacks, a symptom which is also conceptualised to be the result of a complex cognitive process (Finzi-Dottan et al., 2007). Thus flashbacks may not be experienced

in the same way as experienced by those in the general population. These findings may therefore support the adaptation of cognitive theories based on developmental level. However, there are a number of alternative explanations that should be ruled out first. Because of the paucity of research in this area, it is not known whether the sample recruited were typical in terms of the rates of PTSD symptomatology expressed. It is therefore conceivable that this group had low rates of trauma symptomatology, which would mean that very few had actually experienced the full range of trauma symptomatology. If this was the case, it is conceivable that certain symptoms characteristic of the disorder were not recognised by the participants. This could therefore lead to confusion, which in turn increases the chance of response biases. Alternatively, these items may have just been more easily misunderstood. A respondent could easily understand question 14 as asking whether the incident had actually occurred again, rather it feeling like it had happened again (i.e., a flashback). Such errors would again lead to lower consistency in response.

4.4.5. Clinical implications. The study offers some evidence that PTSD may be a distinct and separable disorder in people with intellectual disabilities, with findings that the trauma scales were more highly related with each other than with measures of other psychiatric disorders. Moreover, it was found that trauma symptomatology could be reliably measured. These observations have important implications for the potential utility of the LANTS and the IES-ID to facilitate case recognition. This is a vital clinical goal considering that the disorder can often be overlooked (Brackenridge & Morrissey, 2010; Hollins & Sinason, 2000; Wigham et al., 2011a). Furthermore, these findings demonstrate that events not normally considered traumatic, such as bullying and bereavement, may be considered so by individuals with intellectual disabilities. It may

therefore be beneficial for clinicians to adopt a flexible and open definition of what may count as a trauma when assessing for trauma symptomatology. As part of this, clinicians should explicitly assess for particular symptoms indicative of PTSD, such as intrusions or flashbacks, which may not be typically included in assessment procedures in this population but could necessitate alternative treatment strategies. There may also be some clinical application for the joint use of the IES-ID and TIF. Between them they mirror criteria outlined in DSM-IV-TR (2000) and they could therefore be used to facilitate clinical diagnosis according to this diagnostic criteria. Although further work is required to investigate this assertion this could have benefits for service decisions.

In terms of treatment, the LANTS and IES-ID could both contribute to valid case recognition of trauma symptomatology, which is a vital part of effective treatment (Bisson & Andrew, 2007; Mevissen & de Jongh, 2010; Mevissen, et al., 2010; Stenfert-Kroese & Thomas, 2006). Moreover, the two trauma scales may provide a useful method of assessing the outcome of any treatment approach. This would be important for any clinical intervention or research into treatment effectiveness. Finally, this study found evidence that people with intellectual disabilities may experience the full range of trauma symptomatology. This should be recognised in treatment approaches, with interventions potentially targeting a wide range of symptoms including intrusions, flashbacks and avoidance strategies.

4.6. Future Directions

Due to the lack of research in this area, there are a significant number of possible areas for future research. This section is therefore split into two sections

covering, firstly, specific suggestions for the LANTS and IES-ID and how this study could be improved upon; and secondly, trauma and intellectual disabilities generally.

4.6.1. LANTS and IES-ID. Studies should aim to further examine the psychometric properties of both the LANTS and the IES-ID by employing a larger sample size and using a wider range of clinical and non-clinical populations. This will provide further evidence of the utility of both scales and the generalisability of the results found in this study. It is also important that future research examines the factor structure of the two measures. This would enable investigation of the usefulness of the subscales of the IES-ID and the informant LANTS and would examine the possibility of subscale development for self-report LANTS. Moreover, considering the finding of this research that the deletion of certain items led to an increase in internal consistency, principal component analysis of the IES-ID is recommended to help establish whether all items are applicable for use in this population. This procedure was used in the development of the children's impact of event scale (Yule, Ten Bruggencate, & Joseph, 1994), which established that certain items were not relevant for children. Researchers should also look to develop clinical cut-offs for these scales by examining sensitivity and specificity. This type of data is often lacking from measures developed for individuals with intellectual disabilities, but would go towards assessing the clinical value of both measures (Hermans & Evenhuis, 2010). Finally, studies may be able to assess the use of these scales as an outcome measure following treatment and address the relationship between the BPVS (Dunn et al., 1997) and the LANTS and the IES-ID in order to specify the receptive language ability necessary for effective use of these measures (Finlay & Lyons, 2001). Research could endeavour to compare the IES-ID and IES in terms of psychometric properties and ease of use.

There are also numerous opportunities to further examine the utility of the TIF, considering the positive reception from services involved in the study and the lack of research into similar methods of assessing trauma in this population. This may also include the addition of ratings to assess whether the trauma could be counted as such according to DSM criteria. For example, questions such as “How much did you feel at risk/in danger?” could be included. This would provide a more stringent criterion for what is traumatic, which may be useful for future research. Finally, it is important that studies use alternative recruitment strategies in order to identify potential participants with higher IQs (but within the intellectual disability range). This would address the problems encountered by this study relating to the skewed distribution in terms of IQ.

4.6.2. General. Further research is required to investigate the symptoms that develop in individuals following a trauma. Longitudinal research would be especially useful in order to establish causal links between traumas and PTSD symptoms, and to also investigate the changes that occur in individuals with intellectual disabilities following a traumatic event. The scales examined in this study may provide a structured basis for this and a further investigation of usefulness criteria set out in DSM-IV-TR (2000). This may necessitate recruiting individuals who present themselves to intellectual disability services following a traumatic event. A larger sample size would also be necessary in order to allow further investigation of how demographic and trauma factors impact on PTSD symptoms, as well as the risk factors for the development of such symptoms in this population. Alongside this, research should look at the effectiveness of different treatment approaches. There is already some evidence that exposure work (Lemon & Mizes, 2002), imagery rehearsal techniques (Stenfert-Kroese & Thomas, 2006), cognitive restructuring (Fernando & Medlicott, 2009) and

EMDR (Mevisen, et al., 2010; Rodenburg, Benjamin, & De Roos, 2009) can be used to treat PTSD in people with intellectual disabilities. Studies could seek to extend and expand these findings.

There is also a need for more theoretically grounded research. One approach would be to investigate the presentation of specific symptoms (i.e., intrusions). This would allow a more focused testing of certain specific theoretical predictions. For example, whether as a result of difficulties in verbal memory those with intellectual disabilities are more likely to experience flashbacks rather than other symptoms, as predicted by DRT (Brewin et al., 2007). Moreover, studies could examine the appraisals engaged in by this population. This could include investigation of whether those with intellectual disabilities exhibit negative appraisals of symptomatology and how this affects the extent of symptoms. Researchers could also explore symptoms of avoidance and whether this population engages in alternative or different coping strategies (such as cognitive avoidance). Finally, comparing individuals with and without intellectual disabilities could be beneficial to examine some theoretical predictions. For example, it would be useful to test the prediction set out by Ehlers and Clark (2000) that those with lower IQs are more likely to process trauma information in a data-driven rather than conceptual-driven way.

4.7. Overall Conclusions

There is evidence from the study to suggest that the LANTS and the IES-ID are robust tools to measure trauma symptomatology in people with intellectual disabilities, and that trauma symptomatology can be reliably measured in this population. Additionally, the findings indicate that PTSD can be identified as a separable disorder

in people with intellectual disabilities, and that intellectual functioning is not related to trauma symptomatology in this population. However, it is clear that more research is required to extend and further establish these results, and address some of the weaknesses of this study. Specifically, studies should further examine the LANTS and IES-ID using a larger sample size, and further investigate the relationship between the LANTS and traumatic events and the utility of the IES-ID subscales. Use of longitudinal and experimental methodologies would also be worthwhile to establish risk factors for the development PTSD in this population, and to test specific theoretical predictions. Nevertheless, these findings represent a noteworthy contribution to an under-researched but burgeoning area.

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Appendix A: Participant information sheet

School of Medicine, Health Policy and Practice
Doctoral Programme in Clinical Psychology



Norwich NR4 7TJ England

Telephone
01603 591507

Fax
01603 593604

‘Measuring how we feel after something upsetting happens’



James Hall

What is it?

- A lot of people have had something very bad happen to them, like being beaten up or being in a car crash. We want to see if we can measure how people feel if something like this has happened to them.

What’s the benefit of doing it?

- This study might help us identify people that feel very upset or bad after something bad has happened to them. We might then be able to come up with better ways of making them feel better and making them well again.

Do I have to take part?

- **NO**, you do not have to take part in this research.
- If you say **YES** it is still okay to change your mind later and say **NO**.
- If you say **NO** your treatment and care will not be affected and the researcher will not contact you again.

What happens if I say YES?

- You will be asked to meet with James twice.
- You will be asked to answer some questions.
- You can choose to have a key worker with you. You could also choose to have an advocate with you. Please tell your key worker or James.

How long will it take?

- The first appointment will take about 1 hour 30 minutes.
- The second appointment will probably take about 50 minutes.
- You can have as many breaks as you like.

