

**An exploratory investigation of how people with
intellectual disabilities experience anxiety and
depression.**

Submitted for the Doctorate in Clinical Psychology
University of Leicester

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Declaration

I declare that this thesis is the result of my own work. It has not been submitted to any other institution or for any other qualification.

Summary

1) Literature Review - Anxiety and depression: The experiences of people with intellectual disabilities.

Literature on the experiences of people with intellectual disabilities of anxiety and depression is reviewed, with emphasis on how these experiences might be similar or dissimilar to those of the general population. The review considered factors that make people with intellectual disabilities vulnerable to anxiety and depression, issues in the assessment of anxiety and depression with this client group and the applicability of psychological understandings of anxiety and depression to people with intellectual disabilities. The literature suggested that people with intellectual disabilities typically experience anxiety and depression in very similar ways to the general population. Implications for clinical practice and directions for future research are discussed.

2) Research report - An exploratory investigation of how people with intellectual disabilities experience anxiety and depression.

This study aimed to explore the experiences of eight people with intellectual disabilities of anxiety and depression. Semi structured interviews were conducted and the transcripts were analysed using Interpretative Phenomenological Analysis (IPA; Smith, 1995). Four super ordinate themes emerged; 1) identifying a change in affective state; 2) Describing these changes feel different; 3) understanding the experience, making sense of the changes, labelling them and relating them to internal factors; 4) Coping with the changes. The findings are discussed in relation to the

existing literature, implications for clinical practice are outlined and directions for future research are suggested.

3) Critical Appraisal

A critical reflection on the research process from the perspective of the researcher, highlighting the decision making process, the ups and downs of the research process and the lessons learnt for future project implementation.

Word Count

Literature Review:

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References:

2655

Research Report:

Main text:

13855

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2062

Critical Appraisal:

Main text:

4317

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320

Total

Main text:

26422

Including references and appendices:

31495

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Addenda One **Interview Transcripts (Separately bound)**

**Anxiety and depression: The experiences of people with
intellectual disabilities**

A Review of the literature*

*This review has been prepared for submission to the Journal of Applied Research in Intellectual Disabilities. Notes for contributors to this journal are included in Appendix P.

Anxiety and depression: The experiences of people with intellectual disabilities. A review of the literature

Introduction

Until recently the needs of people with intellectual disabilities who experience mental health problems have largely been overlooked. There are difficulties in identifying affective difficulties, such as anxiety and depression, in people with intellectual disabilities (McBrien, 2003). This may have been a factor in the lack of support they have received. Understandings of whether people with intellectual disabilities could experience affective difficulties have changed greatly over the years. Whilst it is now widely accepted that people with intellectual disabilities do experience anxiety and depression, questions are still raised as to whether this experience would be the same as that of the general population. For example, Syzmanski and Grossman (1984) argued that the emotional states of people with intellectual disabilities are biological in origin and qualitatively different from the general population.

This literature review aims to explore the experiences of anxiety, depression and associated negative affective states for people with intellectual disabilities. It also considers whether these are different from those of the general population. The review will begin by briefly presenting the history and context of interest in working psychologically with people with intellectual disabilities and the prevalence rates of anxiety and depression in this population. The search strategy will be outlined before the review considers the major areas of interest identified through the literature search. Finally, implications for clinical practice and future research will be discussed.

History, context and prevalence

Historically the mental health needs of people with intellectual disabilities attracted little research or clinical attention. The Victorian view that people with intellectual disabilities were 'untreatable' persisted into the early 20th century (Andrews, 1996; Caine *et al.*, 1998; Neugebauer, 1996; Rushton, 1996). Interest in applying psychological techniques to this client group grew with the advent of behaviourism in the 1950s, but their mental health needs continued to be overlooked.

There are a number of explanations for this lack of interest. First, Priest and Gibb (2004) suggest that people with intellectual disabilities were thought to be incapable of experiencing mental health problems due to cognitive and intellectual deficits. Second, diagnostic overshadowing of mental health problems, whereby clinicians attribute changes in behaviour to an individual's intellectual disability has been well documented (see Reiss *et al.*, 1982 for more details). Third, there is the notion that people with intellectual disabilities do not experience anxiety and depression in the same way as the general public (Szymanski & Grossman, 1984).

Evidence has shown that people with intellectual disabilities do experience anxiety and depression. Although the exact figures have varied, research suggests that around 40 per cent of individuals with intellectual disabilities have mental health problems (Birch *et al.*, 1970; Tonge *et al.*, 1996; Borthwick-Duffy, 1994; Corbett, 1979).

Prevalence rates for most common mental health problems within this population are significantly higher than in the general population. Symptoms of depression have been reported in up to 44 per cent (Marston, Perry & Roy, 1997) and 57 per cent

(Meins, 1993) of clinical samples of people with intellectual disabilities. Major depression has been reported in between 1 and 5 per cent of people with intellectual disabilities (Cooper, 1996). Anxiety disorders amongst individuals with mild intellectual disabilities are thought to be at least as common as in the general population. Matson *et al.* (1997) report prevalence rates of anxiety between 2-25 per cent.

In the 1990s a number of policies and documents for professional guidance began to emerge which addressed the need for service provision for people with intellectual disabilities and mental health problems. The Royal College of Psychiatrists produced 'Meeting the mental health needs of people with learning disabilities' in 1996. This document promoted joint working between specialist intellectual disability and mainstream services to meet the needs of this client group and ensure equality of access to services. Similar statements can be found in 'Valuing People' (Department of Health, 2001a), a document which has been extremely influential in outlining service provision in health, education and social care for people with intellectual disabilities.

Search strategy

A narrative literature review was undertaken, whilst employing a systematic approach to identify studies relevant to anxiety, depression and negative affective states in people with intellectual disabilities. Literature searches in English language psychology, psychiatry, nursing, medical and social science peer reviewed journals were conducted. The following databases were accessed: Ovid Online, Psychlit, Psycharticles and Web of Science to identify relevant studies produced between 1970 and 2007. Manual searches of relevant journals and published books were also conducted (see Appendix A). The reference lists of articles identified through this process were used to identify further relevant literature.

The following terms were used in the searches;

LEARNING DISABILIT*, INTELLECTUAL DISABILIT*, MENTAL
REDARDATION, MENTAL HANDICAP, ADULT, CHALLENGING
BEHAVIOUR, ANXIETY, DEPRESSION, AFFECTIVE DISORDER, MENTAL
HEALTH, EMOTIONAL, ABUSE, HEALTH.

Research articles that examined factors related to people with intellectual disabilities aged 16 years and over and anxiety, depression and negative affect were considered. Some relevant studies of adolescent populations were considered. Types of articles included critical reviews, theoretical and empirical studies. Studies that focused on particular conditions (for example autism, Tubular Sclerosis) were not included as it was felt that these might reflect issues that were specific to that clinical group.

The literature found through these methods were grouped into those addressing vulnerability factors, assessment issues, and the application of theoretical models in the treatment of people with intellectual disabilities. This review examines each in turn.

Definitional Issues

Intellectual disability

The terms 'learning disability' and 'intellectual disability' are currently used interchangeably in the UK. This review uses the term 'intellectual disability' in line with the guidance for authors of the Journal of Applied research in Intellectual Disabilities. The Professional Affairs Board of the British Psychological Society defines the three core criteria for intellectual disability as:

- Significant impairment of intellectual functional;
- Significant impairment of adaptive / social functioning;
- Age of onset before adulthood.

All three criteria must be met for a person to be considered to have an intellectual disability.

Anxiety / depression

The definitions of anxiety and depression are defined clearly in DSM IV and ICD 10 (see Appendix B). For the purpose of this review, the terms *anxiety* and *depression* will be used when they have been used by the authors of the studies presented.

Evidence suggests a strong co-morbidity between anxiety and depression (for example Clark & Watson, 1991; Barlow *et al.*, 1996). The two conditions are considered to be linked by a common negative affect, which consists of several specific emotional states including fear, sadness, anger, contempt and disgust (Watson & Clark, 1992). In this review the terms *negative affect* or *negative affective states* will be used to indicate conditions under which individuals could be expected to experience either anxiety, or depression, or both.

Vulnerability factors

Organic and biological factors

Several factors have been identified which make people with intellectual disabilities more vulnerable to negative affect. Priest and Gibb (2004) suggest that prenatal brain damage, birth injury and low intelligence are all in themselves risk factors for the development of mental health problems. They also suggest that communication difficulties limit the extent to which individuals are able to make their distress explicit and add to the frustration they experience. Furthermore, people with intellectual disabilities tend to have higher health needs than the general population (Department of Health, 2001) and are more likely to experience chronic health problems. Links have been found between physical health problems and depression (Rutter, 1976; Gardiner, 1980; Motet-Grigorias & Schuckit, 1986; Richards, 1986).

Adverse life events

Exposure to adverse life events and social factors over which an individual has limited control, can make people vulnerable to depression and anxiety (for example Brown & Harris, 1978, Zubin & Spring, 1997). This has been demonstrated to be true of people with intellectual disabilities. Stavrakiki and Mintsoilis (1997) for instance, reported a correlation between the frequency of disruptive life events and depressive disorders. Bramston, Fogarty and Cummins (1999) reported that people with intellectual disabilities experience many of the same stressors as the general population, highlighting how being bullied, bereaved or arguing with family and friends were found to be highly stressful for both student populations and people with intellectual disabilities. Whilst many of the factors may be the same, McGillivray and

McCabe (2007) emphasise the need to question whether the impact of such events is different for people with intellectual disabilities, as this has yet to be conclusively established. The following sections consider vulnerability factors common to the experience of anxiety and depression across populations. The focus is on research relevant to people with intellectual disabilities.

Experience of failure

People with intellectual disabilities have often had repeated experiences of failure across their home and school lives, attended 'special needs' classes or schools and witnessed their peers and siblings surpass their achievements (Nabuzoka, 2000). Such experiences can lead to a state of 'learned helplessness' whereby an individual believes that their efforts to help themselves will inevitably fail. Reynolds and Miller (1985) found that young adults with intellectual disabilities scored significantly higher than non-disabled peers on self-report measures of academic learned helplessness and depression. The relationship between learned helplessness and depression was not discussed in this small scale (n=52) study and the findings should be interpreted cautiously as the participants were not clinically depressed. No further examples of learned helplessness in relation to people with intellectual disabilities were identified in the literature.

Social support

Social support, particularly having at least one close inter personal relationship, has been highlighted as important to psychological well being (Hughes, 1999; Duck, 1991). Adequate social support has often been found to be lacking in the lives of people with intellectual disabilities. Several studies have found that opportunities for

friendship for people with intellectual disabilities are restricted (for example Katz & Yekutiel, 1974; Krauss *et al.*, 1992; Petrovski & Gleeson, 1997).

In a large scale study (n =1542) of people with intellectual disabilities living in supported accommodation, Emerson and McVilly (2004) found that levels of reported friendship activity (for example having a friend round for a meal) were low. The majority of participants were drawn from within areas of significant social deprivation, however, the authors do not comment on how financial implications may impact on friendship activities. No control group was used in the study, therefore it is not possible to consider whether the findings varied from the general population within the same localities.

Stigmatisation

Having an intellectual disability has been widely considered to be a stigmatised identity (Goffman, 1968, Edgerton, 1967). Several studies have suggested that people with intellectual disabilities are aware of this stigma (Jahoda *et al.*, 1990; Davis & Jenkins, 1997; Rapley *et al.*, 1998). Jahoda and Markova (2004) defined stigma as arising 'when a person differs from the dominant social norms ... and is negatively evaluated by others' (p.712). They also argue that stigma may significantly impact on an individual's self image and consequently emotional and psychological well being. Crocker and Quinn (2000) suggested that a wide range of social and psychological factors might determine how the stigma is experienced by an individual. For instance, an individual who expected to encounter prejudice might experience less emotional impact on doing so than an individual who expected to be treated fairly. Dagnan and Sandhu (1999) have suggested that having a positive

social role, such as having a job, can protect an individual from the emotional damage of stigma. However, people with intellectual disabilities are less likely to hold such roles, for instance due to limited employment opportunities (Department of Health, 2001).

Managing social deprivation

Low socio-economic status has been widely considered as a risk factor for anxiety and depression within the general population (for example Brown & Harris, 1978). The prevalence of intellectual disability is higher amongst those in poorer social circumstances (Leonard & Wen, 2002). Jahoda *et al.* (2006) suggest that people with intellectual disabilities may lack the psychological and practical resources to cope with situations of such adversity. They describe, for instance, the impact that limited literacy and numerical skills would have on managing the demands of daily life. Helsel and Matson (1988) found that holding a negative view of one's social skills is associated with depression. Within the general population, people may be able to draw on successes in other areas of life to compensate for areas of deficit. Linville (1987) described this as "psychological complexity" and it is considered to be a protective factor against depression. People with intellectual disabilities may have fewer areas of strength and success to fall back on (Jahoda *et al.*, 2006).

Abuse

The negative implications for psychological well being following physical, emotional and sexual abuse are well documented. Sexual abuse in particular has been linked to higher rates of mood disorder and other psychiatric conditions (Andreotti *et al.*, 1999). People with intellectual disabilities are considered to be particularly

vulnerable to abuse (McCarthy & Thompson, 1997). The list of factors that makes them more at risk than members of the general population is extensive and includes communication difficulties, power differences with carers, lack of knowledge about inappropriate behaviour, compliance and not being believed. In a study of 84 cases of abuse of people with intellectual disabilities, Turk and Brown (1993) found that emotional trauma or distress was reported in just over half. Sequeria and Hollins (2003) highlight the methodological limitations of this study however, noting for instance, that data was drawn from care staff reports and formal assessment of the psychological impact was not undertaken. This could indicate that emotional distress was not accurately reported and the actual rates of distress may be higher. Sobsey and Mansell (1994) suggested that behavioural difficulties and emotional distress were common effects of abuse in people with all levels of intellectual disability. They also highlighted that there may be social consequences, such as the loss of a day or residential placement, for the victim of abuse. This secondary effect would again have a negative impact for the individual's psychological and emotional well being.

The studies presented so far have considered the factors that may make people with intellectual disabilities vulnerable to anxiety and depression. The literature suggests that many of these factors are the same as in the general population. However, people with intellectual disabilities may not have the psychosocial resources that can lessen the negative impact of difficult life events and circumstances.

Assessment issues

Recognition of a mental health problem of any kind in any member of the population is subjective and complicated by individual differences in presentation. Within the population of people with intellectual disabilities the list of complicating factors is considerable. Researchers have considered the impact of a variety of factors including professional knowledge, diagnostic criteria, different sources of information and differences in presentation. Each of these factors will be considered in turn, in relation to how they impact on the conclusions reached about the presence and experience of anxiety and depression in people with intellectual disabilities.