Are there bad things that could happen?

- You will be asked about bad things that have happened to you. This may make you feel upset.
- You can talk to the James if you feel upset.
- Answering these questions will not change the treatment or support you get at the moment.

What if you are unhappy about the research?

- You can stop at any point during the study and tell James that you don't want to carry on.
- This will not will change your treatment and care.

Then...

- You can talk to James or someone you know about it. His telephone number is on the bottom of this sheet.
- If you remain unhappy and you want to make a formal complaint, you or your keyworker could contact the Patient Advisory Liaison Service (PALS) in Norfolk on 0800 587 4132.
- If you wish to get further help you can contact the Independent Complaints and Advocacy Service on 0845 456 1084.

Will my information be kept secret?

- Yes, your name and other details about you will be locked away so no one else can see it.
- James will write about the information he has collected but will make sure that there are no personal details about you.

But...

- If you tell us something that means you or someone else is at risk of harm, we may have to tell you doctor, nurse, social worker or keyworker. James will discuss this with you first.
- We may look at your clinical records. We will ask you if this is ok.

What happens at the end?

- The results will be written about. No names will be given.

Has the research been checked?

- People have looked at the study to check it is safe.

What if I have more questions?

- Speak to your key worker who will contact James. He will answer any questions you have.

Supervised by Dr Peter Langdon

Department of Psychological Sciences,
Norwich Medical School,
University of East Anglia,
Norwich,
NR4 7TJ
Telephone: 01603 593310

Appendix B: Key-worker information sheet

School of Medicine, Health Policy and Practice
Doctoral Programme in Clinical Psychology



Norwich NR4 7TJ England

Telephone
01603 591507

Fax
01603 593604

‘Measuring how we feel after something upsetting happens’

Who are the researchers?

James Hall
Dr Peter Langdon

What is it about?

People with an intellectual disability are more likely to be exposed to an event that may be considered traumatic. However, there is currently no formal way of assessing if people with an intellectual disability have symptoms of post traumatic stress. This research aims to address this need by comparing two recently developed questionnaires that measure such symptoms. We hope to establish whether these are good at identifying symptoms of PTSD in people with an intellectual disability.

To do this individuals with an intellectual disability are been asked to complete the two questionnaires, in addition to other measures of mental health and cognitive ability. As part of this we are asking their keyworker to also fill out a questionnaire that asks questions about the participants’ abilities and mood. The participant has given permission for you to fill out this questionnaire.

What’s the benefit of doing it?

This study might help us identify better those people with an intellectual disability that exhibit symptoms of PTSD following a traumatic event. This may then help us develop a better understanding of such symptoms in this

population, and therefore aid the future development of effective treatments.

Do I have to take part in this research?

NO, you do not have to take part in this research. If you do agree to be involved and then change your mind, you can withdraw at any time without giving a reason.

What happens if I say YES?

You will be asked to complete a questionnaire. This should only take 20 minutes. You will be required to complete the same questionnaire twice, with approximately two weeks between sittings. This can be completed at a place and time of your choosing. You could do this at the same time that the individual for whom you are keyworker undertakes their assessments, or another separate time could be arranged. Alternatively, this questionnaire could be posted to you or left in your pigeonhole. Please let the researcher know your preference.

Are there any bad things that could happen?

In the unlikely event that you do feel upset or distressed as a result of this study, the assessment will be stopped and you will have the opportunity to discuss how you feel with the researcher. You will also be reminded that you can withdraw from the study at any time. If you want further support following this, you will be advised to talk to your G.P.

What if I am unhappy about the research?

You can stop at any point during the study and tell the researcher that you no longer wish to take part. Any information you gave will then be destroyed.

Then...

You can talk to James or his academic supervisor. Their contact details are on the bottom of this sheet. If you wish to make a formal complaint you should contact your staff union.

Will my information be kept secret?

All data is anonymised and the service user will not be able to see the

answers you give. The information that you provide will be stored in such a way that you can not be personally identified. The information will be kept under lock and key and treated as confidential under the Data Protection Act (1998).

What will happen to the results of the research study?

The anonymised results will be written up for an assignment as part of our Doctoral training in Clinical Psychology. The results may be also written up for publication in a journal and might be presented at a research conference. No personal information about you will be included in these reports.

Who has reviewed the study?

The study has been reviewed by tutors on the University of East Anglia Doctorate in Clinical Psychology training programme. It has also been reviewed and approved by the Hertfordshire NHS research ethics committee and the local Research and Development teams.

Contacts

If you want more information or wish to complain, you can call UEA on 01603 593310 (Monday to Friday) and ask to speak to:

James Hall or
Dr Peter Langdon (Clinical Psychologist)

Or write to either of these people at:

Department of Psychological Sciences,
Norwich Medical School,
University of East Anglia,
Norwich,
NR4 7TJ.

Thank you for your help in this study.

Appendix C: Participant consent forms

School of Medicine, Health Policy and Practice
Doctoral Programme in Clinical Psychology



Norwich NR4 7TJ England

Telephone
01603 591507

Fax
01603 593604

Participant Identification Number:

CONSENT TO SHARE DETAILS FORM

Title: Measuring how we feel after something upsetting happens

Name of Researcher: James Hall

I _____ agree to my contact details been shared for the above research project, with the above researcher.

Name of participant

Date

Signature

Name of key worker/advocate

Date

Signature

Contact Details

Full name:	
Address:	
Telephone number:	
Keyworker Name	
Keyworker Telephone Number	
Who should I contact about making an appointment? (Please Circle)	Me / Keyworker

Appendix C: Participant consent form

School of Medicine, Health Policy and Practice
Doctoral Programme in Clinical Psychology



Norwich NR4 7TJ England

Telephone
01603 591507

Fax
01603 593604

Participant Identification Number:

Title: Measuring how we feel after something upsetting happens
Name of Researcher: James Hall

Please tick \checkmark the box if you agree with the sentence:

I confirm that I have read and understood the information sheet dated _____
explained to me by _____.....

I have asked any questions I wanted to.....

I understand I do not have to take part in the research.....

I understand I can leave at any time without giving a reason.....

I understand that it will not affect my care if I choose not to take part...

I am happy for _____ (Key-worker) to complete a questionnaire about
me.

I agree for the research team to look at my clinical notes.....

I understand that if I tell James about something bad that happened to me,
which no one else knows about, he may tell other people about this (e.g.
my doctor, social worker, nurse, my key worker).....

I understand that people from the NHS may check the work James is doing to make sure he is following the rules. I agree that this is okay.....

I agree to take part in the research.....

My name: _____ **Date:** _____

Signature: _____

Researcher's name: _____ **Date:** _____

Signature: _____

Appendix D: Key-worker consent form

School of Medicine, Health Policy and Practice
Doctoral Programme in Clinical Psychology



Norwich NR4 7TJ England

Telephone
01603 591507

Fax
01603 593604

Participant Identification Number:

Title: Measuring how we feel after something upsetting happens.

Name of Researcher: James Hall

Please tick \checkmark the box if you agree with the sentence.

I confirm that I have read and understood the information sheet explained to me by James Hall.....

I have asked any questions I wanted to.....

I understand I do not have to take part in the research.....

I understand I can pull out at any time without giving a reason.....

I understand that should I disclose any information that legally requires action, confidentiality will be broken.....

I agree to take part in the research.....

My name: _____ **Date:** _____

Signature: _____

Researcher's name: _____ **Date:** _____

Signature: _____

Appendix E

Measures included in the study are provided on the 43 subsequent pages.

Trauma Information Form

Date _____
Participant identification number _____

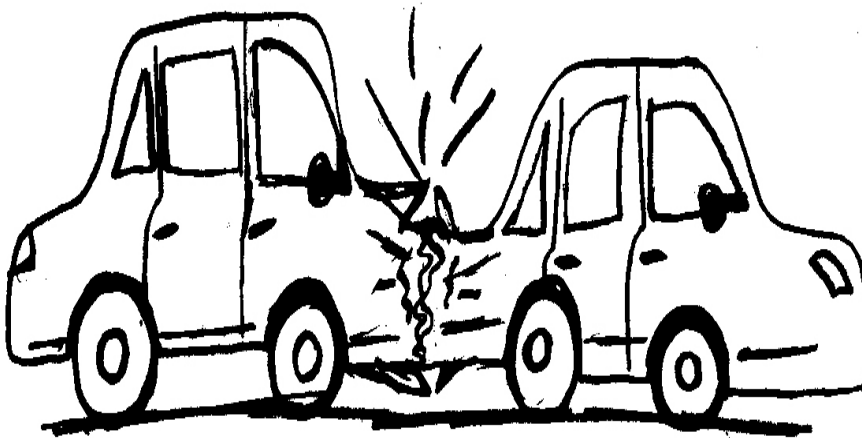
Trauma Information Form

INSTRUCTION: "Many people have lived through or seen something bad that made them very upset and very frightened. I would like to ask you a few questions about things that have happened in your life."