Professional Knowledge

'Diagnostic overshadowing' occurs when the label of intellectual disability takes priority over or hinders the recognition of emotional and psychological problems (Reiss *et al.*, 1982). This is thought to be a common occurrence in the identification of mental health difficulties, including anxiety and depression, in people with intellectual disabilities. Levitan and Reiss (1983) demonstrated the diagnostic overshadowing effect across several professional groups including social workers, psychiatrists and psychologists. Further evidence of diagnostic overshadowing was found by Mason and Scior (2004) in a large clinical vignette study of 133 clinical psychologists and 90 psychiatrists. Clinicians were less likely to consider diagnosing people with intellectual disabilities with schizophrenia or substance related problems or treat them with psychiatric admission or medication.

The majority of studies into diagnostic overshadowing have employed vignettes and it has been suggested that the clinical significance of the findings is limited by the failure to use other methodologies. In fact, Jopp and Keyes (2001) questioned whether overshadowing was a 'methodological artefact' of clinical vignette studies, in that the lack of information available in the vignette leads to a different diagnosis than would be expected in a real life clinical interactions.

For the majority of the general population, difficulties with negative affect are first identified by their general practitioner (G.P.). In a report for Mencap, Singh (1997) reported that GPs would welcome further training in meeting the physical and mental health needs of people with intellectual disabilities. This suggests that those who work on the front line of health and social care may realise that they may not be identifying anxiety and depression in people with intellectual disabilities.

Furthermore, Bates *et al.* (2004) and Quigley *et al.* (2001) suggested that care staff with this client group lack knowledge and training in relation to mental health problems and affective disorders. This has implications in terms of the reporting and assessment of the problem to professionals. Therefore, there seems to be a need for further training for professionals and support staff working in this area.

Diagnostic criteria

Several studies have concluded that the standard diagnostic criteria are adequate for use with people with intellectual disabilities (Matson *et al.*, 1999; Prasher & Hall, 1996; Tsiouris *et al.*, 2003). The standard diagnostic criteria are outlined in DSM-IV and ICD –10. The only necessary modification suggested was the use of appropriate behavioural equivalents suitable for people across the range of intellectual disability.

Further to this, McGilivray and McCabe (2007) have argued that individuals with mild / moderate intellectual disability experience symptoms in common with the standard diagnostic criteria. Their study used a range of modified self-report scales to identify levels of depressive symptomology and 39.1 per cent of participants demonstrated symptoms of depression according to the Beck Depression Inventory II (Beck *et al.*, 1996). The most frequently reported indicators of depression (or risk of depression) were sadness, self criticism, loss of energy, crying and tiredness. These are consistent with the standard diagnostic criteria. All of the participants for this study were drawn from vocational or supported employment projects and therefore may not have been representative of the client group as a whole in that they had considerable opportunities for social interaction and employment. No measure of intellectual functioning was taken, therefore it was not possible to consider if there were any differences in rates of depression across the ability range.

In contrast, Cooper and Collacott (1996), Hurley (1996) and Davis *et al.* (1997a) reviewed the literature and suggested that depression may manifest differently in people with intellectual disabilities. Hurley (1996) reviewed case studies of people with Down's Syndrome and noted an absence of cognitive symptoms. Davis *et al.* (1997a) suggested that people with moderate to severe intellectual disabilities may display more behavioural symptoms of anxiety and depression, including self harm and temper tantrums. All the authors suggested that alternative diagnostic criteria should be developed.

However, McBrien (2003) has noted a number of methodological weaknesses in the studies included in the above reviews. These include low sample size, inadequate

descriptions of the intellectual disability and inconsistent definitions of depression. McBrien also noted that the psychometric properties of many of the scales used in these studies are open to question. The scales used were often modifications of existing instruments such as the Beck Depression Inventory (Beck *et al.*, 1996) and the Zung Depression Scale (Zung, 1965) and normative data for the intellectual disability population is not available. McBrien has recommended the use of the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities / Mental Retardation (DC- LD, Royal College of Psychiatry, 2001) criteria for depression, which are designed for use alongside the ICD-10 standard criteria for people with mild intellectual disabilities.

Differences in presentation and symptoms of affective disorder

One of the key discussions in this area is whether people with intellectual disabilities experience the same symptoms as those in the general population. Marston *et al.* (1997) studied the symptoms of 36 individuals across the intellectual disability range who had a diagnosed depression. Within the mildly disabled group the core features of an ICD 10 diagnosis of depression were significantly higher in the depressed group than the non-depressed group. These core features were depressed mood, reduced energy and reduced interest. As the levels of disability increased, the core features were less significant and behavioural symptoms were more frequent. These included self injury, aggression and screaming. This suggests that people with mild intellectual disabilities may present with similar symptoms to the general population but people with moderate to severe intellectual disabilities may present with different symptoms.

Tsiouris *et al.* (2003) obtained completed Clinical Behaviour Checklist for Persons with Intellectual Disability reports from 92 people from with borderline to moderate intellectual disabilities (CBCPID; Marston *et al.*, 1997). Depressed and non-depressed groups were established but were not matched on age or gender. Again, the authors suggested that the core features of depression (which were depressed mood, reduced energy and reduced interest) were good measures of depression in people with intellectual disabilities. They found no evidence that challenging behaviours such as aggression and self injury should be considered as symptoms of depression (Marston *et al.*, 1997). They suggested that the core DSM IV features of depression should be used in the assessment of people with intellectual disabilities. The authors highlighted differences in the samples which may have contributed to the different findings of the two studies, for example the participants in the later sample were older and contained more people with Down's Syndrome, both of which are associated with lower rates of challenging behaviour (Corbett *et al.*, 1979; Day, 1985; Collacott *et al.*, 1998).

Informant versus self-reports of affective disorder

A further factor in the identification of affective disorders in people with intellectual disabilities is the use of self or informant reports. This section will consider research relating to the abilities of people with intellectual disabilities to report on their experiences of negative affect. First, studies that use quantitative methods will be presented. These have typically examined the use of checklists and questionnaire measures. Second, studies that have used qualitative methods to explore people with intellectual disabilities reports of their experiences of negative affect will be presented.

Quantitative studies of self-report measures

In the past, diagnosis of anxiety or depression relied heavily on information gathered from informants. Informant reports are subject to bias, being based on the values and understandings of the informant and so may not accurately reflect the experience of the individual (Burt, 1999). Moss *et al.* (1996) argue that reliance on informant reports may lead to clinicians missing 'a vital source of clinical information' (p.457).

Masi *et al.* (2002) aimed to examine the concurrent validity of informant and self-report versions of a number of assessment tools, both general and specific, for anxiety and / or depression¹. A sample of 50 adolescents with mild to moderate intellectual disabilities who had a received a diagnosis of depression and / or anxiety were included in the study.

Individual participants' comprehension of the self-report measures were carefully established. Correlational analysis suggested high convergent validity of the general measures and the authors suggested that these could be used reliably as general screening instruments to determine psychiatric cases.

Anxiety measures were highly correlated with the general measures and were significantly inter-correlated, suggesting they too were suitable for the identification of anxiety in people with intellectual disabilities. However, low convergent validity was found between the depression measures, indicating that they should be used tentatively.

¹These measures were; The Psychopathology Instrument for Mentally Retarded Adults (PIMRA, Matson *et al.* 1984), the Child Behaviour Checklist (CBCL, Achenbach & Edelbrock, 1983) and the Zung Self Rating Depression Scale (Zung, 1965)

The authors advocated the use of structured interviews with both clients and key informants. Caution should be taken in generalising these findings to adults living in the community as the participants were aged 11-18 living in residential accommodation. Also several child specific measures were used, which may not be valid for use with adults.

The use of self-report data to assess the emotional and behavioural problems of adolescents with intellectual disabilities was supported by Douma *et al.* (2006). The study aimed to consider whether the Youth Self-report (YSR; Achenbach, 1991a) could be used to assess emotional and behavioural problems in adolescents with moderate to borderline intellectual disabilities. The sample included 281 adolescents with intellectual disabilities. A test of intellectual functioning was administered (WISC-II; Weschler, 1991) and participants were grouped according to higher IQ (≥ 70) and lower IQ (< 70). The results were compared to those of 1047 adolescents without intellectual disabilities and to the results of the Child Behaviour Checklist (Achenbach & Edelbrock, 1983) administered to their parents. The study supported the use of the YSR for both groups (higher and lower intellectual disability). Agreement between parents' reports of difficulties and adolescents' self-reports was generally low, in line with findings from non-intellectual disabled adolescents. However, agreement was higher for parents of anxious/ depressed children with intellectual disabilities. The authors questioned whether intellectually disabled adolescents spend less time outside the home and therefore their difficulties are more noticeable to their parents and also whether they are less able to conceal emotional problems than adolescents from the general population. The problem scores reported by adolescents with intellectual disabilities tended to be the same as or lower than

those from the general population. This is contrary to other studies which have tended to use parent or teacher rather than self-reports and found problem scores for adolescents with intellectual disabilities to be higher. The YSR was completed independently by adolescents without intellectual disabilities but it was administered as an interview to those with disabilities. It is possible that face-to-face contact led to a reluctance to disclose difficulties, particularly those which might be considered negative (for example aggressive behaviour).

Moss *et al.* (1996) also found disagreement between self and informant reports. The Psychiatric Assessment Schedule for Adults with a developmental disability (PAS-ADD, Moss *et al.*, 1993) was used with 100 adults with an intellectual disability. The authors found that, if the self-report interview had not been completed, 35.2 per cent of the cases would have gone undetected. The authors found considerable discrepancies between some of the self and informant reports: in some cases one report would suggest an individual showed no symptoms, another report would suggest a diagnosis. They considered how lack of recognition by informants might contribute to this discrepancy. Moss *et al.* (1996) suggested that it is essential to interview both the respondent and informant during assessment.

The studies presented so far in this section suggest that the standard diagnostic criteria are appropriate for use with people with intellectual disabilities. They also suggested that they experience many of the same symptoms of anxiety and depression as the general population and that they are able to discuss these experiences.

Exploring negative affect through qualitative methods.

In recent years there has been growing interest in using qualitative methodologies to explore directly the views and experiences of people with intellectual disabilities. In adopting a qualitative approach there is an implicit assumption that the participants will be able to self-report on the phenomenon that is under investigation. Topics that have been explored include identity (Davies & Jenkins, 1997), loneliness (McVilly *et al.*, 2006), physical interventions with people who display challenging behaviours (Hawkins *et al.*, 2005) and in-patient psychiatric care (Longo & Scior, 2004).

Mitchell *et al.* (2006) interviewed six adults with intellectual disabilities about their experiences of traumatic events, with consideration to the diagnostic criteria of PTSD. The transcripts were analysed using Interpretative Phenomenological Analysis (IPA; Smith *et al.*, 1995) The participants described in detail the mental, emotional and physical effects of the trauma such as headaches and intrusive thoughts, for example “it upset me, made me cry”. They described avoiding people and places associated with the traumatic event and trying not to have thoughts about it as ways of coping with the worry that they were still at risk. Mitchell *et al.* highlighted how difficult this can be for people with intellectual disabilities as they can often be dependent on people who were implicated in the traumatic event (for example abuse by a family member).

The study illustrated how the participants often struggled to understand why the event had happened. Several participants attempted to blame someone for the event.

Whilst this seemed to be useful in minimising the guilt and shame some participants experienced as a result of the trauma, for some it perpetuated the belief that the world is a dangerous place, maintaining their anxieties about future traumas. Mitchell *et al.*

felt that there were similarities between the responses the participants described to trauma and the diagnostic criteria for PTSD in the general population.

Issues over the quality of qualitative research have been raised and guidance has been produced to ensure the reliability and validity of findings that emerge through qualitative methodologies (Elliot *et al.*, 1999). Mitchell *et al* (2006) addressed several of these issues, for instance, they 'situated the sample' by providing background details about the participants and 'grounded the examples' using quotes to illustrate how interpretations were reached. Consideration was given to the construction of the interview schedule, as demonstrated by discussions of the pilot interviews. Booth and Booth (1996) suggest that care is taken over the design of interview schedules for use with people with intellectual disabilities in order to maximise engagement. They suggest using direct questions, developing rapport and agreeing an agenda to minimise anxiety. The first author made explicit potential influences on the interpretations reached, such as previous clinical experiences using a cognitive framework. However, as an IPA study, the findings of this study are interpretations of the experiences relevant to the sample and there are significant difficulties in attempting to generalise the findings to the wider client group.

The second relevant paper is by Wilson *et al.* (2005) who aimed to explore young people with intellectual disabilities' understandings of depression and anxiety, treatment, and the impact on their lives. Eight young people (aged 14-25) with intellectual disabilities and their carers and professionals were interviewed. Wilson *et al.* found that the participants tended to describe their mental health in terms of

unpleasant emotional and physical sensations associated with negative affect. They rarely spoke in abstract terms, but phrases such as '*panic*', '*fed up*' and '*frightened*' were common. A number of the young people identified feeling angry, or irritated, or acting aggressively as signs that they were becoming depressed. Some said that they 'took their feelings out' unfairly on other people, particularly family. Some talked about feeling worthless and described harming themselves. Participants who experienced anxiety reported feeling constantly worried and were often unable to identify a cause for this.

Participants were able to identify contributory factors for their difficulties. They and their carers described how difficult life experiences, such as losing loved ones and being bullied, contributed to their distress. Physical health problems such as epilepsy and bowel conditions were a major source of anxiety and embarrassment. Many discussed experiences typical of teenage years such as family tension and feeling restricted by their parents. None of the participants had sought help themselves, this was typically arranged by families and school through GPs. Many of the participants (young people and carers) described the value of having someone to talk to and this was often a health or social care professional.

The report was rich with examples and details are given about the backgrounds of the participants. However, limited information was provided as to the procedural details, for instance, the method of analysis was not described. The ability range reflected within the sample was not detailed. Little was reported of the influences of the researcher on the findings reached and it was not clear how the examples from carers

and the young people were integrated. Again it is difficult to generalise the findings beyond the sample.

The two papers presented in this section demonstrate that qualitative methodologies can be used to explore the experiences of people with intellectual disabilities of negative affect. Within the studies the participants were able to report on various aspects of their experiences such as emotional, physiological and behavioural changes and consider factors that contributed to their distress. The experiences reported were typically in common with those reported by the general population. The studies also highlight the importance of addressing quality issues within qualitative research.

Theoretical Models of affective disorders in people with intellectual disabilities

In the past a therapeutic disdain existed towards people with intellectual disabilities (Bender, 1993). Psychotherapy was rarely offered as they were considered unlikely to benefit. Therefore, unlike members of the general population who received psychological interventions, people with intellectual disabilities would continue to experience negative affect with little intervention. In recent years a small but growing body of research has developed which examined the applicability of psychological models and interventions for people with intellectual disabilities. The focus has been on psychodynamic and cognitive behavioural approaches and so these are considered in turn below.

Psychodynamic model

In psychodynamic approaches emphasis is placed on the development of a therapeutic relationship between therapist and client. It is believed that by establishing a safe and trusting relationship with the therapist the clients can re-enact and successfully resolve underlying emotional conflicts and, by doing so, alleviate their distress.

During psychotherapy the therapist attempts to understand 'the latent or unconscious meaning of the client's communication' (Beail *et al.*, 2005, p.248) through the process of transference. Transference, as first outlined by Freud (1912), occurs when feelings about events and relationships from the past are applied to relationships in the present. Using transference the therapist will help the client to resolve long standing interpersonal issues. Wilner (2005) found that 17 per cent of clinical psychologists

working with people with intellectual disabilities use a psychodynamic approach yet there has been very little published research into its efficacy.

Beail *et al.* (2005) measured the effectiveness of psychodynamic psychotherapy in routine clinical practice using readily available and well established outcome measures. Statistical analysis suggested that there were significant reductions in clinical distress and improvements in interpersonal functioning and self-esteem. Previous studies by Beail and colleagues, (Beail & Warden, 1996; Beail, 1998) have also documented gains made by clients with intellectual disabilities through psychodynamic intervention.

The majority of the research into the efficacy of psychotherapy with people with intellectual disabilities has used a naturalistic, open trial design. Such studies typically involve small teams or solitary clinicians engaging in routine practice. Pre and post therapy measures are administered to clients / participants. There are a number of limitations with these studies. These include the lack of control groups, the use of opportunistic samples and the influence of non-specific therapeutic factors.

While the outcomes point to the possible value of psychodynamic psychotherapy for this client group, the underlying processes of successful treatment remain unclear (Wilner, 2005). Although Beail (1998) highlights the role of listening with undivided attention to the feelings of the clients, Wilner (2005) points out that this is not a factor specific to psychodynamic psychotherapy.

Cognitive Behavioural Models

Cognitive behavioural treatment models for anxiety and depression have proved to be highly effective with the general population (Hawton *et al.*, 1989), so much so that they are recommended as the treatment of choice by the National Institute of Clinical Excellence (NICE). In a study of psychotherapeutic interventions being used by clinical psychologists working in UK services for people with intellectual disabilities, 35 per cent reported using cognitive behavioural therapy (CBT) methods 'frequently' or 'very frequently' (Nagel & Leiper, 1999). However, there has been considerable debate as to whether people with intellectual disabilities have the necessary skills to participate in CBT (see special issue of *Journal of Applied Research in Intellectual Disabilities* (2006, vol.19 for a full review). These skills include the ability to recognise and label emotions, make links between events and emotions and identify and describe the role of thoughts in experiences (Joyce, 2006). This section will consider studies that have explored the role of cognitive variables in the experiences of people with intellectual disabilities and the applicability of cognitive models for this client group.

Cognitive variables involved in affective disorder

Cognitive therapy was developed by Beck (1967) who postulated that negative thoughts about one's self, the world and the future lead to anxiety and depression. The role of such cognitive variables in negative affect in people with intellectual disabilities has been considered in a number of studies. An early study by Matson *et al.* (1983) did not support an association between cognitive variables and depression. They found no differences in the frequency of negative self-statements made by depressed or non-depressed people with intellectual disabilities.

The majority of studies published subsequently have supported the view that cognitions are of relevance to the experience of negative affect for people with intellectual disabilities. Nezu *et al.* (1995) used a matched control group of 107 people with mild intellectual disabilities to examine the cognitive variables associated with depression. Both self-report (BDI) and informant based (PIMRA) measures of depression were used. Higher rates of depression were correlated with participants' negative automatic thoughts, sense of hopelessness and poor social support. Significant differences were also found between depressed and non-depressed groups on all the measures. These findings suggest that cognitions were implicated in depression and that participants were able to report such cognitions.

Esbensen and Benson (2005) also found that people with intellectual disabilities were able to report cognitions associated with depression. The study aimed to examine the cognitive variables associated with Beck's cognitive triad theory and the hopelessness theory of depression using a matched control group of 73 individuals with borderline to moderate intellectual disabilities. The cognitive variables studied (automatic thoughts, the cognitive triad, hopelessness, attributions and self-esteem) were all significantly correlated with depressed mood. Significant differences between depressed and non-depressed groups were reported on all variables except hopelessness. The findings again supported the association of cognitions in the development and maintenance of anxiety and depression in people with intellectual disabilities. However, the majority of participants were of Caucasian background (86 per cent) which limits how far the findings can be generalised to more diverse populations. Also 75 per cent of the participants were in employment and this factor may have implications for the frequencies and kinds of cognitions reported, for

instance, having a job has been found to be a protective factor against negative affect (Dagnan & Sandhu, 1999).

Glenn *et al.* (2003) found further evidence for the role of cognitions in negative affective states for people with intellectual disabilities. The study aimed to test whether there was a relationship between anxiety and depression and whether these could be predicted by the presence of negative cognitions. These hypotheses were supported. The sample was relatively small (46 people with mild to moderate intellectual disabilities) and they were recruited from a housing and employment project and so, again, may have had more opportunities for work and social interaction than many people with intellectual disabilities. The presence of anxiety, depression and negative cognitions was determined using self-report measures. These measures were adapted for the study and the possibility of changes to their psychometric properties was highlighted by the authors.

In their study Glenn *et al.* also examined the cognitive specificity hypothesis, which suggests that separate patterns of cognition exist for separate conditions (for example anxiety and depression). However, their findings did not support the specificity theory in that similar cognitions were reported for both anxiety and depression. The authors discussed the difficulties of developing 'pure' measures of anxiety or depression and their associated cognitions within any population.

Dagnan and Sandhu (1999) also examined the idea that cognitive factors influence depression in people with intellectual disabilities and explored the role of social comparison on the affective states of this group. They aimed to examine the

relationship of social comparison with self esteem and depression in people with intellectual disabilities. The relatively small sample consisted of 43 individuals from across the ability range. The findings demonstrated that self esteem and negative social comparison were associated with higher rates of self-reported depression.

Cognitive models of affective disorder

While a number of studies have investigated the role of cognitive variables in anxiety and depression in people with intellectual disabilities, there has been very little research into whether cognitive models as applied to the general population are appropriate for this client group.

The diathesis- stress model suggests that a person who attributes negative events to internal, stable and global events is at higher risk of depression if faced with stressful life events (Ambramson, Metalsky & Alloy, 1989). Esbensen and Benson (2006) found that the participants did make negative attributions following stressful events. Both attributional style and experiencing greater numbers of stressors were independently predictive of depression. However, participants also made negative attributions in the absence of stressors and so the interaction between stress and attribution was not predictive of depression. Therefore the diathesis stress model of depression was not supported.

Esbensen and Benson (2007) attempted to evaluate whether Beck's cognitive triad (1967) is related to depressed mood in people with intellectual disabilities. The triad consists of negative views about self, the world and the future. The findings showed that people with intellectual disabilities with depression held negative views of

themselves consistent with the cognitive triad, supporting suggestions that Beck's cognitive theory of depression is applicable to people with intellectual disabilities. However, it was also found that the cognitive triad as reported over a four month period was not predictive of subsequent depressed mood. This finding does not support the use of Beck's model with people with intellectual disabilities.

Both studies used the same sample (n=73) participants who were recruited from supported housing agencies. The sample reflected the borderline – moderate ability range, 70 per cent of participants being within the mild range. The majority of the participants were of Caucasian background and in employment, which limits how far the findings can be generalised. The sample also included people suffering from a number of different psychiatric illnesses (for example bi-polar disorder, dysthymia and personality disorder). It is difficult to judge the impact of this diversity on their eventual findings. It is possible that this impacted on the cognitions and attributional styles reported.

Several of the measures used were adapted from child measures and no information on their psychometric properties when completed by people with intellectual disabilities was provided. All measures were administered by interviews and this (as noted previously) may bias response. In particular this can lead to participants minimising their distress so as not to be seen in a negative light.

The studies presented in this section suggest that people with intellectual disabilities, like the general population, are able to identify cognitions and discuss them in relation to negative affective states. Whilst the studies do not provide comprehensive support

for cognitive theories of depression for this client group, further research is need as there have only been two empirical studies.

Clinical Implications

Service provision

Policies such as 'Meeting the mental health needs of people with learning disabilities' (Royal College of Psychiatrists, 1996) and 'Valuing People' (Department of Health, 2001a) promote equal access to services and joint working between specialist intellectual disability and mainstream services to meet the needs of this client group. This review has highlighted how people with intellectual disabilities are affected by negative affect, anxiety and depression and that their experiences have much in common with the general population.

Assessment issues

The suitability of the diagnostic criteria of anxiety and depression for people with intellectual disabilities remains unclear. In a recent paper McBrien (2003) recommended the use of the DC-LD measure which is designed for use alongside the standard ICD-10 criteria. Of course, an individual approach to assessment is generally advocated, as this allows opportunities to discuss difficulties directly with both service user and carer.

Therapeutic issues

People with intellectual disabilities are particularly vulnerable to negative affect due to psychosocial issues such as a lack of social support, stigmatisation and financial difficulty. When working therapeutically around such difficulties, an awareness of the social context of the individual should be maintained and clients should be supported to make changes to aversive circumstances where possible. Many of the difficulties

arise from a lack of social integration which leads people with intellectual disabilities to feel isolated and stigmatised. Policies such as 'Valuing People' aim to address this by promoting community integration.

Evidence around the applicability of the cognitive behavioural model suggests that some aspects of the theory are appropriate for use with people with intellectual disabilities. Clinicians using CBT treatment programmes for anxiety and depression should ensure that clients understand the concepts they are being asked to consider and that they have access to the thoughts and feelings under investigation for example negative automatic thoughts.

The small number of relevant qualitative studies highlight the importance of establishing what is important for the client when discussing their difficulties. It also emphasises the need to consider an individual's level of understanding and ability in order to design and ask questions that the individual can engage with.

Research implications

Assessment and identification

New assessment tools continue to be developed for identifying anxiety and depression among people with intellectual disabilities. However, several studies have suggested that the standard diagnostic criteria are appropriate. This warrants further investigation, particularly in relation to the use of behavioural equivalents and the applicability of the standard criteria for people with moderate intellectual disabilities. Self-report measures were seen to be useful in gaining a fuller picture of the individual's difficulties. Further exploration is needed of the psychometric properties of self-report measures which have been adapted from standard or child focused measures.

Theoretical understandings

The role of cognitive variables in depression and anxiety amongst people with intellectual disabilities has recently come under examination. This is an area that warrants further empirical investigation. It would be particularly helpful to pinpoint more accurately which aspects of the cognitive triad, if any, are related to negative affect within this population. For instance, if negative views of self were to be implicated in people with intellectual disabilities' experiences of negative affect, this could lead to tailored intervention plans that include cognitive restructuring.

Findings with regards to cognitive models of depression for people with intellectual disabilities have been inconsistent. Further exploration is needed of the general applicability of cognitive behavioural models as the research is limited to two small

scale studies based on the same population. The generalisability of the findings across the client group is somewhat limited. It would also be beneficial to consider other cognitive theories of depression (for example Gilbert, 1992, 2000) and also of anxiety (for example Wells, 1997), as these have yet to be explored with people with intellectual disabilities.

More empirical research is also needed into alternative psychological understandings of negative affect in people with intellectual disabilities, for instance the psychodynamic model. Ideally this would adopt more rigorous research designs than the open trials that have dominated the research to date. Controlled trials for instance, would strengthen the credibility of the evidence.

Qualitative research

People with intellectual disabilities have been demonstrated to be able to engage well with qualitative techniques such as semi-structured interviews, as long as careful consideration is given to the construction and administration of the interview schedule. Qualitative research appears to be an effective way of exploring the subjective experiences and understandings of difficult topics such as negative affect. More research of this nature would be welcomed as it would not only add interesting insights into how this client group experience and understand difficulties such as anxiety and depression but it would create further opportunities to consider the effectiveness of qualitative research techniques when used with people with intellectual disabilities.

Summary

The review explored factors that make people with intellectual disabilities vulnerable to negative affect, highlighting the many similarities with the general population.

However, it seems likely that people with intellectual disabilities may find themselves exposed to such factors more frequently than the general population and they may have less psychosocial resources to help them cope.

The review highlighted the complexities of diagnosing and assessing anxiety and depression in people with intellectual disabilities. On the whole, the research suggests that the standard diagnostic criteria for anxiety and depression are appropriate for this client group and that they experience the same symptoms as the general population.

The value of including the direct reports of people with intellectual disabilities in assessment was highlighted in the findings of several studies that confirmed that they are able to discuss and report their emotional states. This was further demonstrated in qualitative studies of negative affect.

Cognitive behavioural interventions are often the recommended intervention when a member of the general population is affected by an emotional disorder. These interventions are based on cognitive models of the emotional disorders. It is clear from this review that many people with intellectual disabilities are able to identify and report on their thoughts associated with negative affect. However it remains unclear whether cognitive interventions and models are always relevant or suitable for people with an intellectual disability. There is a need for further research to explore the usefulness and suitability of the different psychological approaches for those suffering anxiety or depression in this population. In addition such research will need to take

account of the different ranges of intellectual disability and take into account the fact that people with intellectual disabilities may quite frequently experience adverse social contexts that are known to be associated with negative affect.

The diverse range of issues presented in this review illustrates how interest in negative affect amongst people with intellectual disabilities has increased in recent years. This is a far cry from the days when they were considered incapable of such experiences. People with intellectual disabilities do experience anxiety and depression and the experience appears to be much the same as that of the general population.

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**An exploratory investigation of how people with
intellectual disabilities experience anxiety and
depression**

Research Report

Abstract

Objective: This study aimed to explore the experience of anxiety and depression from the perspective of people with intellectual disabilities.

Method: Eight individuals participated in a semi – structured interview. The transcripts were then analysed using IPA Methodology (Smith, 1995).

Results: Four superordinate themes emerged: 1) identifying a change in affective state 2) describing how these changes feel different 3) understanding the experience, making sense of the changes, labelling them and relating them to internal factors 4) coping with the changes.

Discussion: The findings are discussed in relation to the existing literature, implications for clinical practice are outlined and directions for future research are suggested. It is suggested that the people with intellectual disabilities who participated in the study experienced anxiety and depression in many of the same ways as the general population.

Introduction

It is estimated that around 40% of individuals with intellectual disabilities have additional mental health needs (Birch *et al.*, 1970; Tonge *et al.*, 1996; Borthwick-Duffy, 1994; Corbett, 1979). People with intellectual disabilities have been reported to experience anxiety and depression at the same or higher rates than the general population (Marston, Perry & Roy, 1997; Meins, 1993; Cooper, 1996).

In the past, people with intellectual disabilities were considered incapable of experiencing anxiety and depression due to their cognitive and intellectual deficits (Priest & Gibb, 2004). 'Diagnostic overshadowing' meant that changes in people's emotional state or behaviour were automatically attributed to their intellectual disability and alternative explanations were not sought. It is now accepted that people with intellectual disabilities experience a range of symptoms that would usually be associated with anxiety and depression. This is reflected in professional guidance issued by the government (DoH, 2001) and professional bodies (RCP, 1996).

As such there is a need to increase professional knowledge about the experience of anxiety and depression for people with intellectual disabilities. The published literature explores the factors which make people with intellectual disabilities vulnerable to the symptoms anxiety and depression, issues in identification and assessment and the theoretical models that offer a psychological understanding of anxiety and depression in people with intellectual disabilities. These factors will be discussed in brief before the specific aims of this study are outlined.