"I am going to show you some pictures of bad or not nice things that could happen to people that may make them upset or frightened. I would like you to tell me if any of them have happened to you, or if you have seen them happen. Remember there is no right or wrong answers."

Car or plane crash

Please tick ✓ if this
has happened to you



Fire or Explosion



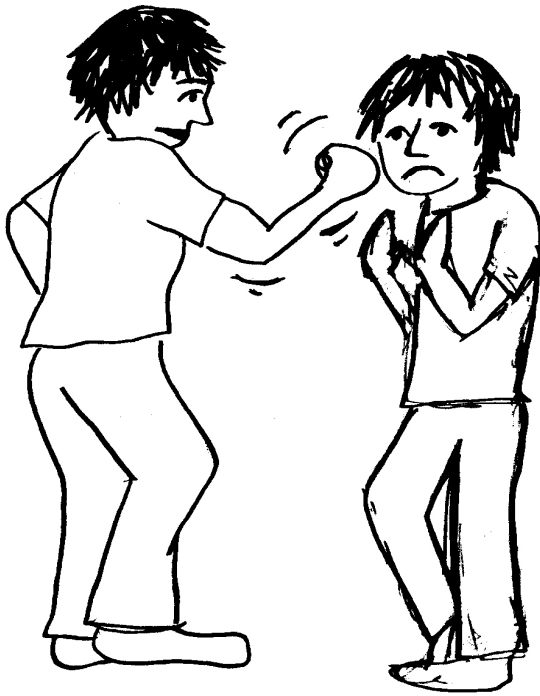
Please tick ✓ if this has happened to you

Earthquake, flood, hurricane, or other very bad and dangerous weather



Please tick ✓ if this has happened to you

Beaten up by someone



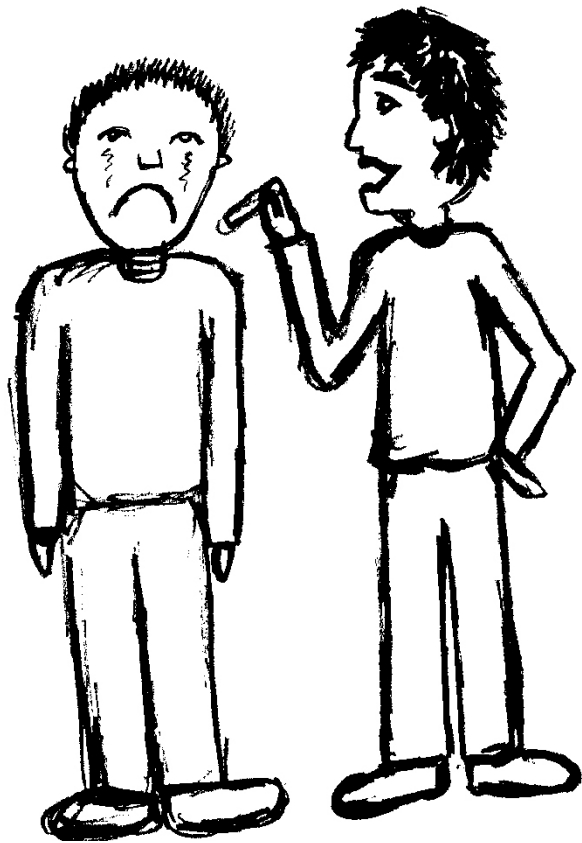
Please tick ✓ if this has happened to you

Someone using a weapon against you (for example, a knife or gun)



Please tick ✓ if this has happened to you

Been Bullied



Please tick ✓ if this has happened to you

Someone touching you in a place that you didn't want them to



Please tick ✓ if this has happened to you

Someone having or trying to have sex with you when you didn't want them to



Please tick ✓ if this has happened to you

Been in a place where a war is happening



Please tick ✓ if this has happened to you

Locked in somewhere when you did not want to be (for example, in prison or as a hostage)



Please tick ✓ if this has happened to you

Torture



Please tick ✓ if this has happened to you

An illness that meant you could die. Or an getting so badly hurt or injured you thought you might die.



Please tick ✓ if this has happened to you

Someone that you liked very much has died when you didn't expect it



Please tick ✓ if this has happened to you

INSTRUCTION: "Can you think of anything else that has happened to you that has made you very upset or very frightened?"

INSTRUCTION: "Out of the things that have happened to you, which one has upset you the most?"

PLEASE TICK

- | | | | |
|------------------------|--------------------------|-------------|--------------------------|
| Car or plane crash | <input type="checkbox"/> | War Zone | <input type="checkbox"/> |
| Fire or Explosion | <input type="checkbox"/> | Prison | <input type="checkbox"/> |
| Natural Disaster | <input type="checkbox"/> | Torture | <input type="checkbox"/> |
| Beaten up by someone | <input type="checkbox"/> | Illness | <input type="checkbox"/> |
| Been bullied | <input type="checkbox"/> | Bereavement | <input type="checkbox"/> |
| Someone using a weapon | <input type="checkbox"/> | Other | <input type="checkbox"/> |
| Sexual Assault | <input type="checkbox"/> | | |

"When did this happen?" (CIRCLE ONE)

- | | |
|-------------------------------------------------------|--------------------------------|
| Happened since told about meeting James/ Recent Event | Before Last Christmas |
| Between last Christmas and now | When I was a child or teenager |

THIS FOLLOWING QUESTION SHOULD BE ASKED AFTER THE ADMINISTRATION OF THE IES-ID.

"Now I would like you to tell me how much the problems you told me about before have got in the way of the following areas in your life over the past few weeks. Please just answer yes or no to each question".

- | | | |
|---------------------------------------|------------|-----------|
| Work / day centre | YES | NO |
| Relationships with friends and family | YES | NO |
| Going out and having fun | YES | NO |
| School / College work | YES | NO |
| How happy you are with life | YES | NO |



**Lancaster and Northgate Trauma Scale for
Intellectual Disabilities.
*Self-Report Version***

Instructions

This measure is designed as a semi structured interview to be completed by a qualified member of staff.

The measure begins with 3 screening questions designed to assess whether the respondent is able to understand the rating system used.

Screening Questions.

What is your favourite food?.....

(a.) Do you like(*favourite food*)?

No

A little

Sometimes

A lot

What is a food you really hate.....?

(b.) Do you like(*hated food*)?

No

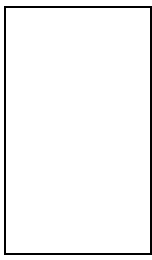
A little

Sometimes

A lot

What is your favourite TV programme?

(c.) Do you like.....(favourite TV programme)?



No



A little



Sometimes



A lot

Screening Question Scoring

Please indicate the respondent's answers on the grid below.

(a.)	No	A little	Sometimes	A lot
(b.)	No	A little	Sometimes	A lot
(c.)	No	A little	Sometimes	A lot

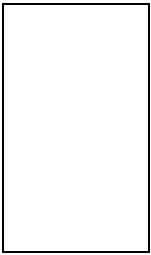
If the respondent's answers fall in the shaded areas continue with the interview. If their responses fall outside the shaded areas end the interview at this point.

Read the following example to the respondent:

The next questions describe the ways people sometimes feel, after stressful things have happened. Think about how you have been feeling over the past few days. Here is an example:

Question 3

Worries have been going round and round in my head.



No

A little

Sometimes

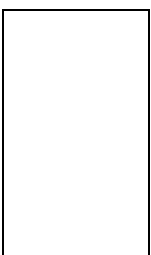
A lot

If worries have been going round and round in your head every day this week you would say 'A lot'.

If worries were going round and round in your head once this week then say 'A little'.

Read the following questions to the respondent and circle their answers. If the respondent does not understand a question please indicate this and go on to the next question.

1. I feel worried – e.g. I feel wound up, I can't breathe properly, and my heart is pounding.



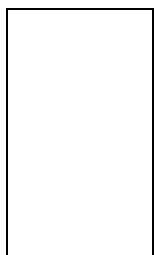
No

A little

Sometimes

A lot

2. I feel down e.g. I feel sad, I cry a lot, and don't enjoy things.



No



A little

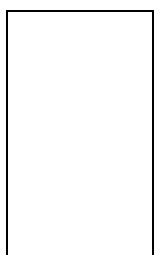


Sometimes



A lot

3. Worries have been going round and round in my head.



No



A little

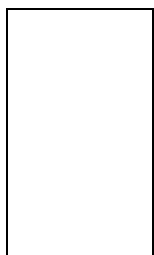


Sometimes



A lot

4. If you get too close or friendly with people, they hurt you.



No



A little

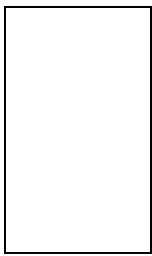


Sometimes



A Lot

5. I get on with people OK.



No



A little

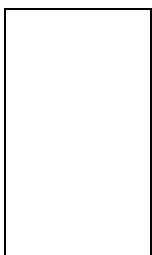


Sometimes



A lot

6. I have bad dreams or nightmares.



No



A little

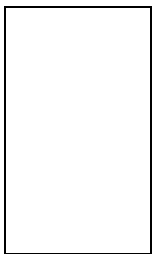


Sometimes



A lot

7. I like myself, e.g. I am as good as other people; I am proud of myself.



No



A little

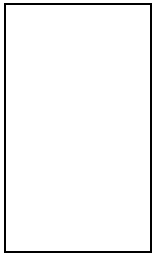


Sometimes



A lot

8. I need help with things I used to be able to do more easily, like getting washed or dressed.



No



A little

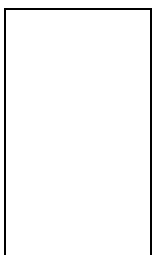


Sometimes



A lot

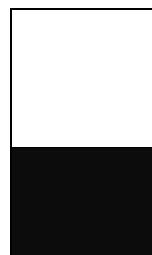
9. I feel frightened, like something bad is going to happen.