Vulnerability to anxiety and depression

People with intellectual disabilities may be at increased vulnerability for affective disorders (Marston, Perry & Roy, 1997; Meins, 1993; Cooper, 1996). Whilst some of this vulnerability is directly linked to the intellectual disability, for instance brain damage or communication difficulties, most of the vulnerability factors are the same as the general population. It is, however, recognised that people with intellectual disabilities are more likely to endure adverse experiences and life events, for instance, poverty (Leonard & Wen, 2002), abuse (Turk and Brown (1993), negative life events and social difficulties (Emerson and McVilly, 2004). These factors have been linked to an increased risk of affective disorder. Experiences of abuse, failure and stigmatisation are thought to impact negatively on self-esteem and psychological well being (Crocker & Quinn, 2000; Reynolds & Miller, 1985; Andreotti *et al.*, 1999). People with intellectual disabilities may lack the alternative personal strengths and role models that can mediate against the effects of such experiences (Dagnan & Sandhu, 1999; Jahoda *et al.*, 2006). Social support can also be a protective factor against the development of affective disorders but, again, this is often an area lacking in the lives of people with intellectual disabilities (Emerson & McVilly, 2004).

It can therefore be suggested that the factors that precipitate the development of anxiety and depression in this client group are the same as those for the general population. However, people with intellectual disabilities may experience more adverse experiences and life events and be less able to cope with them.

Issues in the assessment of anxiety and depression in people with intellectual disabilities

Recognition of a mental health problem of any kind in any member of the population is subjective and complicated by individual differences in presentation. There are a number of factors that make identification of affective disorder even more complicated with people with intellectual disabilities. These include 1) the inadequacy of diagnostic criteria (Matson *et al.*, 1999; Prasher & Hall, 1996; Tsiouris *et al.*, 2003) 2) the training received by professionals (Reiss *et al.*, 1982; Singh, 1997; Bates *et al.*, 2004; Quigley *et al.*, 2001) 3) the view that people with intellectual disabilities with depression present differently to members of the general population (Marston *et al.*, 1997; Matson, 1999, Tsiouris *et al.*, 2003) and 4) the use of self reports or informant reports in assessment (Masi, 2003; Moss *et al.*, 1996; Douma *et al.*, 2006).

Generally studies suggest that the symptoms of depression experienced by people with mild intellectual disabilities seem to reflect those of the general population, suggesting that the standard diagnostic criteria may be appropriate (Matson *et al.*, 1999; Prasher & Hall, 1996; Tsiouris *et al.*, 2003). The use of self report measures of depression and anxiety suggests that people with mild intellectual disabilities are able to describe their own experiences of anxiety and depression (Moss *et al.*, 1996; Masi *et al.*, 2002; Douma *et al.*, 2006).

Only two studies have been identified which directly address how people with

intellectual disabilities describe their experiences of emotional distress. Both of these employed a qualitative methodology which implicitly implies that the participant is able to report on his or her own experience.

Mitchell *et al.* (2006) used the Interpretative Phenomenological Approach (IPA; Smith *et al.*, 1995) to interview six adults with intellectual disabilities about their experiences of traumatic events. The participants described in detail the mental, emotional and physical effects of the trauma such as headaches and intrusive thoughts, for example *“it upset me, made me cry”*. There were clear similarities to the post trauma experiences reported by members of the general population. Participants also described avoiding people and places associated with the traumatic event and trying not to have thoughts about it as ways of coping with the worry that they were still at risk. Often the participants struggled to develop an understanding of why the event had happened.

Wilson *et al.* (2005) produced a report for the Foundation for People with Learning Disabilities which outlined eight case studies of people aged 16-26 years with intellectual disabilities who had experienced anxiety and depression. Interviews with young people, their carers and professionals involved in their care, video diaries and photographs were used to collect information. The method of analysis was not described in the report. The participants described the emotional states, behaviours and physiological sensations they experienced, typically in quite concrete terms, for example *“nervous, I get sweaty palms, I feel a bit sick”*. There was little discussion of the thoughts that the young people associated with anxiety but some of the participants described specific worries for example *“oh, I'm going to fail this”* and

some described wishing they had not been born. Some of the young people and members of their support networks described precipitating factors that led to the development of their difficulties, these included the lack of social activity, illness and family tension.

Some of the difficulties in identifying and assessing anxiety and depression in people with intellectual disabilities have been highlighted. These problems particularly relate to disagreement over whether people with intellectual disabilities have the same experiences (specifically symptoms) as members of the general population and how well they are able to describe their experiences. Mitchell *et al.* (2005) and Wilson *et al.* (2005) demonstrated that qualitative methodologies could be employed with people with intellectual disabilities to discuss difficulties with affect, which impact on them emotionally, cognitively, behaviourally and physiologically.

Theoretical models of affective disorders in people with intellectual disabilities

There has been very little evaluation of whether psychological models of anxiety and depression are appropriate for understanding and treating people with intellectual disabilities. Evaluations of psychodynamic approaches have been limited to naturalistic examinations of routine outcomes (Beail *et al.*, 2005; Beail & Warden, 1996; Beail, 1998) although significant reductions in distress have been demonstrated.

More recent research has focused on the cognitive behavioural model, although findings have been some what mixed. Empirical investigation of the diathesis-stress

model (Esbensen & Benson, 2006) and Beck's cognitive triad model (Esbensen & Benson, 2007) have been undertaken. Whilst negative cognitive patterns and increased experience of negative life events were associated with depressed mood, the models were not fully supported by the findings. Further research is needed as the applicability of cognitive models cannot be ruled out on the basis of two relatively small scale studies.

There has been some support for the view that people with intellectual disabilities are able to describe certain cognitive variables such as automatic thoughts, the cognitive triad, hopelessness, attributions and self-esteem (Esbensen & Benson, 2005). These variables were linked with higher rates of self reported depression (Esbensen & Benson, 2005; Glenn *et al.*, 2003; Nezu *et al.*, 1995). Differences in cognitive patterns were observed between depressed and non- depressed groups (Esbensen & Benson, 2005; Nezu *et al.*, 1995), but cognitive specificity, the separate patterns of thoughts believed to exist for separate conditions (for example 'something awful will happen' for anxiety and 'life isn't worth living' for depression, Glenn *et al.*, 2003) were not observed¹

There has been limited research into the applicability of theoretical models of anxiety and depression for this client group. Some support has been shown for the role of cognitions in the development and maintenance of anxiety and depression in people with intellectual disabilities.

¹ Examples of thoughts drawn from the Cognition Checklist (CCL) Beck *et al.* (1987)

Summary

Large numbers of people with intellectual disabilities suffer from anxiety and depression. People with intellectual disabilities experience many of the same contributory factors in the development of anxiety and depression as the general population. However, complicating issues in assessment and limited demonstrated efficacy of psychological models means that the needs of this group continue to go unmet.

An understanding of what it is like for a person with intellectual disabilities to experience anxiety and depression is missing from the literature. There has been very little research that has directly addressed the subjective experience of emotional distress in people with intellectual disabilities. Qualitative studies have demonstrated that people with intellectual disabilities are able to discuss a broad range of issues connected to their experiences, including their thoughts, feelings, behaviours and understandings of anxiety and depression. Wilson *et al* (2005) considered the experiences and understanding of anxiety and depression of young people with intellectual disabilities (aged 14-25 years). However, this study did not focus solely on the perspectives of people with intellectual disabilities as it included carer's views. It also reflected only the views of a younger age range. There is, therefore, a need to develop further insight into the experiences of anxiety and depression in adults with intellectual disabilities.

Aims of the study

In keeping with guidance from the Department of Health (2001) and Royal College of Psychiatry (1996) to address the mental health needs of people with intellectual disabilities, there is a clear need to develop further professional understandings of people with intellectual disabilities' experiences of anxiety and depression. This will help inform psychological intervention and service provision. This study will explore the experiences of people with intellectual disabilities who have difficulties with the symptoms associated with anxiety and depression and have received a psychological intervention from a health professional. Areas of consideration include how people with intellectual disabilities recognise symptoms and behaviours associated with anxiety and depression, how they make sense of their experience, why they believe they are having the experiences and how they manage their difficulties. Specifically this study will develop knowledge of 1) how people with intellectual disabilities experience anxiety and depression and 2) how they understand these experiences. Such findings have the potential to influence psychological assessment, formulation and intervention.

Method

Rationale for design

In selecting a methodology with which to explore how people with intellectual disabilities experience anxiety and depression, a qualitative approach seemed a natural fit. Willig (2001) suggests that qualitative researchers are concerned with the '*quality and texture*' (p9) of an experience, seeking to explore the sense people make of their world and the meanings they attribute to events. Furthermore, McVilly *et al.* (2006) suggest that the use of qualitative techniques is in keeping with the '*growing recognition of the importance of listening to people with disability relate their experiences*' in order to develop an understanding of their experience and work with them effectively.

In order to focus on the individual experience of anxiety and depression, methodologies which consider the role of the individual in social processes (for example grounded theory) or which examine the function of an individual's language (for example discourse analysis) were excluded. IPA (Smith & Osborne, 2003) provided a theoretical and procedural framework through which to explore the experiences of people with intellectual disabilities of anxiety and depression. It allows for consideration of their '*embodied experience*' (Kearney & Rainwater, 1996) of anxiety and depression and exploration of how they understand what happens to them.

Participants

Eight participants were recruited to this study. All of the participants recruited were subject to the following inclusion and exclusion criteria:

Inclusion Criteria

- participants were 18 years old or over;
- participants had received input from a clinical professional with the community learning disability health support teams for difficulties related to anxiety or depression;
- the clinical professional had been involved with the individual within the last six months¹; and
- the clinical professional considered that the individual had made some progress in overcoming their initial difficulties and that participation in the study would not cause them distress.

Exclusion criteria

- individuals who had very limited or no verbal communication were excluded as this would make the use of semi structured interviews and the IPA method of analysis very limited; and

¹ Evidence suggests that people with learning disabilities are more prone than the general population to difficulties with memory, so the experience needed to be recent enough for clarity of recall.

- individuals who had additional mental health problems were also excluded as this may have impacted on their ability to focus solely on their experiences of anxiety and depression.

Formal Diagnosis of intellectual disability

The Professional Affairs Board of the British Psychological Society (2000) defines the three core criteria for intellectual disability as:

- Significant impairment of intellectual functional;
- Significant impairment of adaptive / social functioning;
- Age of onset before adulthood.

All three criteria must be met for a person to be considered to have an intellectual disability.

The researcher was aware that not every individual who received a service from the Community Learning Disability Health Support Teams would have undergone a formal assessment of intellectual functioning. Completing such assessment requires a lot of effort on the participant's behalf and the results can impact on their self-esteem and the services they receive. The researcher felt that it was unethical to expect participants to undergo formal assessment for the purposes of this study and that the use of assessment could lead potential participants to decline.

Formal Diagnosis of anxiety / depression

Similarly, formal diagnoses of anxiety or depression were not sought. The individuals who participated in this study considered themselves to have difficulties associated with anxiety or depression and it was their understandings and experiences of this that the study aimed to explore.

Recruitment to the study

Clinical professionals within Community Learning Disability Health Support Teams were asked to identify and approach individuals who they felt might be appropriate to participate in the study. Letters of introduction and information sheets were provided to be given to the potential participants (Appendix C and D). The researcher did not approach the potential participants until verbal consent to do so had been given to the clinical professional who had approached them. Telephone contact or a face to face meeting was then made directly with the individual where possible to discuss the purpose and process of interview and to make an appointment to meet.

Ethical considerations

Informed consent to participate

Utmost care was taken to ensure that participants were able to give informed consent. This involved ensuring that potential participants fully understood the nature of the research and that they were under no obligation to participate. Meetings were arranged with potential participants (and supportive others if they wished) to explain

the research and information sheets were provided. All verbal and written information was presented in accordance with Mencap (2000) guidelines (Appendix E). Each participant's right to withdraw at any point was stressed before and during the interview. No attempt was made by the principal researcher to influence the participant's decision and it was stressed that participation or non-participation would have no impact on the care they received currently or in the future from the hosting Care Trust. Participants (or their supporting person) were asked to sign a form to say they understood the purpose and process of the research and consented to participate (Appendix F).

Confidentiality

Confidentiality was discussed with participants from the outset and they were made aware of the circumstances under which the researcher would discuss details with a third party (that is risk of harm to themselves or others). The individual employed to transcribe the interviews was asked to sign a confidentiality agreement (Appendix G). All of these details were provided on an information sheet to the participant. No identifying details were used in the research report and participants were asked to choose their own pseudonym.

Potential for distress

Talking about episodes of psychological distress can be difficult. All the participants were considered by clinical health support team professionals to have made

significant progress in overcoming their difficulties and were emotionally and psychologically able to tolerate the research without it causing distress. Time was allowed in the interview to discuss any issues that arose as a result and any distress resolved. Participants were aware that appropriate others would be informed should their level of distress deem this necessary. All participants were provided with a debriefing letter containing the contact details of the clinical professional most recently involved in their care and also a further clinical psychologist (Appendix H) who was available should they continue to experience distress.

Ethical approval

Ethical approval for this study was granted on July 19th 2006 by the North Sheffield Research Ethics Committee (Appendix I). A revision to the research protocol was approved on 22nd February 2007 (Appendix J). This granted permission for the interview transcripts to be transcribed by a third party and for participants to be approached who had worked with other clinical professionals within the Community Learning Disability Health Support Teams.

Participant characteristics

Of nine participants contacted, eight agreed to participate. Table 1 provides details of each participant's characteristics.

Table 1

Participants characteristics

Pseudonym	Age	Living arrangements	Health Support Team Professionals involved	Minimum length of time known to Health Support Team
Carl	40	Supported accommodation	clinical psychologist	9 years
Sarah	55	Lives with parents	clinical psychologist, community nurse	11 years
Gemma	41	Own home	Assistant psychologist, Community nurse	5 years
Reginald	49	Lives with mother	clinical psychologist, community nurse	8 years
Peter	59	Lives with wife	community nurse	7 years
Adam	65	Unknown	clinical psychologist, community nurse	3 years
Belinda	33	Unknown	clinical psychologist	4 years
Beverley	40	Lives with husband	Trainee clinical psychologist, community nurse	10 years

The mean age of the participants was 47.75 years (range 33 - 65 years). There was an equal ratio of male to female participants. All the participants were White British.

Two lived alone, two were married and lived with their spouse, two lived with family, and the living arrangements of two participants were unknown. The mean length of

Health Support Team involvement was 7.125 years (range 3 - 11 years). Seven of the eight participants had undertaken an intervention with a psychologist (Assistant, Trainee or Qualified Clinical Psychologist), one of the eight participants had undertaken an intervention from a community nurse.

Researcher characteristics

IPA acknowledges the interpretative role of the researcher in the research process and the findings generated and it is important to acknowledge any prior assumptions. The researcher is a 27 year old female trainee clinical psychologist of White British origin. Previous clinical experience in a Community Learning Disability Team had led to an interest in the mental health experiences of experience of people with intellectual disabilities. Potential factors that may influence the research include: 1) Prior experience of working with people with intellectual disabilities; 2) a clinical interest in cognitive models of therapy; 3) knowledge of the literature prior to commencing the empirical research; and 4) personal experience of anxiety.