No



A little

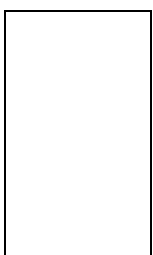


Sometimes



A lot

10. My sleep is bad e.g. I can't get to sleep, I keep waking up, or I wake up too early.



No



A little

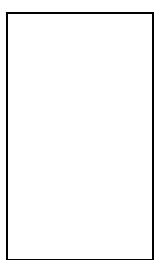


Sometimes



A lot

11. I want to smash things up.



No



A little

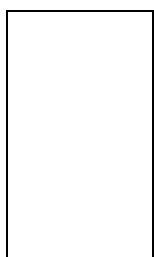


Sometimes



A lot

12. I want to hurt people e.g. hit them, push them, pull their hair, or fight with them.



No



A little

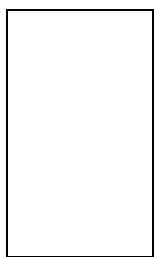


Sometimes



A lot

13. I feel like hurting myself really badly.



No



A little

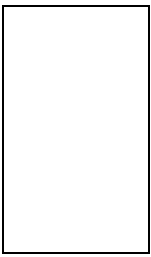


Sometimes



A lot

14. I enjoy going out.



No



A little

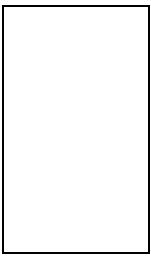


Sometimes



A lot

15. I feel jumpy and on edge.



No



A little

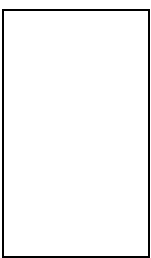


Sometimes



A lot

16. People say bad things about me.



No



A little

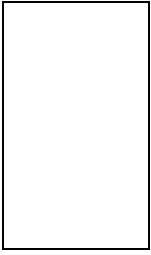


Sometimes



A lot

17. I feel guilty.



No



A little

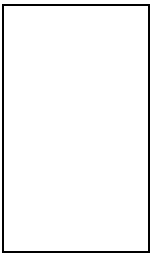


Sometimes



A lot

18. I feel happy.



No



A little

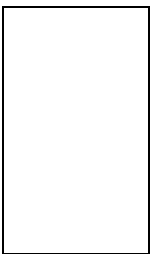


Sometimes



A lot

19. I just want to be left on my own.



No



A little

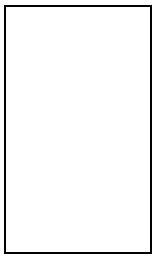


Sometimes



A lot

20. I enjoy my food.



No



A little

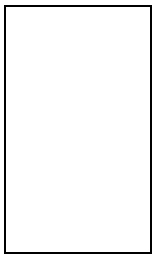


Sometimes



A lot

21. I feel unwell or run down e.g. stomach upsets, aches and pains.



No



A little

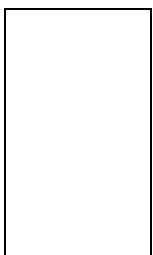


Sometimes



A lot

22. My mood changes quickly e.g. I can go from feeling very happy to feeling very low or angry, and I can't seem to shake it off.



No



A little

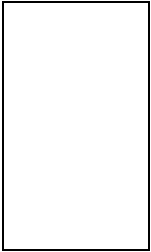


Sometimes



A lot

23. I can keep my mind on things e.g. watching TV.



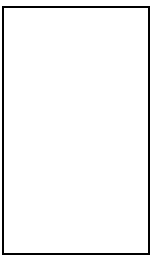
No

A little

Sometimes

A lot

24. I still like the things I used to like doing e.g. I still enjoy my hobbies.



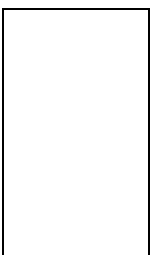
No

A little

Sometimes

A lot

25. I care about the way I look.



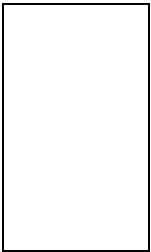
No

A little

Sometimes

A lot

26. I can talk to people OK.



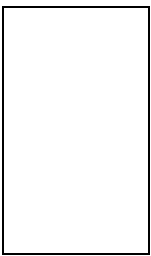
No

A little

Sometimes

A lot

27. When bad things happen I feel it's my fault.



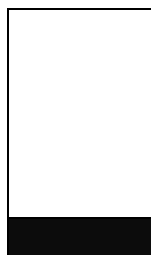
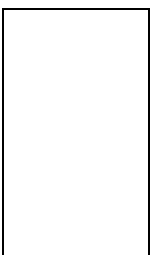
No

A little

Sometimes

A lot

28. Eating is the only thing I enjoy.



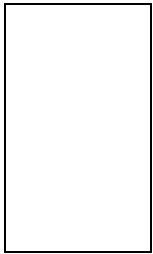
No

A little

Sometimes

A lot

29. I can get out of bed OK on a morning.



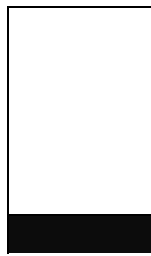
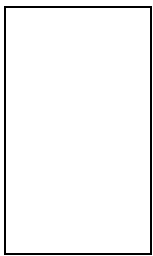
No

A little

Sometimes

A lot

30. I look forward to the future and the good things that could happen e.g. going on holiday, meeting new people.



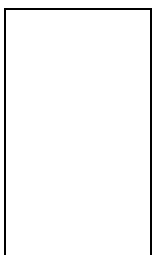
No

A little

Sometimes

A lot

31. I feel like I'm in a daze e.g. things don't feel real; I forget where I am or what I'm doing.



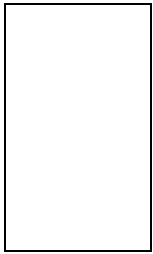
No

A little

Sometimes

A lot

32. I feel cut off from my feelings e.g. I feel numb.



No



A little

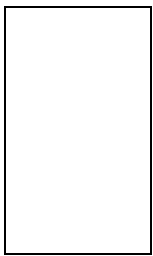


Sometimes



A lot

33. I feel alone. I don't feel close to anybody e.g. nobody understands what I've been through.



No



A little

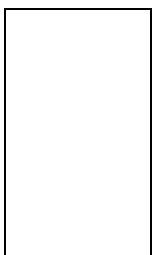


Sometimes



A lot

34. Sometimes bad things from the past feel like they are happening again.



No



A little



Sometimes



A lot



**Lancaster and Northgate Trauma Scale for
Intellectual Disabilities.
*Informant Version.***

This measure is a list of statements describing the ways people may behave if they have experienced stressful life events. The measure must be completed by a paid or family carer who has known the person for a minimum of one year.

Your name:

Date:

The name of the person who you are completing the form about:

Relationship to the above named person e.g. job title:

Please read the questions - if the behaviour applies to the person, please consider whether it has been happening more than usual over the past 12 months. If the behaviour is always present and no change has occurred please indicate 'same as usual'.

Please indicate how often the behaviour has occurred during the **past month**, and indicate its' severity by circling the scores in the boxes.

When rating the severity please consider the following:

Mild – although present within the past month the behaviour has *little or no impact* on the person themselves or those around them.

Moderate – the behaviour has a *moderate impact* on the person's functioning or those around them. The behaviour *may be compensated for* e.g. by increasing carer support.

Severe – the behaviour *severely disrupts the person's functioning* in daily living or is severely disruptive to those around them e.g. restricts their access to community facilities.

E.g. suppose the person was mugged and since then they have been avoiding going out of the house in the evening. As a result they have missed going out with their boyfriend, and going to the pictures with friends. The person has still been going out during the day and friends have visited on an evening.

So for question 7 - '*Avoiding certain things due to fear or anxiety, more than is usual for them e.g. particular people, situations, or going out.*' - you would tick '*several times a week*', and '*moderate*'.

If the person was not leaving the house at all, and no one was visiting them you would tick '*several times a day*', and '*severe*'.