Data collection

Semi structured interviews were used to collect the data. Particular consideration was given to the design of the interview schedule (Appendix K) to maximise participants' abilities to answer. Suggestions made by Prosser and Bromley (1998) include using short sentences, using single clause sentences, avoiding questions about abstract conceptions and avoiding double negatives.

Time was spent prior to each interview establishing that the participants fully understood the purpose and process of the interview and allowing the interviewer and participant to develop rapport. All interviews were conducted at a place of the participant's choosing, venues included their homes, day centres and the psychology base at a community health centre. The interviews lasted between forty minutes and an hour and fifteen minutes. Breaks were taken where necessary and participants chose who was present at the interview. On three occasions participants opted to have their partners or key workers stay with them throughout the interview.

Data analysis

The interview transcripts were analysed using Interpretative Phenomenological Analysis (IPA). IPA aims to explore the thoughts and feelings of an individual about a particular phenomenon, in this instance anxiety and depression. It acknowledges that the meanings people attach to phenomena will influence their experience of it. In this sense IPA adopts a realist approach to the production of knowledge. It developed as an approach to qualitative research within psychology in the 1990s. The theoretical foundations of IPA are phenomenological, being interested in the ways in which people gain knowledge and understanding of the social world they live in. IPA considers that people do not passively absorb an 'objective reality' (Brocki & Weardon, 2006) but reach their understandings through interpretation of their 'biographical stories'.

It is the aim of IPA to examine participants' personal accounts and consider how they

make sense of their experiences. It does not attempt to produce objective statements or claim to discover truths. IPA does however, assume a chain of connection between an individual's thinking and their emotional state. Smith and Osborn (2003) emphasise IPA's theoretical alliance to cognitive psychology, viewing individuals as 'cognitive, linguistic, affective and physical beings' (p52).

Whilst IPA attempts to take an insider perspective (Conrad, 1987) it acknowledges that research is a dynamic process, complicated by the researcher's own views and internal processes. Smith and Osborn (2003) describe this as a 'double hermeneutic'. They suggest that 'the researcher is trying to make sense of the participant trying to make sense of their world' (p51). Using IPA requires the researcher to have an awareness of the social, cultural and linguistic influences that shape the accounts of their participants and the interpretations they make of these (Patton, 2002). For instance, within this study the researcher was aware that the constructions used of anxiety and depression in designing the study, in particular the interview schedule, were drawn from a professional understanding and the definitions provided by diagnostic systems. The constructions used by the participants were drawn from a variety of sources, including their family, the media and the professionals who have been involved in their care. Participants with intellectual disabilities are likely to integrate phrases and definitions provided by others into their accounts of anxiety and depression in much the same way members of the general public might. However, some of the participants may have impaired verbal abilities as part of their intellectual disabilities. This could mean that in some instances participants might not have fully understood the explanations of anxiety and depression provided by others or they may

lack the linguistic skills to provide sophisticated accounts of their experience.

Issues around the role of language in IPA research with the general population have been raised. Willig (2001) suggests that IPA assumes that individuals are able to use language to '*capture [their] experience*' (p63) and in doing so ignores the arguments of other perspectives, such as discourse analysis, that language, and its availability to an individual, '*precedes and shapes*' (p63) experience. Within this study, in order to try and capture the essence of the participants' experience as opposed to their linguistic skills and available language, the researcher examined the accounts carefully for evidence of lived experience. This included looking for context to be provided for reports of experience, for example, '*this happened to me in this situation and I felt...*', also for non verbal behaviours that supported the accounts, such as touching parts of the body whilst describing symptoms.

IPA studies take an idiographic approach (Smith *et al.*, 1995), concentrating on a small sample size in order to present the perceptions and understandings of a group in detail. A purposive approach to sampling is used, identifying participants for whom the research question will be significant (Smith & Osborn, 2003). The participants are positioned as experts on their experiences (Reid *et al.*, 2005), a position traditionally denied to people with intellectual disabilities but in keeping with increasing efforts by the NHS to listen to the voices of service users.

The stages undertaken in the analysis of data from an IPA perspective have been documented by Smith & Osborn (2003) and Willig (2001). However Smith & Osborn

(2003) stress that these stages should be viewed as guidance rather than protocol by the researcher. The following is an account of the researcher's engagement with the data, using the stages described by Willig (2001).

Stage 1) Initial engagement with the text

The researcher ensured the accuracy of the transcript and reflected on the process of the interview by listening to the tape. After several readings of the transcript, initial thoughts and observations were recorded in the left-hand margin. This included noting key points, asking questions and commenting on language.

Stage 2) Identification of themes

On subsequent readings, preliminary themes that characterised the text were noted and labelled in the right hand margin. The aim was to capture the essence of what had been said by the interviewee. Some psychological terminology (for example 'behavioural indicators') was introduced at this stage.

Stage 3) Clustering of themes

A list of all the themes identified in stage two was produced and the researcher considered how these related to each other. The themes were organised into clusters that seem to fit together based on shared reference points and hierarchical relationships. Clusters of themes were then labelled. The researcher ensured that the themes related directly to the original data by referring back to the original text as the lists of themes were produced.

Stage 4) Production of a summary table

Summary tables of the themes were produced, including quotations and identifying line numbers. This created transparency within the data analysis process as the origins of the theme were clearly indicated within the text. As the table was created superordinate and subordinate themes were identified and labelled. At this stage themes which seemed only marginally related to anxiety and depression or emerged only fleetingly were excluded in order to capture the essence of the experience. A second table of 'master themes' was produced for each participant which included superordinate and subordinate themes. This process (that is stages one to four) was repeated for each participant.

Integrating cases

The individual master themes were then integrated to create an overall master theme table which reflected the experiences of all the participants. This was achieved by listing the master themes from each individual transcript and clustering again. Natural clusters occurred through the use of consistent labels and others emerged due to their relationship to a particular aspect of the experience of anxiety and depression. The themes were labelled in a way that reflected the experiences of the participants and the table was again checked to ensure it reflected the original transcripts.

Validation

Colleagues and supervisors were asked to comment on the above process, demonstrating that the connections between the original text and the themes generated were transparent. These perspectives were then reflected in the analysis. Validation

from at least one participant was sought. This individual agreed to discuss with the researcher the themes that were generated from their interview. Their comments would then have been integrated into the analysis, however, due to difficulties in arranging a suitable time to meet meant that this stage of validation was not completed within the time scale.

A worked example of the process of analysis is included in Appendix L.

Quality Criteria

In order to address questions that have been raised over the reliability and validity of qualitative research, the guidelines produced by Elliott *et al.* (1999) have been followed in this study. These include making explicit potential influences on the researcher, ensuring that the reader can understand how findings were reached based on the data presented and checking that the interpretations made of the data are credible. Table 2 illustrates how quality checks were incorporated into the design of the study.

Table 2

Publishability guidelines for qualitative research (Elliott et al., 1999) and how they are addressed in the study.

Publishability guideline (Elliott et al., 1999)	How this is demonstrated in the study
Owning one's perspective <i>Authors should specify theoretical orientations and personal anticipations, personal experiences of training</i>	Inclusion of statement about the researcher's clinical and personal background
Situating the sample <i>Author describes the research participants and their life circumstances in order that the reader can judge who the findings might reflect</i>	Inclusion of basic demographic information and living arrangements and involvement with Community Health Support Teams.
Grounding the examples <i>Author provides examples of the analytic procedures used and the understanding developed.</i>	Inclusion of worked example of analysis process in Appendix L, also examples from the reflexive diary kept throughout the research process
Providing credibility checks <i>Researcher checks the credibility of categories, themes or accounts.</i>	Having a field supervisor who has extensive experience working with people with intellectual disabilities to comment on the themes and categories.
Coherence <i>The understanding developed by the author forms a narrative for the reader</i>	Clarity in presentation of data and interpretations, use of diagrams to superordinate themes with examples of these taken directly from the text.
Accomplishing general vs. specific research tasks <i>Limitations of generalising the findings to other contexts are specified</i>	The study specifies that the findings relate only to the participants, reflecting their unique experiences.
Resonating with readers <i>The study stimulates the reader to feel that the work accurately reflects the subject or has added to their knowledge of the area.</i>	Supervision was used to discuss the applicability and presentation of the findings.

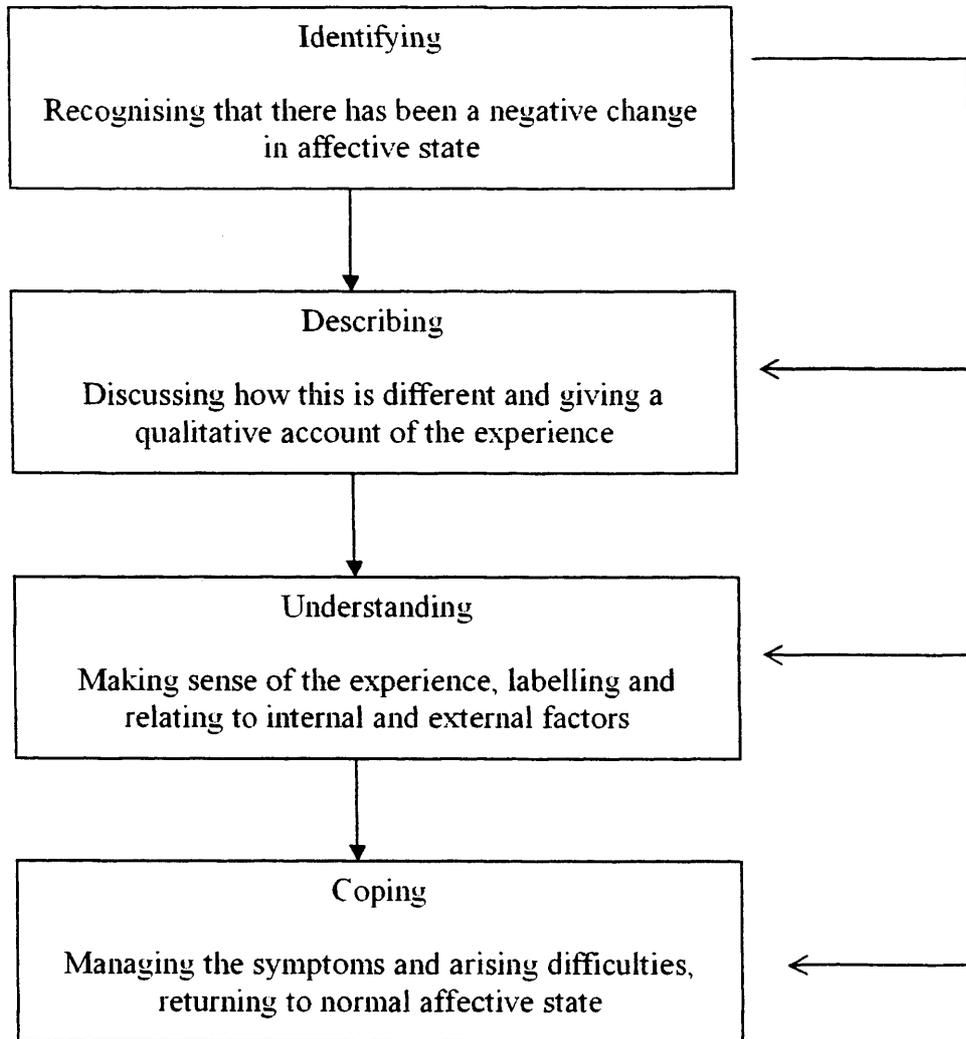
Results

In describing what it was like to experience anxiety and depression, four distinct elements emerged in the participants' accounts. These were:

- 1) identifying that there had been a negative change in their affective state;
- 2) describing how their affective state was different and giving a qualitative account of the experience;
- 3) understanding and making of sense of what the changes were and why they occurred. participants labelled their experiences and related them to internal and external factors; and
- 4) coping with the changes and arising difficulties and returning to their normal affective state.

Figure 1

Diagram to illustrate how superordinate themes may represent stages within the experience of anxiety and depression for participants



The four superordinate themes that emerged from the participants' accounts might be seen to represent different stages in experiencing anxiety and depression. Firstly there is a need to identify that a negative affective change has occurred within one's self. All the participants were able to identify such changes. However, progression through the remaining stages need not be linear. The degree to which participants were able to describe their experiences and had developed an understanding of what

the difficulty was and why it was occurring varied considerably. This did not prevent all of the participants from highlighting ways of coping with their difficulties. This suggests that being able to describe anxiety and depression in detail and develop an understanding of the difficulties did not prevent the participants from coping with negative affective change.

The four superordinate themes and the associated subordinate themes are now discussed in detail in the supporting account.

1) Identifying anxiety and depression

The participants used the terms 'anxiety' and 'depression' interchangeably throughout the interview (as will be discussed) therefore the term 'negative affective state'¹ will be used as indicative of the affective and behavioural changes experienced as a result of anxiety and / or depression. All of the participants were able to identify times when they had experienced negative changes in their affective state, although the level of detail varied considerably. Reginald physically demonstrated how his muscles became tense during difficult exchanges with his family. Paul and Adam were able to describe a general sense that something was different, '*my nerves are going again*'² (Paul 187). Several of the participants described visible changes in their appearance (and that of others) indicating that something was not 'right', '*you're not right you, you look worn down*' (Beverley 260).

¹ Negative affect as defined by Watson and Clark (1995) refers to a general feeling of upset or unpleasant physiological arousal. It encompasses a range of negative mood states including fear, sadness, anger and guilt

² Quotes from participants are printed in *Italics*. The researcher's words are printed in *bold italics*.

Both Adam and Beverley suggested that such changes were particularly evident in the face and eyes, 'its in me face' (Adam 180); 'is there something different about them then?' 'Yeah'. 'What's different?' 'Sad, miserable weepy eyes' (Beverley 222-225).

Other participants generated considerable numbers of physiological, emotional and behavioural indicators that they were experiencing negative affective states. There was considerable overlap between those indicators the participants felt were indicative of anxious and depressed states and it proved difficult to distinguish between them in analysis. A summary of these indicators is provided in the table below. A fuller list is provided in Appendix M.

Table 3

Examples of indicators of anxiety and depression suggested by the participants

Type of Indicator	Participant examples
Physiological	<ul style="list-style-type: none"> • 'shaky hands' (Carl 483) • 'you can see in his, his shoulders go all stiff' (Sarah 195) • 'I can hyperventilate' (Belinda 200) • 'they might be tearful' (Carl 401) • 'lost lots and lots of weight' (Belinda 226) • 'me legs were jelly' (Sarah 263)
Emotional	<ul style="list-style-type: none"> • 'Bit worried like' (Belinda 286) • 'a bit moody' (Carl 505) • 'you might be a little bit afraid' (Belinda 74) • 'just feelings generally rubbish' (Sarah 259)
Behavioural	<ul style="list-style-type: none"> • 'I just went really quiet' (Belinda 156) • 'they might be smoking a lot more' (Carl 487) • 'twiddling my hair' (Sarah 201) • 'not wanting to go out' (Carl 391) • 'they'd stare into space' (Gemma 158)

The participants tended to draw directly from their experiences to discuss the indicators of anxiety and depression, often giving quite specific examples, *'it came up from me stomach'* (Sarah 50). Some were able to generalise from their experiences and describe what other people might experience: *'How would they feel if they were depressed?'* *'Erm, just feeling down all the time'* (Carl 404-405), others found this more difficult: *'no, I've been through it me self but I, I can't think of, I can't see other people'* (Gemma 168).

2) Describing anxiety and depression

Again, all of the participants were able to describe their experiences of anxiety and depression in varying degrees of detail, sometimes in response to direct questions and sometimes not. Some of the participants would focus on one aspect of their experience and others would discuss the different aspects more widely. There was some understandable overlap as the participants expanded on the themes used to identify their negative affective states. In describing what it is like to experience anxiety and depression participants discuss firstly, the associated physiological changes, secondly, behavioural changes, thirdly emotional changes and finally the thoughts experienced during times of anxiety and depression

2.1 Physiological change

The physiology associated with negative affective states was discussed by the majority of participants. Sarah, who recounted both her own experiences of anxiety and depression and those of her father, described vividly the many symptoms she had

experienced, often using simile to illustrate for example '*my head were really like er an elastic band*' (24). Several of the participants discussed symptoms connected to feelings in the stomach (for example '*Can you feel it in different parts of your body?*' '*In one place*'. '*One place? Where's that?*' '*Here*' [*points to his stomach*] Adam 86-90), in the chest (for example '*me heart went like that*' [*demonstrates thumping heart*] Beverley 44), and feeling dizzy (for example '*sometimes I get dizzy and that*' Paul 319).

2.2 Behavioural change

In discussing what it is like to experience anxiety and depression, participants commonly referred to their behaviours. At times the participants would directly link their actions to their affective state, for example '*taking too much showers cos the water relaxes ya, sometimes*' (Carl 491), though this state was not always explicitly labelled as anxiety or depression.

Several participants described behaviours indicative of a lack of motivation, particularly in relation to depression. Carl explained that people who are depressed '*just don't feel like doing owt*' (417) and Gemma shared these thoughts, '*I didn't want to do anything*' (172). Sarah and Belinda were more explicit and talked directly about a lack of motivation, again in relation to depression: '*its when you're not motivated... when I'm depressed I don't want to do anything*' (Sarah 84-86).

Connected to this lack of motivation was an avoidance of social contact discussed by half of the participants: '*I weren't bothered about people*' (Gemma 172).

Self harm was mentioned by six of the participants and suicide by four, although several talked of such behaviours in relation to others rather than themselves. Paul and Belinda described hurting themselves. Paul provided little by way of context for his actions: *'I do something, sometimes, sometimes if I don't do owt, I walk about and stuff, around the house a lot, I walk about'. 'Pacing around the house? Yeah?'* *'Hurt myself on t'wall.'* (313). Belinda linked her self harm to her affective state and explained why: *'I actually clouted myself on the head a couple of times....it got rid of some of that frustration'*. Beverley's suggestion was that suicide was a last resort for *'People don't get any help'* (211), although she frequently referred to such behaviour as *'daft'*, indicating that she did not believe this to be a wise way to resolve negative affective states.

Three of the participants recounted becoming aggressive, either shouting (Adam 449) or hitting out at people, *'sometimes I take it out on our lass (coughs) and I shouldn't do (Paul 179)'* or damaging property, *'I threw them to t'other side of t'room'* (Gemma 38). The participants linked these behaviours to negative affective states, *'Bad moods'* (Paul), *'breakdowns'* (Gemma) and *'going mad'* (Adam), but did not specify them as anxiety or depression.

2.3 Emotional change

All of the participants discussed the emotions they experienced as a result of negative affective states. The level of detail again varied between participants and not all labelled their experiences explicitly as anxiety or depression. Reginald discussed getting *'angry'* as a result of negative social interaction and Paul described how the

feelings inside made him *'feel like I'm going mad'* (79). Feeling *'upset'*, *'frightened'* and *'angry'* were mentioned frequently by the participants. Belinda felt that fear was common to both anxiety and depression (74). Sarah described feeling frightened not only as a result of anxiety but also because of how depression impacted on her and changed her: *'this is what frightened me first time because I was never like this'* (99). She was also frightened by some of the symptoms she experienced. She was the only person to mention hearing *'voices'* and was troubled by their presence, their content and the implications for ability to control her actions: *'So that kinda alarmed me that because I thought oh crikey if I'm gonna be in you know kitchen and I start with them I'm gonna be getting knives or summat out t'drawer'* (99).

A couple of the participants described a build up of feelings that they struggled to contain: *'things build up inside'* (Carl 24); *'when you're really, really cross, like you feel like exploding'* (Belinda 82). This was experienced as something that happens inside their bodies. Accounts of the emotions experienced were often accompanied by strong descriptors. Several participants described *'terrible'* feelings, particularly in relation to panic attacks (Sarah and Gemma). Depression was commonly discussed as feeling *'down'* (for example *'down in the dumps'* Carl 425) and at its worst *'rock bottom'* (Belinda 93).

The loneliness and isolation the participants experienced came through very strongly in the metaphorical accounts they produced. This was captured by Sarah's account: *'I just felt like I were in a box in a tight, er in a like in down in cave in a box only I couldn't and I were that pinned in and I were frightened in this box'* (32). This sense

of being trapped was echoed, by Belinda: *'you feel like there is something trapping you inside, stopping you from moving forward'* (54). Darkness was another common feature of their accounts: *'its like a big black cloud that comes over t'top of ya'* (Gemma 36) and *'I can have a day when its black'* (Sarah 125). The theme of failure and breakdown was also evident. Gemma was concerned that under pressure she would *'end up cracking up'* (310), similarly Belinda explained how depression can make you *'feel like you've gone to pieces'* (52). Sarah produced another vivid description of depression and anxiety, describing how her cognitive abilities were impaired by the experience in mechanical terms: *'it's like a cog in your head that goes off balance'* (95).

2.4 Cognitive Change

The feelings that the participants described were often echoed in their thoughts. Several discussed thoughts concerned with loneliness: *'being on your own'* (Gemma 129) and not being able to cope alone: *'And if there's nobody there to fix it for ya, you've had it really'* (Carl 613). Death and suicide featured in a couple of people's thoughts, particularly Carl's: *'they might be thinking of ways to kill themselves'* (423). Sarah, again used descriptors of darkness when talking about her thoughts: *'they can be nasty things ... its always black ... its never nice things its usually dark things...'* (239). The past, particularly bereavement, was another common theme, *'Oh yeah, I'm missing my mom and dad and my granddaughter'* (Paul 274).

During their interview the majority of the participants discussed 'worrying'. Whilst these worries were diverse and individual, there were several commonalities. Many of

the participants worried about the health and well being of their loved ones:

'whoever's poorly and then worrying about em' (Sarah 131). Their own health and safety was also a concern for some, for example *'it might have been a tumour' (Gemma 270)*. Uncertainty about the future was frequently discussed either in a very general sense: *'a lot of people think about things that's gonna happen' (Sarah 220)* or as specific concerns for example *'will I get another job?' (Belinda 158)*. Worries were not limited to major concerns. Beverley explained how she became concerned by every day occurrences: *'anything, erm like anything, erm, owt, you got a bill, I whittle, got letter, I whittle' (197)*.

There was a sense from some of the participants that the quantity of the thoughts they experienced could be overwhelming. Gemma described how *'When you're sat thinking about things and everything comes flooding back' (62)*. Paul similarly felt that when he was *'wound up'* he thought about *'Everything'*. Confusion at times of negative affective state seemed apparent, particularly when experiencing extreme states, which several of the participants described as *'break down'*. A loss of thoughts seemed to accompany this experience: *'even your mind has gone completely empty, there's nothing in it' (Belinda 106)*.

3) Understanding

The majority of participants had developed an understanding of what anxiety and depression were as constructs and why they experienced the associated negative affective states. Reginald and Paul however, did not demonstrate such an

understanding in their accounts. Neither could give an explanation for why they felt anxious or depressed or what they thought anxiety or depression were, for example '*I don't know love, what is it?*' (Reginald 318). The understandings of the other participants fell broadly into three subordinate categories. Firstly they considered what anxiety and depression were and developed a conceptualisation that allowed them to explain and understand what the difficulties were. Secondly they considered why such difficulties had occurred within the context of their lives and finally they reflected on the impact of anxiety and depression on their lives.

3.1 What is this problem?

What is the difference between anxiety and depression?

Due to the frequent co-morbidity of anxiety and depression, this study invited participants to discuss their experiences of both. It was apparent that for the participants there was little delineation between the two conditions. Some were able to give fairly clear differentiation when asked directly what anxiety or depression were for example Belinda explained that '*Anxiety is when you get worried about things*' and depression feels as though '*you've gone to pieces*'. Some of the explanations were hazier, for instance, Carl was very definite that depression was '*low moods*' (32), however, his definition of anxiety was not dissimilar, '*getting upset inside*'. Most had a sense that there was a difference but several participants were not able to explain the distinction, '*different some how, I don't know why but*' (Beverley 146).

As the participants attempted to identify and describe anxiety and depression there was a lot of crossover in how they labelled their experiences. All, at some point during their interview, used the labels of anxiety and depression interchangeably. In some cases this would be a straightforward changing of the terms. For instance, when asked how anxiety had been explained to her, Belinda went on to say, '*...when you're like, you can get depressed as a child*', discussing depression rather than anxiety. On numerous occasions participants would describe an aspect of their experience of a disorder which would more usually be associated with the other, '*What's depression?*' '*When you err (pause) nerves and all that lot, nerves, and when you get bad nerves and that*' (Paul 119).

Another term that was used frequently to describe negative affective states was '*break down*'. There is little in the participants' accounts to exclusively link '*breakdown*' to either an anxious or depressed state and it seemed to relate to both. The concept of '*breakdown*' is explored again a little later.

Are the difficulties constant?

There was a general consensus among the participants that anxiety and depression were beyond ordinary experiences, it was different to just feeling sad or being frightened. A particular note of difference that was often highlighted was that the emotional and physiological feelings associated with anxiety / depression lasted longer, '*Does it last as long the feelings?*' '*[Pause] No.*' '*No. Which one lasts the longest?*' '*That feeling upset.*' (Carl 67-8).

Many of the participants gave a sense that both anxiety and depression (or both experienced together) are fluctuating conditions: *'sometimes I'm alright, sometimes I'm not'* (Paul 147). Sarah talked several times about her *'blips'*, periods during which she felt her anxiety and depression returned. She described living with her difficulties as *'like being on a see saw'* (261). Sarah, like Gemma and Adam, saw it as inevitable that the states of negative affect would return: *'I always feel a bit down before Christmas'* (Gemma 460). Some of the participants viewed their episodic difficulties as enduring: *'I mean, it may come back, there is no guarantee it will just go away forever but it always goes at some point'* (Belinda 314).

Several of the participants reported that the onset of negative affective states was unpredictable and found this lack of warning quite distressing: *'You can change, and you can change alright and sometimes you can [clicks fingers] click like that'* (Paul 223).

This is an illness

A number of the participants had quite medicalised conceptualisations of anxiety and depression. Some spoke directly of illness or not being well: *'ah, depression. [pause] well, [pause] I weren't very well any way er'* (Gemma 170). Several talked about their *'nerves'*: *'Yes, to calm me nerves a bit'* (Reginald 270). Belinda made indirect references to a genetic predisposition to depression: *'Yeah, and it runs in the family'* (28). Anxiety and depression were also related to mental health problems by a number of participants and from their accounts a hierarchy of the severity of conditions seemed to emerge. Sarah talked about having *'just generally anxiety and depression'* (101) and not *'schizophrenia'*, which would have been much more

frightening for her. However, she explained that having anxiety and depression at the same time would result in a *'bad day'* (109). Belinda felt that for her, experiencing depression was worse than anxiety: *'... because whereas with anxiety it can just be the odd worry ... with depression it's more like you feel like more psychiatric level'* (54). She also talked about varying levels of depression which impact on her differently: *'It just makes you give up when you feel really, really severely depressed'*(56). The concept of breakdowns emerged again, in relation to severity, being seen as serious and significant episodes of mental ill health: *'I had a bad breakdown'* (Gemma 38). Breakdowns were used by a couple of participants as markers in recounting the history of their difficulties: *'I had me first breakdown in, when I was about 13'* (Sarah 10).

Using metaphors

As well as being a means of describing negative affective states, metaphors provided a model through which Sarah and Beverley could understand their difficulties.

Beverley explained anxiety as feeling like a *'zombie'* (88). In doing so she portrayed how she felt confused and isolated and struggled to function in the real world. Lack of functioning is also a feature of Sarah's metaphorical explanation of depression:

'something must have gone off, a cog she [clinical psychologist] explained it its like a cog in your head that goes off balance, she says it's a cog that goes off, off the centre she says it's a cog in your head that you're alright and then suddenly something'll trigger and it goes all hay wire' (95). Her account of mechanical failure suggests that she believes her depression occurs in response to a particular circumstance placing too much pressure on her and overloading her capacity to cope. Sarah indicates that

elements of this understanding were developed with a clinical psychologist. Belinda's understandings also seem to have been shaped by professionals, as she draws on a cognitive analytic framework to conceptualise her depression: '*you can get depressed as a child but like the adult part of you protects the smaller side, the small part of ya.*' (20), but she struggled to recall the finer details suggesting that she has not fully integrated this model into her understanding. Gemma and Beverley similarly recall that anxiety and depression were explained to them by clinical psychologists, but again could not recount the detail.

3.2 *Why has this happened to me at this time in my life?*

A major factor in understanding anxiety and depression for the majority of participants was considering what had happened in their lives to make them experience a negative affective state. Some did not make direct causal links between their circumstances and affective state, just described situations that they had found difficult. Reginald struggled to explicitly discuss anxiety or the effects it had on him. However, throughout the interview he made frequent reference to a difficult family relationship and acknowledged that this made him upset: '*Him at home isn't it. Drives me up the wall*' (Reginald 28).

The remaining participants generated a considerable number of contributing factors, both gleaned from their own experience and postulated from what others might experience.¹

¹It is beyond the word limit of this report to present all of these factors as several were specific to the individual. The factors that were common across participants are presented, a fuller list is provided in Appendix N.

Family Health and Well Being

As the participants described when talking about their thoughts, the health and well being of their families and friends influences their affective state, particularly if someone is unwell: *'she goes to the hospital, fortnight ago... and she was going on Thursday, "I'm going to die" I says, "don't be daft" I went, my heart went like that [demonstrates thumping heart]' (Sarah 44).*

Bereavement and loss

Again, losing a loved one was reported by many participants as negatively impacting on their affective state, with them typically describing thoughts and feelings associated with depression: *'Cos me dad had died...' 'And how does that make you feel?' '... Well it well it don't make me happy' (Sarah 80-83).*

Past experiences

Many of participants described past experiences that had been difficult and they were keen not to repeat. Often these were very individual: Paul disliked hospitals after having an operation and Sarah was nervous about going to crowded places after being pushed in a night club. Gemma and Beverley had been the victims of crime, leading them to move home and increase their security. Gemma also tried to avoid going out at night.