There may be questions that you cannot answer because you are not with the person all the time e.g. about sleep. You may be able to get the information from another person e.g. night staff. Otherwise please indicate if you don't know.

	Don't know	Same as usual	Frequency							Severity (see below**)		
			None	Monthly	Weekly	Several times a week	Daily	Several times a day	Mild	Moderate	Severe	
1. More repetitive behaviour or movements than is usual for them - e.g. rocking	1	1	1	2	3	4	5	6	1	2	3	
2. More obsessive than is usual for them e.g. in cleaning or personal care.	1	1	1	2	3	4	5	6	1	2	3	
3. Social withdrawal e.g. isolating themselves, and spending more time alone than is usual for them. Avoiding social contact and avoiding being	1	1	1	2	3	4	5	6	1	2	3	
4. Loss of daily living skills in which they were previously independent e.g. preparing a sandwich or a drink, getting dressed, or using public transport.	1	1	1	2	3	4	5	6	1	2	3	
5. More difficulty regulating emotions than is usual for them – e.g. sometimes elated, and sometimes depressed.	1	1	1	2	3	4	5	6	1	2	3	
6. More difficulty than usual in maintaining relationships e.g. may not be getting on with people they usually get on with.	1	1	1	2	3	4	5	6	1	2	3	
7. Avoiding certain things due to fear or anxiety, more than is usual for them e.g. particular people, situations, or going out.	1	1	1	2	3	4	5	6	1	2	3	
8. More verbal aggression than is usual for them e.g. shouting at people,	1	1	1	2	3	4	5	6	1	2	3	
9. More physical aggression towards other people than is usual for them e.g. attacking people or fighting.	1	1	1	2	3	4	5	6	1	2	3	

*****Mild** – although present within the past month the behaviour has *little or no impact* on the person themselves or those around them.
Moderate – the behaviour has a *moderate impact* on the person's functioning or those around them. The behaviour *may be compensated for* e.g. by increasing carer support.
Severe – the behaviour *severely disrupts* the person's functioning in daily living or is severely disruptive to those around them.

	Don't know	Same as usual	Frequency						Severity**			
			None	Monthly	Weekly	Several times a week	Daily	Several times a day	Mild	Moderate	Severe	
10. Describing flashbacks (feeling or behaving as though the stressful event was happening again).	1	1	1	2	3	4	5	6	1	2	3	
11. Expressing more feelings of guilt or self-blame than is usual for them.	1	1	1	2	3	4	5	6	1	2	3	
12. Extremely alert to danger more than is usual for them e.g. often checking or watching for something bad to happen.	1	1	1	2	3	4	5	6	1	2	3	
13. More difficulty concentrating than is usual for them e.g. finding it hard to attend to a task that would previously engage them e.g. looking at a magazines, watching TV.	1	1	1	2	3	4	5	6	1	2	3	
14. More irritability than is usual for them, e.g. easily losing their temper, having a lower threshold than usual for becoming annoyed or argumentative.	1	1	1	2	3	4	5	6	1	2	3	
15. Taking recreational drugs.	1	1	1	2	3	4	5	6	1	2	3	
16. Reporting more bad dreams or nightmares than is usual for them.	1	1	1	2	3	4	5	6	1	2	3	
17. Harming self e.g. cutting, hitting, biting or severely scratching self, banging their head, swallowing inedible objects.	1	1	1	2	3	4	5	6	1	2	3	
18. More easily startled, jumpy or nervous than is usual for them.	1	1	1	2	3	4	5	6	1	2	3	
<p>**Mild – although present within the past month the behaviour has <i>little or no impact</i> on the person themselves or those around them. Moderate – the behaviour has a <i>moderate impact</i> on the person's functioning or those around them. The behaviour <i>may be compensated for</i> e.g. by increasing carer support. Severe – the behaviour <i>severely disrupts</i> the person's functioning in daily living or is severely disruptive to those around them.</p>												

	Don't know	Same as usual	Frequency						Severity**		
			None	Monthly	Weekly	Several times a week	Daily	Several times a day	Mild	Moderate	Severe
19. Expressing lower self esteem than is usual for them e.g. seeing self in a poor light compared to other people.	1	1	1	2	3	4	5	6	1	2	3
20. Less verbal communication or less talkative than is usual for them.	1	1	1	2	3	4	5	6	1	2	3
21. A change for the worse in their functioning at work, or college, or day	1	1	1	2	3	4	5	6	1	2	3
22. Symptoms of depression e.g. low mood, crying, sadness.	1	1	1	2	3	4	5	6	1	2	3
23. Symptoms of anxiety e.g. sweating, shaking, difficulty breathing, or palpitations.	1	1	1	2	3	4	5	6	1	2	3
24. Difficulty making new relationships e.g. new friends, which is out of character for them.	1	1	1	2	3	4	5	6	1	2	3
25. Seeking reassurance more than is usual for them.	1	1	1	2	3	4	5	6	1	2	3
26. Expressing more mistrust, wariness or suspicion of people than is usual for	1	1	1	2	3	4	5	6	1	2	3
27. More paranoid than is usual for them e.g. they are worried (without good reason) that people are getting at them.	1	1	1	2	3	4	5	6	1	2	3

****Mild** – although present within the past month the behaviour has *little or no impact* on the person themselves or those around them.

Moderate – the behaviour has a *moderate impact* on the person's functioning or those around them. The behaviour *may be compensated for* e.g. by increasing carer support.

Severe – the behaviour *severely disrupts* the person's functioning in daily living or is *severely disruptive to those around them*

	Don't know	Same as usual	Frequency							Severity**		
			None	Monthly	Weekly	Several times a week	Daily	Several times a day	Mild	Moderate	Severe	
28. Changes in appetite – eating more or less than is usual for them.	1	1	1	1	2	3	4	5	6	1	2	3
29. Being run down and reporting more minor ailments than is usual for them e.g. headaches, stomach upsets, aches and pains or infections.	1	1	1	1	2	3	4	5	6	1	2	3
30. Appearing less aware of their surroundings than is usual for them – being in a	1	1	1	1	2	3	4	5	6	1	2	3
31. A flare up of long-standing health complaints – a recurrence or worsening of existing psychiatric or physical illness.	1	1	1	1	2	3	4	5	6	1	2	3
32. More overly sexualized behaviour than is usual for them e.g. shouting sexual phrases, preoccupation with sex, or inappropriate touch.	1	1	1	1	2	3	4	5	6	1	2	3
33. Being intimate and over friendly with people sometimes but cold towards them at other times – something which is not usual for them.	1	1	1	1	2	3	4	5	6	1	2	3
34. Talking about the same worries over and over again - more than they usually do.	1	1	1	1	2	3	4	5	6	1	2	3
35. A lack of interest in planning for the future, or in what positive things the future could hold. A negative view of the future – which is out of character for them.	1	1	1	1	2	3	4	5	6	1	2	3
36. More restricted range of affect or emotions, than is usual for them e.g. inhibited in the expression of happiness or sadness.	1	1	1	1	2	3	4	5	6	1	2	3
<p>**Mild – although present within the past month the behaviour has <i>little or no impact</i> on the person themselves or those around them.</p> <p>Moderate – the behaviour has a <i>moderate impact</i> on the person's functioning or those around them. The behaviour <i>may be compensated for</i> e.g. by increasing carer support.</p> <p>Severe – the behaviour <i>severely disrupts</i> the person's functioning in daily living or is <i>severely disruptive</i> to those around them.</p>												

	Don't know	Same as usual	Frequency							Severity**		
			None	Monthly	Weekly	Several times a week	Daily	Several times a day	Mild	Moderate	Severe	
												1
37. Instances of acute distress.	1	1	1	2	3	4	5	6	1	2	3	
38. Less interest in personal care than is usual for them e.g. in their appearance, showering, or changing their clothes.	1	1	2	3	4	5	6	1	2	3		
39. Smoking or drinking more than is usual for them.	1	1	2	3	4	5	6	1	2	3		
40. Causing more physical damage to property than is usual for them e.g. smashing, breaking, or throwing things.	1	1	2	3	4	5	6	1	2	3		
41. Reporting an increase in disturbed sleep patterns e.g. difficulty getting to sleep, or waking up in the night and not being able to get back to sleep.	1	1	2	3	4	5	6	1	2	3		
42. Demonstrating more hyper-vigilance (watching out for something bad to happen)	1	1	2	3	4	5	6	1	2	3		
43. Avoiding talking about certain things e.g. talking about their feelings, emotions, or personal information, which is out of character for them.	1	1	2	3	4	5	6	1	2	3		
44. Lack of interest in activities that used to be very important to them e.g. hobbies.	1	1	2	3	4	5	6	1	2	3		
45. More social anxiety than is usual for them e.g. anxious in groups, or in public	1	1	2	3	4	5	6	1	2	3		
46. Numb or lacking in emotion when talking about things that would usually upset	1	1	2	3	4	5	6	1	2	3		
<p>**Mild – although present within the past month the behaviour has <i>little or no impact</i> on the person themselves or those around them.</p> <p>Moderate – the behaviour has a <i>moderate impact</i> on the person's functioning or those around them. The behaviour <i>may be compensated for</i> e.g. by increasing carer support.</p> <p>Severe – the behaviour <i>severely disrupts</i> the person's functioning in daily living or is <i>severely disruptive</i> to those around them</p>												