Every day stresses

More than half of the participants reported finding the tasks of everyday life, such as house work, managing their money and holding down a job to be stressful and anxiety

provoking: *'what was it like moving?' 'Anxious [laughs']...and why was that?' '... just getting all flustered'* (Carl 324-7). Such struggles were common regardless of whether participants lived with the support of their families or independently.

Family / Relationship difficulties

Several participants described how tensions within their family were difficult and led to them feeling anxious or depressed. Sarah explained how she felt she was often excluded from family concerns and this made her more anxious: *'then I'm wondering what's hap, what's they've done. So I'd be worrying all day then'*. Belinda and Gemma both talked about separating from partners as very difficult experiences. Belinda described how, *'its like you've lost part of you and even though its for the best'* (166). Gemma felt that a break up had led her to take an overdose, *'we were having a row and I walked out and I went to [pause], bought some beers and sat in t'park [pause] took me medication with me'* (450).

Social interaction

Gemma and Carl's accounts suggested they had very few relationships in their lives: *'Yeah I keep meself to meself I don't bother people'* (Gemma 296). Carl directly linked *'not having enough friends'* (88) to depression. Both described how they would like to know more people, *'what would you have liked to have happened?' '[pause] meet people and just get out more and try and socialise more'* (Carl 550-1).

All of the participants described having had difficulties with social interaction. Many were wary of people they didn't know, *'people that I don't know I don't talk to'* (Adam 227) because *'some might be nasty'* (Carl 273). Half of the participants

reported experiences of being bullied. Carl and Adam related this to having an intellectual disability *'if they hear about your learning difficulties some people pick on ya'* (Carl 104). Both of their stories suggested that they had endured such experiences over many years: *'I run away from school me, I didn't go.'* *'Did you not? Was school not a good time?'* *'No, people was picking on me all the time'* (Adam 432). Adam, now in his sixties, felt it important to raise this when asked at the end of the interview if there was anything else he would like to add, highlighting the personal relevance of the story.

Having a disability

Other participants made references to links between their intellectual disability and anxiety and depression. Not understanding what was happening or not being understood was something that distressed a number of participants. Belinda described becoming frustrated and anxious when *'other people are not grasping what you want'* (144). Gemma recounted a very specific example, that again made her anxious: *'I didn't know what were happening with t'smoke alarm'* (212).

A couple of participants spoke about the restrictions they had experienced as a result of having an intellectual disability. This issue was most apparent for Carl, who described how there were restrictions on what he could own, how he spent his money and what he could achieve with his life, as a result of attitudes towards his intellectual disability: *'there's always boundaries or something that stops you from doing things'* (94). Sarah, in her fifties, talked about how she felt her parents were a little *'over cautious'* because of the difficulties they experienced with her birth. She felt that this

restricted her independence: *'but sometimes I don't always want to go out with them at weekend'* (208).

Beverley stated specifically that her difficulties with Asperger's syndrome / Autistic Spectrum Disorder put her at greater risk of anxiety and depression: *'You can get lots of depression and anxiety, especially on the autistic spectrum'* (46). She also felt that her *'disabilities'* explained why she had experienced repeated episodes of depression: *'it helps me make sense of why I've been depressed all my life'*.

3.2) What control do I have over this problem?

Belinda and Beverley seem to have accepted anxiety and depression as a part of who they are. Belinda's statement suggests that she takes it as read that professionals will know she has depression: *'it was a fact that they knew I'd got depression anyway'* (26). Beverley used phrases indicative of anxiety to describe herself: *'I am a whittley arse'* (191). Sarah struggles to see anxiety and depression as inherent to who she is and becomes distressed by the changes she observes in herself: *'I was never like this'* (99).

Gemma and Adam similarly view some of the behaviour they associate with negative affective states as out of character: *'Makes me do wrong things'* (Adam 181) and *'Sometimes I'll shout at me mom. [Pause] but I always make it up with me mom... its not her fault.'* *'No. But you think bottling things up has made you like that?'* *'Hmm'* (Gemma 388-92). They, along with Paul, seemed to perceive their responses at times of anxiety or depression as beyond their control: *'When anybody gets me mad*

or owt, that's it, me nerves and all that lot, I do get mad yeah' (Paul 139).

3.3 What impact do these difficulties have on my life?

Following on from issues around being in control of one's actions, Belinda and Sarah's accounts suggest that their fear of not being in control is one of the major impacts of affective disorder on their lives. For Sarah there seems to be concern that she won't be in control cognitively and she is scared of what might happen: *'it just throws all your brain out of ... I wouldn't have it again cos it were horrible' (97).*

Belinda dislikes the vulnerability of other people seeing the emotions she has failed to contain: *'it's really embarrassing when you break down in public when you cry in front of people' (252).*

Gemma and Paul both dislike the impact anxiety and depression have on their relationships: *'I take it out on our lass sometimes and I shouldn't do' (Paul 179).*

Carl feels that his difficulties stop him from getting on with his life, he expressed concern that with out the right help depression can *'Take over your life completely' (701).* Others described how it stopped them from doing certain things: *'does it stop you doing things that you enjoy?' 'Yeah, yeah, yeah' 'why's that?' 'Because I don't want to go facing crowds again' (Sarah 245-7).*

4) Coping

All the participants identified ways in which they attempt to cope with negative affective states. Being able to cope in these difficult times was clearly important to

the participants, many using words such as; '*It's something you've got to do*' (Gemma 442); '*I've got to calm down*' (Paul 291), indicating their need to be able to manage their affective state. Beverley described how she tried to manage her difficulties for the sake of her family: '*You've just got to carry on?*' '*Yes...I got our [three children]*' (82). There were serious consequences for Paul, as if he couldn't keep the aggressive behaviours he sometimes displayed when he was anxious under control '*...they ring the police up*' (293).

The themes generated by the participants in relation to coping fell into two categories: the strategies they use to manage their affective states and the support they receive to do this.

4.1 What can I do to manage my difficulties?

Avoidance

Avoidance or retreat from difficult situations was mentioned by five of the participants: '*when I feel sad I walk away*' (Adam 210). Sarah and Reginald, who both live with their families, described going to their bedrooms to escape from tensions. Some would avoid situations they knew would make them anxious, for instance Paul felt anxious in crowds so he avoided shopping: '*I don't do shopping*' (70). Both Gemma and Beverley had left neighbourhoods where they felt unsafe.

Activities

All of the participants described engaging in activities and hobbies they enjoy in order

to help themselves feel better. Going out, listening to music and watching television / DVDs were the most frequently mentioned activities, with an emphasis on cheering themselves up: *'...and I did so we watched it all way through last night.'* *'And how did you feel afterwards?'* *'Oh I felt happy about that'* (Reginald 68-70). Smoking, exercise, using the computer and tending to pets were also mentioned, demonstrating how many of the participants sought to keep themselves occupied: *'keeps me busy, I like doing em'* (Paul 173).

Techniques from professionals

Half of the participants described using breathing to help them bring symptoms of anxiety under control. Adam was particularly clear that he had learnt this strategy from a clinical psychologist, *'Why did you see [clinical psychologist]?' 'Breathe.'* *'Breathing? Did you do some breathing is that right?'* *'Yeah'* (9-13). Sarah and Carl also described relaxation and visualisation techniques that helped them calm down. Belinda described using the *'skills'* she had learnt through Cognitive Behavioural and Cognitive Analytic therapies in some detail and spoke about using problem solving techniques: *'now I've got a lot stronger at my problem solving and I find it really helpful'* (277). Reginald also made reference to psychological intervention, asking for a *'new blue diary and stickers'* which the researcher was aware he used to record his feelings. Sarah and Gemma described how they found it helpful to try to think positively *'I've always been taught to think positive'* (Sarah 220). They did not describe how this coping strategy was developed but there was no evidence of guidance from professionals.

Medication

The majority of the participants mentioned medication: *'make sure I'm taking me medication right'*, (Carl 683). There was however, no discussion of how medication worked, how well it worked or why it worked. A couple knew the names of their medication, others referred to it by type: *'gave me another injection'* (Beverley 158).

3.2 Who will support me through this?

Most of the participants were very clear that it was helpful to have someone to talk through their problems with: *'it helped to talk to someone instead of just keeping it bottled up'* (Gemma 380). Families were often relied on to provide this support, as well as practical support, physical reassurance and cheering up. Only Beverley, Belinda and Paul briefly mentioned having friends they could talk to. Belinda was the most explicit, describing what she called her *'trust cell'*: *'I have 4 or 5 friends, close friends that I can call at any time, certain time, or one of them email or text and I know that I can ask them for advice and support'* (304).

Professional support was discussed, mostly focused around community nurses and clinical psychologists from the Community Health Support Teams, though Gemma and Carl mentioned other sources (for example Samaritans, ambulance staff).

Understandings of professional roles were a little mixed. Adam and Reginald could not explain what a clinical psychologist was. Beverley knew they had something to do with *'mental health'*(36). Belinda was the clearest about what a clinical psychologist was: *'they erm helps sometimes they can help you with assessments, erm they can help you with recap on your skills to rebuild and get your confidence back'*. All were

clear that the professionals were there, *'well for some help'* (Reginald 24) and this typically would be achieved through talking, *'we talk about problems'* (Carl 3).

Sarah and Belinda saw involvement from the Community Health Support Team Professionals as vital to their well-being. Sarah explained how she relies on her *'link'* into the Community Health Support Team: *'its like a link and if I'm alright with me links clipped and then it goes apart then I'm in limbo. Then I'm thinking who else do I talk to about a problem?'* (267). Belinda felt that involvement with professionals had kept her out of hospital: *'I actually thought I was bad enough to be admitted to a psychiatric unit but like with the right support and the right people helping and the right services, things got easier again'*. However, both Sarah and Belinda described having experienced difficulties with gaining access to services and the continuity of support in the past, for instance: *'So really it's only got to be its you've got to get to crisis point. Which you don't want to get to crisis point. When you need one'* (Sarah 273). Sarah was more positive about current provision, *'you've only got to ring'* (105) as were others, *'when I want to get in touch with him I ring him up'* (Paul 4).

Discussion

The findings of this study were organised into four super-ordinate categories which described what people with intellectual disabilities understood about anxiety and depression, what their experiences were of anxiety and depression and how they made sense of and coped with anxiety and depression.

This section will focus on three broad issues highlighted by the super-ordinate themes. Firstly, the value of using the constructs of anxiety and depression with people with intellectual disabilities, secondly, the social context of their experiences and thirdly, the insights provided by the study of the how people with intellectual disabilities relate their experiences of psychological distress to others. The implications of the findings for clinical practice and future research are discussed before a brief consideration of the methodological limitations of the study.

The value of 'anxiety' and 'depression' as constructs with people with intellectual disabilities

Given the frequent co-morbidity of anxiety and depression this study aimed to investigate experiences of the two conditions concurrently. It was expected that the separate constructs of anxiety and depression, in line with ICD 10 / DSM IV -TR diagnostic criteria, would be explored individually, with consideration given to when participants felt they experienced the two conditions simultaneously.

All of the participants were able to identify changes in their affective states that were suggestive of anxiety and depression. They described changes in their emotional, physiological, behavioural and cognitive states. Several studies have argued that people with intellectual disabilities do experience anxiety and depression (Marston *et al.*, 1997; Meins, 1993; Cooper, 1996; Matson *et al.*, 1997) and that they experience symptoms in common with the standard diagnostic criteria (Mcglivray & McCabe, 2007; Matson *et al.*, 1999; Tsioursis *et al.* 2003).

The factors that the participants reported as indicative of experiencing anxiety and depression were in line with the ICD 10 diagnostic criteria (World Health Organisation, 1993). However, it became apparent through analysis that the participants tended not to delineate between the two conditions. At times they used the terms anxiety and depression interchangeably and many struggled to give clear and consistent definitions of the separate conditions.

The participants consistently described physiological, emotional and behavioural experiences that they linked simultaneously to both anxiety and depression. Also whilst some of the participants in this study were clear in associating certain thoughts specifically with anxiety or depression, with others there was considerable overlap in which thought accompanied which affective state. Within the general population numerous studies have failed to empirically distinguish between the constructs of anxiety and depression (Clark & Watson, 1991; Kendall & Watson, 1989; Maser & Clonginer, 1990), whereas self-report measures have found anxiety and depression to be highly correlated (Clark & Watson, 1991). This led Clark and Watson (1991) to

specifically with anxiety or depression, with others there was considerable overlap in which thought accompanied which affective state. Within the general population numerous studies have failed to empirically distinguish between the constructs of anxiety and depression (Clark & Watson, 1991; Kendall & Watson, 1989; Maser & Clonginer, 1990), whereas self-report measures have found anxiety and depression to be highly correlated (Clark & Watson, 1991). This led Clark and Watson (1991) to propose a 'tripartite' model which groups the symptoms of anxiety and depression into three subtypes; those specific to anxiety (for example, symptoms of somatic tension and arousal, such as shortness of breath, dizziness, dry mouth); those specific to depression (for example feeling disinterested, de-motivated, lacking enjoyment in life) and those which are commonly expressed by both anxious and depressed individuals (for example, restlessness, irritability and concentration difficulties). This final subtype, which reflects the general distress experienced by people with anxiety and / or depression is termed negative affect.

There was considerable evidence from the participant's reports that their experiences reflected this tripartite model. The participants commonly described symptoms and experiences that fell within the negative affect subtype, those which are common to both anxiety and depression. They were less able to identify the factors that related specifically to anxiety or depression within their experiences.

Within this study the construct of negative affect more accurately reflected the experiences of the participants than the constructs of anxiety and depression. Therefore, it could be argued that anxiety and depression as constructs defined by the

psychiatric diagnosis system are not meaningful to people with intellectual disabilities and therefore may hamper professional understanding and psychological intervention of their distress. Questions have been raised about the appropriateness of standard psychiatric diagnosis for people with intellectual disabilities (for instance Cooper & Collacott, 1996; Hurley, 1996; Davis *et al.* 1997a). In recent years there has also been growing dissatisfaction with the use of psychiatric diagnosis systems to understand psychological distress within the general population. Firstly, psychiatric diagnoses are based on the assumption that biological abnormalities lead to mental health problems. Like conventional medical diagnoses, they also assume that different problems will have different pathologies. However, Moncreiff (2007) argues, that underlying pathological profiles for specific psychiatric diagnoses have not been convincingly demonstrated. For instance, there is no consistent evidence to suggest that people diagnosed with depression have reduced levels of serotonin or catecholamine prior to treatment with antidepressant medication (Moncreiff & Cohen, 2006). Further to this, the labelling and component criteria of psychiatric diagnoses means that two people with the diagnosis may have no symptoms in common (Bannister, 1968). Secondly psychiatric diagnosis assumes that psychological experience will conform to pre-defined patterns. Various studies, for example Bentall (2003) have demonstrated that people's emotions and behaviours do not easily fit diagnostic criteria. Boyle (2007) argues that psychiatric diagnostic criteria deflect attention away from the content of people's difficulties and experiences. It becomes sufficient to say that someone experiences panic or depression, rather than exploring the circumstances that cause them to panic, what life events might have lead to them feeling depressed and how they cope with these feelings. Similarly, May (2007)

suggests that the diagnostic process detaches an individual's experience from its social and historical context. May discusses how jointly developed understandings of distress, that use the clients own terms and experiences can lead to increases in psychological and social functioning.