	Don't know	Same as usual	Frequency							Severity**		
			None	Monthly	Weekly	Several times a week	Daily	Several times a day	Mild	Moderate	Severe	
47. Fearful – expressing an expectation that something bad will happen.	1	1	1	2	3	4	5	6	1	2	3	
<p>**Mild – although present within the past month the behaviour has <i>little or no impact</i> on the person themselves or those around them.</p> <p>Moderate – the behaviour has a <i>moderate impact</i> on the person's functioning or those around them. The behaviour <i>may be compensated for</i> e.g. by increasing carer support.</p> <p>Severe – the behaviour <i>severely disrupts</i> the person's functioning in daily living or is severely disruptive to those around them.</p>												

Impact of Event Scale Revised for people with Intellectual Disabilities (IES-ID)

INSTRUCTION: *“Hello, my name is Lots of people have lived through or seen something bad that made them very upset or scared. I would like to ask you a few questions about the upsetting thing that you told me about before - the _____ . Do you have any questions before we start?”*

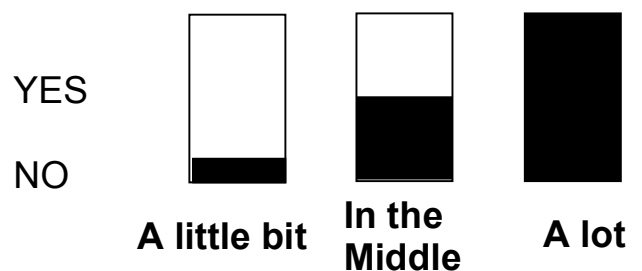
PLEASE READ OUT EACH ITEM TO THE RESPONDENT. IF THEY ANSWER YES TO A QUESTION SAY:

“I would like you to say how much this has upset or scared this has made you over the past week. Has it upset you a little bit, in the middle, or a lot? Remember there is no right or wrong answer.”

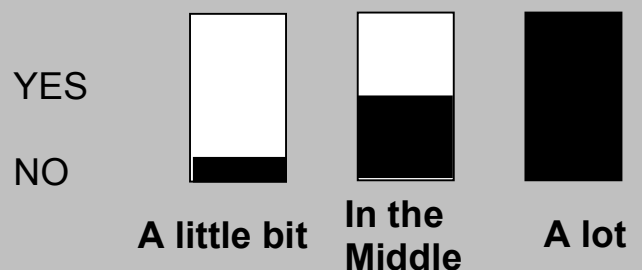
REPEAT AND SHOW THE RATING SCALES AS NECESSARY. HOWEVER, WITH SUBSEQUENT QUESTIONS THE INSTRUCTION COULD BE SHORTENED TO:

‘How much has this upset or scared you?’

1. Have you had trouble getting to sleep?
(e.g., staying awake for a long time when you are trying to sleep)

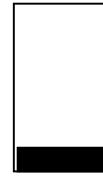


2. Have you felt angry? (e.g., have you wanted to smash or break things?)



3. Have you being jumpy or easily scared? (e.g., when someone walks up behind you)

YES



NO

A little bit

In the Middle

A lot

4. Have you not wanted to talk about _____? (e.g., when people ask you questions about it, have you tried not to answer them?)

YES



NO

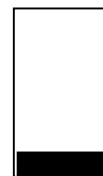
A little bit

In the Middle

A lot

5. Have you tried not to get upset when you remembered _____? (e.g., have you tried to stop crying when you remembered _____?)

YES



NO

A little bit

In the Middle

A lot

6. Have you remembered _____ when you didn't mean to? (e.g., thoughts of _____ have popped into your head when you were doing something else?)

YES



NO

A little bit

In the Middle

A lot

7. Have you felt that _____ hadn't really happened? (e.g., has it felt like you had dreamt it).

YES



NO

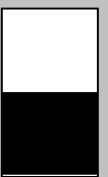
A little bit

In the Middle

A lot

8. Have you tried to keep away from places or people that make you remember _____?

YES



NO

A little bit

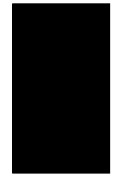
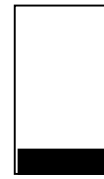
In the Middle

A lot

9. Have pictures of _____ come into your head when you didn't want them to? (e.g., Have pictures of what happened pop into your head when you were doing something else?)

YES

NO



A little bit

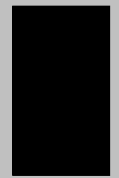
In the Middle

A lot

10. Have things kept making you remember _____? (e.g., do you keep seeing or hearing things that makes you remember _____?)

YES

NO



A little bit

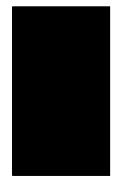
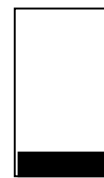
In the Middle

A lot

11. Have you tried not to talk about or think about _____?

YES

NO



A little bit

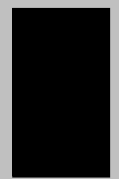
In the Middle

A lot

12. Have you been upset because of _____ but not asked for help?

YES

NO



A little bit

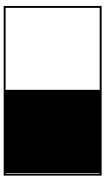
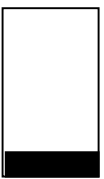
In the Middle

A lot

13. Have you found it difficult to have strong feelings? (e.g., difficulty crying or being very happy)

YES

NO



A little bit

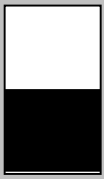
In the Middle

A lot

14. Have you felt like _____ was happening again?

YES

NO



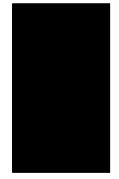
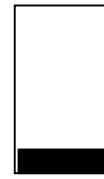
A little bit

In the Middle

A lot

15. Have you felt upset or scared when something reminds you of _____?

YES



NO

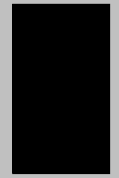
A little bit

In the Middle

A lot

16. Are there times when the feelings about what happened are too much (e.g., times when you have cried so much/ been so scared you don't think you can cope with them on your own).

YES



NO

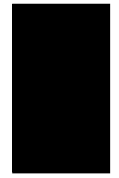
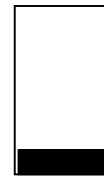
A little bit

In the Middle

A lot

17. Have you tried to get rid of memories of _____? (e.g., have you told the memories to go away?)

YES



NO

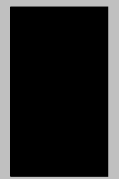
A little bit

In the Middle

A lot

18. Have you found it hard pay attention to the same thing? (e.g., have you found it hard to watch the whole of a TV program?)

YES



NO

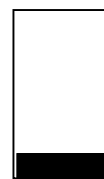
A little bit

In the Middle

A lot

19. Have you had feelings in your body when you think about _____? (e.g., sweating, trouble breathing, feeling sick, and heart beating fast).

YES



NO

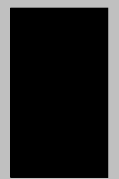
A little bit

In the Middle

A lot

20. Have you had bad dreams or nightmares about _____?

YES



NO

A little bit

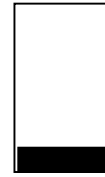
In the Middle

A lot

21. Are you being extra careful? (e.g, checking to see who is around you)

YES

NO



A little bit

In the Middle

A lot

22. Have you had trouble staying asleep? (e.g., have you woken up a lot in the night?)

YES

NO



A little bit

In the Middle

A lot

INSTRUCTION: “Thank you for answering these questions. That was very helpful.”

Office Use (scoring)

I _____

A _____

H _____

TS _____

**GLASGOW DEPRESSION SCALE FOR
PEOPLE WITH A LEARNING DISABILITY (GS-LD)**

Administrative instructions

Each question should be asked in two parts. First the participant is asked to choose between a 'yes' and 'no' answer. Use the symbols, if necessary, if there answer is 'no', the score is that column ('0' or '2') should be recorded. If their answer is 'yes', they should be asked if that is 'sometimes' or 'always', and the score recorded as appropriate. Some respondents will be able to use the three-point scale from the start, others might learn the 'rules' as you proceed.

Supplementary questions (*italics*) may be used if the primary question is not understood completely. If a response is unclear, ask for specific examples of what the participant means, or talk with them about their answer until you feel able to allocate it to a response category.

**GLASGOW DEPRESSION SCALE FOR
PEOPLE WITH A LEARNING DISABILITY (GS-LD)**

Name:

Date of Birth:

Date:

Examiner:

Questions (Part 1)

	In the last week.....	Never/No	Sometimes	Always/A lot
1	Have you felt sad? <ul style="list-style-type: none"> • <i>Have you felt upset?</i> • <i>Have you felt miserable?</i> • <i>Have you felt depressed?</i> 	0	1	2
2	Have you felt as if you are in a bad mood? <ul style="list-style-type: none"> • <i>Have you felt bad-tempered?</i> • <i>Have you felt as if you want to shout at people?</i> 	0	1	2
3	Have you enjoyed the things you have done? <ul style="list-style-type: none"> • <i>Have you had fun?</i> • <i>Have you enjoyed yourself?</i> 	2	1	0
4	Have you enjoyed talking to people and being with other people? <ul style="list-style-type: none"> • <i>Have you liked having people around you?</i> • <i>Have you enjoyed other people's company?</i> 	2	1	0
5	Have you made sure you have washed yourself, worn clean clothes, brushed your teeth and combed your hair? <ul style="list-style-type: none"> • <i>Have you taken care of the way you look?</i> • <i>Have you looked after your appearance?</i> 	2	1	0
6	Have you felt tired during the day? <ul style="list-style-type: none"> • <i>Have you gone to sleep during the day</i> • <i>Have you found it hard to stay awake during the day?</i> 	0	1	2
7	Have you cried?	0	1	2
8	Have you felt you are a horrible person? <ul style="list-style-type: none"> • <i>Have you felt others don't like you?</i> 	0	1	2
9	Have you been able to pay attention to things (such as watching TV)? <ul style="list-style-type: none"> • <i>Have you been able to concentrate on things (like television programmes)?</i> • <i>What is your favourite [television programme]? Are you able to watch it from start to finish?</i> 	2	1	0
10	Have you found it hard to make decisions? <ul style="list-style-type: none"> • <i>Have you found it hard to decide what to wear, or what you would like to eat, or do?</i> • <i>Have you found it hard to choose between two things?</i> 	0	1	2

	{Give concrete example if required}			
11	Have you found it hard to sit still? <ul style="list-style-type: none"> • <i>Have you fidgeted when you are sitting down?</i> • <i>Have you been moving about a lot, like you can't help it?</i> 	0	1	2
12	Have you been eating too little? Have you been eating too much? <ul style="list-style-type: none"> • <i>Do people say you should eat more/less?</i> [Positive response for eating too much OR too little is scored.]	0	1	2
13	Have you found it hard to get a good night's sleep? [Ask questions to clarify information. If a positive response is given to one of the following, score positively] <ul style="list-style-type: none"> • <i>Have you found it hard to fall asleep at night?</i> • <i>Have you woken up in the middle of the night and found it hard to get back to sleep?</i> • <i>Have you woken up too early in the morning?</i> [Clarify time] 	0	1	2
14	Have you felt that life is not worth living? <ul style="list-style-type: none"> • <i>Have you wished you could die?</i> • <i>Have you felt you do not want to go on living?</i> 	0	1	2
15	Have you felt as if everything is your fault? <ul style="list-style-type: none"> • <i>Have you felt as if people blame you for things?</i> • <i>Have you felt that things happen because of you?</i> 	0	1	2
16	Have you felt that other people are looking at you, talking about you, or laughing at you? <ul style="list-style-type: none"> • <i>Have you worried about what other people think of you?</i> 	0	1	2
17	Have you become very upset if someone says you have done something wrong or you have made a mistake? <ul style="list-style-type: none"> • <i>Do you feel sad if someone tells you .../gives you a row?</i> • <i>Do you feel like crying if someone tells you .../gives you a row?</i> 	0	1	2
18	Have you felt worried? <ul style="list-style-type: none"> • <i>Have you felt nervous?</i> • <i>Have you felt tense/would up/on edge?</i> 	0	1	2
19	Have you thought that bad things keep happening to you? <ul style="list-style-type: none"> • <i>Have you felt that nothing nice ever happens to you any more?</i> 	0	1	2
20	Have you felt happy when something good happened? <ul style="list-style-type: none"> • <i>[If nothing good has happened in the past week]</i> 	2	1	0

(GDS-CS)

Name:

Carer for:

Date:

	In the last week.....	Never/No	Sometimes	Always/A lot
1	Has X appeared depressed?	0	1	2
2	Has X been more physically or verbally aggressive than usual?	0	1	2
3	Has X avoided company or social contact?	0	1	2
4	Has X looked after his/her appearance?	2	1	0
5	Has X spoken or communicated as much as he/she used to?	2	1	0
6	Has X cried?	0	1	2
7	Has X complained of headaches or other aches and pains?	0	1	2
8	Has X still taken part in activities which used to interest him/her?	2	1	0
9	Has X appeared restless or fidgety?	0	1	2
10	Has X appeared lethargic or sluggish?	0	1	2
11	Has X eaten too little/too much? If no problem, score 0. (A positive answer to either question means it should be scored. Please tick which response is relevant, beside the question.)	0	1	2
12	Has X found it hard to get a good night's sleep? Please also tick which one of the following options is relevant <ul style="list-style-type: none">• Has X had difficulty falling asleep when going to bed at night? €• Has X been waking in the middle of the night and finding it hard to get back to sleep again? €• Has X been waking very early in the morning and finding it hard to get back to sleep? €	0	1	2
13	Has X been sleeping during the day?	0	1	2
14	Has X said that he/she does not want to go on living?	0	1	2
15	Has X asked you for reassurance?	0	1	2
16	Have you noticed any change in X recently? Please explain what changed you have noticed, in either mood or behaviour	0	1	2

GLASGOW ANXIETY SCALE FOR PEOPLE WITH INTELLECTUAL DISABILITIES

Name:

Date of Birth:

Date:

Examiner:

	Score	Never/No	Sometimes	Always/A lot
	Worries			
1	Do you worry a lot? (... feel worked up/wound up/uptight/up to high doh)	0	1	2
2	Do you have lots of thoughts that go round in your head? (...thoughts that you can't stop/come from nowhere)	0	1	2
3	Do you worry about your parents/family?	0	1	2
4	Do you worry about what will happen in the future? (tailored to the individual, e.g. what will happen if you can't live with your mum anymore?)	0	1	2
5	Do you worry that something awful might happen?	0	1	2
6	Do you worry if you do not feel well? (... if you feel sick)	0	1	2
7	Do you worry when you are doing something new? (... like for the first time)	0	1	2
8	Do you worry about what you are doing tomorrow?	0	1	2
9	Can you stop worrying? (reverse score)	2	1	0
10	Do you worry about death/dying?	0	1	2
	Specific Fears			
11	Do you get scare in the dark? (...think of being in bed with the lights out, would you be scared?)	0	1	2
12	Do you feel scared if you are high up? (...think of being up a high building...)	0	1	2
13	Do you feel scared in lifts or escalators? (Would you go in?)	0	1	2
14	Are you scared of dogs? (Would you go near?)	0	1	2
15	Are you scared of spiders? (Would you go near?)	0	1	2
16	Do you feel scared going to see the doctor or dentist?	0	1	2
17	Do you feel scared meeting new people?	0	1	2
18	Do you feel scared in busy places? (...like crowds, shopping centre)	0	1	2
19	Do you feel scared in wide open spaces? (...nothing round about you)	0	1	2

	Physiological symptoms			
20	Do you ever feel very hot or sweaty? (...all hot and bothered)	0	1	2
21	Does your heart beat faster?	0	1	2
22	Do your hands and legs shake?	0	1	2
23	Does your stomach ever feel funny, like butterflies?	0	1	2
24	Do you ever feel breathless? (...hard to breathe/out of breath)	0	1	2
25	Do you feel like you need to go to the toilet more than usual? (...for a 'pee')	0	1	2
26	Is it difficult to sit still? (...feel you can't sit at peace)	0	1	2
27	Do you feel panicky? (...get into a panicle 'state')	0	1	2

Appendix F: Comparison between items on the IES-R and the IES-ID

IES-R	IES-ID
1. Any reminder brought back feelings about it.	1. Have you felt upset or scared when you remember _____?
2. I had trouble staying asleep.	2. Have you had trouble staying asleep? (e.g., have you woken up a lot in the night?)
3. Other things kept making me think about it.	3. Have things kept making you remember _____? (e.g., have you seen or heard something that makes you remember _____)
4. I felt irritable and angry	4. Have you felt angry or like you are about to get angry? (e.g., have you wanted to smash or break things?)
5. I avoided letting myself get upset when I thought about it or was reminded of it.	5. Have you tried not to get upset when you remembered _____? (e.g., have you tried to stop crying when you remembered _____?)
6. I thought about it when I didn't mean to	6. Have you thought about _____ when you didn't mean to? (e.g., thoughts of _____ have popped into your head when you were doing something else?)
7. I felt as if it hadn't happened or wasn't real.	7. Have you felt that _____ hadn't really happened (e.g., like you had dreamed it).
8. I stayed away from reminders of it	8. Have you tried to keep away from places or people that make you remember _____?
9. Pictures about it popped into my mind.	9. Have pictures of _____ come into your head when you didn't want them to? (e.g. pictures of what happened pop into your head when you were doing something else?)
10. I was jumpy and easily startled.	10. Have you being jumpy or easily scared? (e.g., when someone walks up behind you)
11. I tried not to think about it.	11. Have you tried not to talk about or think about _____?
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	12. Have you been upset because of _____ but not asked for help
13. My feelings about it were kind of numb	13. Have you found it difficult to have strong feelings? (for example, difficulty crying or been happy)
14. I found myself acting or feeling like I was back at that time.	14. Have you felt like _____ was happening again?
15. I had trouble falling asleep.	15. Have you had trouble falling asleep. (e.g., staying awake for a long time

-
- 16. I had waves of strong feelings about it.
 - 17. I tried to remove it from my memory

 - 18. I had trouble concentrating.

 - 19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.
 - 20. I had dreams about it.
 - 21. I felt watchful and on-guard.
 - 22. I tried not to talk about it

- when you are trying to sleep)
- 16. Have you started to feel very upset or very scared about _____
 - 17. Have you tried get rid of memories of _____? (e.g., have you told wanted the memories to go away)
 - 18. Have you found it hard pay attention to the same activity? (for example, watch a TV program)
 - 19. Have you had feelings in your body when you think about _____? (for example, sweating, trouble breathing, feeling sick, heart beating fast).
 - 20. Have you had bad dreams or nightmares about _____
 - 21. Are you being extra careful (for example, checking to see who is around you)
 - 22. Have you tried not to talk about _____
-

Appendix G: Demographic Information Sheet

Participant identification number _____

Gender: **Male** **Female**

What is your date of birth? _____

Service Recruited From: **Day Centre** **Residential Service** **LD Team**

Type of learning disability (if known) _____

How would you describe your ethnicity?

White
Black
Mixed

Asian
Chinese
Other (specify)

Appendix H

Letters relating to ethical approval are provided on the subsequent pages.



National Research Ethics Service
NRES Committee East of England - Hertfordshire

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597733
Facsimile: 01223 597645

25 August 2011

Mr James Hall
Trainee Clinical Psychologist
Cambridge and Peterborough Mental Health Partnership
Norwich Medical School, University of East Anglia
Norwich
NR4 7TJ

Dear Mr Hall

Study title: Measuring symptoms of trauma in adults with intellectual disabilities: Validation of the Lancaster and Northgate Trauma Scales.
REC reference: 11/EE/0263
Protocol number: 2

Thank you for your letter of 15 August 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Alternate Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

[Omit this sub-section if no NHS sites will be taking part in the study, e.g. Phase 1 trials in healthy volunteers]

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

This Research Ethics Committee is an advisory committee to the East of England Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Other conditions specified by the REC

James Hall has appropriately addressed all points in the decision letter with one exception: Point (i) (d) on page 4 of the provisional letter under the heading "Participant Information Sheet for Keyworker", the REC asked for, "information about independent sources of advice" to be provided. The line, "If you remain unhappy and wish to make a formal complaint you could contact the Independent Complaints and Advocacy Service" should be changed to, "If you wish to make a formal complaint you should contact your staff union".

The Head of Beds and Herts ICAS has confirmed that the service is only available to patients making a complaint about treatment or the service they have received from the NHS - it is not for NHS staff.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter from James Hall		17 June 2011
REC application	IRAS Parts A&B 82007/224253/ 1/342	17 June 2011
Investigator CV - James Hall		
Investigator CV - Laura Jobson		
Response to Request for Further Information from James Hall		15 August 2011
Participant Information Sheet	3	07 August 2011
Participant Information Sheet: Keyworker Information Sheet	1	09 August 2011

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Participant Consent Form: Consent to Share Details	2	09 August 2011
Participant Consent Form: Informed Consent for ID sample	2	09 August 2011
Participant Consent Form: Informed Consent for Keyworker	2	09 August 2011
Interview Schedules/Topic Guides - Trauma Information Form (to be administered by the researcher as a semi-structured interview)	2	17 June 2011
Questionnaire: Lancaster and Northgate Trauma Scale for Intellectual Disabilities - Self Report Version and Informant Version	(validated)	
Questionnaire: Impact of Event Scale revised for people with intellectual disabilities (IES-ID)	(non-validated) 1	17 June 2011
Questionnaire: Trauma Information Form	3	09 August 2011
Evidence of insurance or indemnity - Letter from Tracy Moulton		16 June 2011
Evidence of insurance or indemnity - Zurich Municipal		16 June 2010
Evidence of insurance or indemnity - Zurich Municipal		25 May 2011
Protocol	2	09 August 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/EE/0263

Please quote this number on all correspondence

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
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the National Patient Safety Agency and Research Ethics Committees in England*

With the Committee's best wishes for the success of this project

Yours sincerely



PP **Mr David Grayson**
Alternate Vice-Chair


Email: Anna.Bradnam@eoe.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Cc: Ms Tracy Moulton
Research Contracts Manager
Research Enterprise and Engagement Office
The Registry
University of East Anglia
Norwich
Norfolk
NR4 7TJ

Dr Paul Mills, NHS Norfolk
Lakeside 400, Old Chapel Way
Broadland Business Park
Thorpe St Andrew
Norwich
NR7 0WG

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Norfolk Community 
Health and Care

NHS Trust

Ref: 2011LD02

Mr James Hall
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E-mail: paul.mills@norfolk.nhs.uk
www.norfolk.nhs.uk/research

30 August 2011

Dear Mr Hall,

**Re: 2011LD02. Measuring symptoms of trauma in adults with intellectual disabilities:
Validation of the Lancaster and Northgate Trauma Scales (LANTS).**

REC Number: 11/EE/0263

Chief Investigator: Mr James Hall, University of East Anglia

Sponsor: University of East Anglia

Further to your submission of the above project to the R&D office at NHS Norfolk your project has now been reviewed and all the mandatory research governance checks have been satisfied. I am therefore pleased to inform you on behalf of **Norfolk Community Health & Care** that NHS permission (R&D approval) was granted on **30th August 2011** for your study to take place at the following sites:

- LD Services, Norfolk Community Health & Care

Please note that NHS Permission is granted on the basis of the information supplied in the application form, protocol and supporting documentation, if anything subsequently comes to light that would cast doubts upon, or alter in any material way, any information contained in the original application, or a later amendment application there may be implications for continued NHS Permission.

Please note the following conditions of approval.

- Please provide the NHS Norfolk R&D Office with an updated keyworker participant information sheet, as described in the letter of favourable opinion from NRES Committee East of England (Hertfordshire) on 25th August 2011.
- Please note this approval letter does not extend to LD services in Norfolk County Council.

Please note it is your responsibility to ensure that these conditions are disseminated to all parties involved in this project.

You may now begin your study at the above sites.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework. I have enclosed two copies of the Standard Terms and Conditions of Approval. Please sign and return one copy to the R&D office at the above address. Failure to return the standard terms and conditions may result in NHS permission being revoked.

NHS Norfolk hosts the Research Management and Governance Services for NHS Norfolk, NHS Suffolk, NHS Great Yarmouth & Waveney and Norfolk Community Health & Care NHS Trust

Please note, under the agreed standard terms and conditions you must inform the R&D Office at NHS Norfolk of any proposed changes to this study, whether minor or substantial, and to keep the Committee updated on progress. Please note also, if you wish to extend approval to any sites other than those listed above you must apply for this through the relevant R&D office.

If you have any queries regarding this or any other project please contact Paul Mills, R&D Officer, at the above address. Please note, the reference number for this study is **2011LD02** and this should be quoted on all correspondence.

The following documents were reviewed:

Letter of Favourable Opinion from NRES Committee East of England – Hertfordshire, dated 25th August 2011

- Protocol, Version 2, 9th August 2011
- Participant Information Sheet, Version 3, 7th August 2011
- Participant Information Sheet – Keyworker, Version 1, 9th August 2011
*Please note clause above
- Participant Consent Form – To Share Details, Version 2, 9th August 2011
- Participant Consent Form – ID Sample, Version 2, 9th August 2011
- Participant Consent Form – Keyworker, Version 2, 9th August 2011
- Questionnaire – LANTS
- Questionnaire – IES-ID, Version 1, 17th June 2011
- Questionnaire – Trauma Information Form, Version 3, 9th August 2011
- Evidence of Insurance/Indemnity – 16th June 2011 & 25th May 2011
- Investigator CV – James Hall
- Investigator CV – Laura Jobson

Other Documents Reviewed

- Unsigned R&D Form, Lock Code 82007/232295/14/29
- Fully Signed REC Form, Lock Code 82007/224253/1/342
- Signed SSI Form, Lock Code 82007/238098/6/675/110347/220053
- Investigator CV – Peter Langdon

Yours sincerely



Dr Jenny Harries
Joint Director of Public Health
NHS Norfolk & Norfolk County Council
Signed on behalf of Norfolk Community Health & Care

cc: Laura Jobson, University of East Anglia, Academic Supervisor
Tracy Moulton, University of East Anglia, Sponsor Representative
File

Enc