There have been several proposals for a move away from diagnosis towards psychological formulation, whereby psychologists consider an individual's experiences, emotions and behaviours within the context within which they occur (Division of Clinical Psychology, 2000; Pilgrim, 2000). There has particularly been a drive towards psychological formulation within psychosis research, for instance Bentall (2003, 2007) argues that developing understanding of the complaints associated with psychosis (in particular auditory hallucinations and delusions) provide detailed insights into the experience for individual's that are not produced by diagnosis focused studies.

Psychological formulation allows psychologists to understand the content and context of an individual's difficulties. This would seem to be particularly important when the meanings of standard psychiatric diagnostic terms differ between individuals and between clinicians and clients. Within this study people with intellectual disabilities seemed to find the diagnostic construct of anxiety and depression ambiguous. Their constructs of the conditions differed from those of the researcher and their accounts emphasised difficulties related to negative affect rather than specifically to anxiety or depression as defined by ICD 10 or DSM IV TR. It may therefore be more meaningful to develop a psychological formulation, based on their specific

experiences of negative affect rather than anxiety and depression, in order to reach a shared understanding and guide an intervention plan.

The social context of negative affect

The psychological formulation approach considers that distress should be considered within the social context in which it occurs. The participants of the study were all able, to varying degrees, to describe the situations in which they experienced negative affect and the circumstances they believed contributed to their feelings.

Several of the participants suggested that they had very limited social relationships and some directly discussed this as impacting on their mood. Social support, in particular friendship, has often been found to be lacking in the lives of people with intellectual disabilities (Emerson & Mcvilly, 2004; Katz & Yekutieli, 1974; Krauss *et al.*, 1992; Petrovski & Robertson, 2001). Research has suggested that having at least one close interpersonal relationship is an important factor in maintaining psychological well being (Hughes, 1999; duck, 1991) and so with minimal opportunities for such interaction people with intellectual disabilities are missing out on this protective factor.

Many of the participants reported that they had been bullied because they had intellectual disabilities and a number described feeling stigmatised as a result; *'if they hear about learning difficulties they pick on ya' (Carl)*. Carl directly linked this with experiencing negative affect. Cooley (1956) highlighted how being aware of stigmatisation has negative implications for individuals' sense of adequacy and well

for instance, they had failed to remain in employment or struggled to complete tasks. Continued experience of failure can lead to a state of learned helplessness whereby individuals perceive themselves to be powerless to alter a situation and hold themselves responsible for their failings (Seligman, 1974; Abramson, Seligman and Teesdale, 1978). Reynolds and Miller (1985) demonstrated a correlation between learned helplessness in young adults with intellectual disabilities and depression.

How people with intellectual disabilities related their experiences of negative affect to others

Moss *et al.* (1996) suggested that in the past, due to difficulties with interviewing people with intellectual disabilities, much of what was known about their experiences of anxiety and depression was drawn from third party reports. There is now considerable literature regarding effective interview skills with this client group (e.g. Prosser & Bromley, 1998; Booth & Booth, 1996), ensuring that clinicians are better equipped to discuss experiences of mental health problems with people with intellectual disabilities. A number of studies have suggested that people with intellectual disabilities are able to report accurately on their experiences of mental health problems and psychological difficulties, including anxiety and depression (Masi, 2003; Moss *et al.*, 1996; Douma *et al.*, 2006). In line with these findings, all of the participants of this study were able to describe their experiences of negative affect.

However, whilst a number of the participants were able to report on various different aspects of their experience (e.g. their emotions, physical sensations, cognitions), some

found this more difficult. Some participants would concentrate on a particular aspect of their difficulty, for instance a difficult relationship with a family member, or they might avoid answering questions. Findings from Douma *et al.* (2006) suggested that people in the moderate range of ability experienced more difficulty in completing self report measures than those in the mild range. No measures of intellectual functioning were taken for the current study. It is therefore not possible to speculate whether this would account for the differences in the details of participants' accounts of their experiences.

The ability to identify and describe ones own cognitions is considered an essential skill for participation in cognitive behavioural therapy (CBT; Joyce *et al.*, 2006). Several studies have supported the view that cognitive variables such as automatic thoughts are involved in the experiences of people with intellectual disabilities of anxiety and depression (Esbensen & Benson, 2005; Glenn *et al.*, 2003; Nezu *et al.*, 1995). These studies demonstrated that people with intellectual disabilities were able to identify and discuss the thoughts they associated with anxiety and depression. These findings were reflected in the current study. The majority of participants were able to discuss the thoughts, particularly worries, they experienced in relation to negative affect.

Clinical implications

The findings of this study are of clinical relevance. Firstly, the study questions the value of using the psychiatric diagnostic constructs of anxiety and depression with people with intellectual disabilities. It would seem that there is considerable variance between professional conceptualisations of anxiety and depression and those of people with intellectual disabilities who experience them. The term's anxiety and depression may be used as a short hand for distress by both clinicians and clients, but people with intellectual disabilities may not have an explicit understanding of the symptoms the terms convey to others. Time needs to be taken to explore the content of individual's experiences and to develop a psychological formulation of their difficulties. This should use the clients own words and focus on the specific detail of what causes them distress and how they might resolve this. Rather than producing, for instance, an anxiety management plan, the individual complaints (for example feeling dizzy in the town centre) should be addressed in order to design an intervention that is meaningful and usable for a person with intellectual disabilities.

Secondly, the study demonstrated that the participants tended not to delineate between experiences they linked to depression or anxiety. The symptoms and experiences they described had much in common with the negative affect subtype of anxiety and depression, which is characterised by the general distress experienced by both anxious and depressed individuals (Clark & Watson, 1991). A formulation and intervention which is based on negative affect may be more beneficial than a condition specific one as many of the participants of this study reported symptoms common to both

anxiety and depression and were unable to separate them.

Thirdly, the participants were all able to discuss their experiences directly. Whilst the level of detail varied, they were all able to give an account of the difficulties they experienced. This may have been in relation to one aspect of their life that caused them distress or by describing the various symptoms, thoughts and behaviours they related to anxiety and depression. The study highlights the value of including a person with intellectual disabilities' self report of their difficulties in an overall assessment.

Finally, the study highlights the importance of social support for people with intellectual disabilities who experience anxiety and depression. A number of the participants had very limited social support networks. Clinicians and service providers might consider how individuals are linked into services within their communities that promote opportunities for friendship, support and leisure activities in line with 'Valuing People' (DoH, 2001). Organisations such as Mencap organise social events, groups and befriending services for people with intellectual disabilities.

Methodological considerations

The study provides an interpretative understanding of eight participants who had intellectual disabilities and who were considered to have anxiety / depression. The small number of participants means that there are considerable limitations to extending the findings. Validation of the themes by a participant was planned but was not achieved, although the findings were felt by the clinical field supervisor to resonate with her experiences of working with people with intellectual disabilities who had experienced anxiety or depression.

Whilst there was an equal gender balance within the study, all the participants were of white British origin. It is not clear whether cultural issues would have impacted on the experience of anxiety and depression and how these were described to the researcher. It is also unclear whether the findings would be applicable to a more diverse population. Similarly, all of the participants had received treatment for anxiety and depression from a community health support team professional. This may have had an impact on the understandings participants had reached of their difficulties and their abilities to manage their conditions. The reports of people who had not received treatment may have differed, in terms of the coping strategies they used and how equipped they felt to manage their difficulties. Also, at times the influence of psychological understandings of anxiety and depression was apparent in the participants' accounts, for instance Belinda and Sarah's. This may not be the case for someone who has not been involved with a health professional.

No measures of intellectual functioning were taken for the purpose of this study and the decision-making process behind this was outlined in the method section of the report. However, there was an implication to this decision that was not considered at the design stage of the project. Although there were noticeable differences in the accounts produced by different participants, it was not possible to consider whether such differences occurred between people with mild or moderate intellectual disabilities.

Areas for future research

There are a number of potentially valuable areas for future research. Firstly, the methodological limitations of the current study could be addressed. Participants from more diverse backgrounds could be recruited by making the participation more accessible to people for whom English is not their first language. Also information regarding intellectual functioning could be gathered in order to consider any differences in the reports of people with mild or moderate intellectual disabilities. Secondly, there has been no empirical investigation of the tripartite model of anxiety and depression with people with intellectual disabilities. The validity of the constructs has been demonstrated in a number of populations (Watson *et al*, 1995) but has yet to be explored with people with intellectual disabilities. Given the apparent relevance of negative affect to the experiences of people with intellectual disabilities this would seem to be of high theoretical and clinical relevance. Thirdly, qualitative methodologies could be used to explore people with intellectual disabilities' experiences of other mental and physical health difficulties. Fourthly, as the contribution of social factors in the development of anxiety and depression were of considerable significance to the participants, this may warrant further exploration. Research into the social context of depression has been undertaken in relation to the cognitive behavioural model (Dagnan & Sandhu, 1999). This could be explored more generally, again within a qualitative framework. The author is not aware of research into the social context of anxiety. Finally, there is the potential for further investigation into the possible differences in experience and reporting of experience between people with mild or moderate intellectual disabilities. This may impact on the development of validated self-report questionnaires and assessment tools.

Conclusions

This study presented a qualitative exploration of the experiences of people with intellectual disabilities of anxiety and depression. The findings added richness and depth to the existing knowledge of what such experiences are like for this client group. Four superordinate themes were identified, these were considered to represent different aspects of the experience of negative affect: Identifying the problem, describing the changes, understanding what has happened and coping with the difficulties. The study demonstrated that the participants tended not to delineate between the constructs of anxiety and depression, and suggested that the negative affect subtype of the tripartite model of anxiety and depression (Clark & Watson, 1991) may better reflect the experiences of these participants. Clinical implications were discussed, in particular the value of developing a psychological formulation of a client's specific complaints. Areas for further research were highlighted including empirical investigation of the validity of the tripartite model of anxiety and depression with people with intellectual disabilities.

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Critical Appraisal

Critical Appraisal

This section provides a critical reflection on the research process from the perspective of the researcher, highlighting the decision making process, the ups and downs of the research process and the lessons learnt for future project implementation. Many of the points are drawn from the research diary that has been kept since the early ideas for the project emerged

Background to the study

Prior to clinical training I had worked as an assistant psychologist in a community based intellectual disability service and I was keen to return to work clinically in this area. I had worked with several people during this time whose lives had been severely affected by anxiety and depression but who had made remarkable gains through psychological intervention. At the time I was very familiar with the individualised presentations of my clients' anxiety and depression. When I undertook a literature review in the first year of training around the experiences of people with intellectual disabilities of mental health issues, I was struck by how little of this individual experience was reported. It was this that led me to consider undertaking research into what it is like for people with intellectual disabilities to have anxiety and / or depression.

Epistemological considerations

In order to explore individuals' subjective experiences, qualitative research seemed an obvious choice. However, the methodology to employ took a little more consideration. I had experience from undergraduate level of using a discourse

analysis approach (Potter & Wetherell, 1987) to research. However, I did not feel that the epistemology of discourse analysis suited my research question as it seeks to understand the processes through which phenomena are enacted (e.g. through talking), rather than the nature of the phenomena itself. I did not feel that a concentration of language would capture the essence of anxiety and depression for people with intellectual disabilities. I also considered grounded theory (e.g. Glaser & Strauss, 1967) as this was the preferred option for many of my peers. Again, I did not feel that grounded theory's focus on social process reflected my research question. I was also conscious of the debates around critical realist / social constructionist perspectives and felt that trying to discern my position within argument could distract me from hearing the participants' stories as they were told.

I had not heard of IPA prior to training, but as I began to read into the approach I quickly developed a sense that it would enable me to explore the experience of anxiety and depression for people with intellectual disabilities in a way that maintained the individual story and focused on what was relevant to the participants. Its epistemological stance felt appropriate to who I was as both a clinician and a researcher and the stories I wanted to share through the research. Smith and Osborn (2003) make explicit IPA's connection to cognitive models of psychology. However, whereas the cognitive paradigm moved to considerations of information processing, IPA remained committed to investigating meaning and meaning making (see Smith 1996a for more information on the theoretical background of IPA). This fits well with my clinical understanding of anxiety and depression which is drawn mostly from a cognitive behavioural perspective.

Negotiating ethical approval

Preparation of the research proposal for submission for ethical approval took somewhat longer than expected. This was simply due to miscommunication and a lack of understanding of the process on my part. Having been reviewed by the university, the proposal was sent to the sponsoring trust's Research and Development department at Leicester for approval. Unfortunately, it was sent to the wrong address and did not reach its intended recipient for a couple of months. The diligence and kindness of the Leicester R&D department and administrative staff at the North Sheffield Research Ethics Committee (REC) ensured the project was back on schedule and presented to the REC by August 2006. I found the scale and formality of presenting to the Ethics Committee a very daunting process and would consider inviting another member of the research team to attend alongside me in the future.

Recruitment

I used several methods to encourage the psychologists within the Community Health Support Teams to recruit participants for the study. This included attending meetings, producing handouts and posters, and sending emails at key times such as the end of second year trainees' placements. The interview process was scheduled to be completed by January 2007. It quickly became apparent that the psychology department was struggling to identify suitable participants within this time scale. In order to invite recruitment from the wider Community Health Support Teams, I applied to the REC for a major amendment of the recruitment process in January 2007. This was granted after 35 days. Several community nurses came forward with

potential participants and interviews were completed at the end of April 2007. In the end, only one participant had not received input from psychology.

Designing and conducting the interviews

When designing the interview schedule thought was given to the guidance provided by Booth and Booth (1996) to maximise the opportunities for participants to discuss what was important to them. Mitchell *et al.* (2005) described how participants had struggled with self-reflective questions such as '*how do you think the event has affected your life?*', and those involving judgements of time. They reportedly found more concrete questions such as '*when the event happened to you, what did you think would happen to you?*', more helpful. Attempts were made to balance the need for questions to be open ended and non directive, thereby allowing the issues of importance to the participant to be followed, against the difficulties that people with intellectual disabilities can sometimes have with responding to questions that do not have an obvious answer (Sigelman *et al.*, 1982). Therefore questions in the interview schedule typically used active verbs and asked participants to reflect on one specific aspect of their experience at a time, e.g. '*What did you do when that happened?*', '*How did you feel in your body at that time?*'

The slow referral of potential participants meant that it was not possible to pilot the schedule. This led to several occasions during the interviews when the participant did not grasp what I was asking and I had to reframe. I found a couple of participants difficult to understand and found myself drawing on my clinical skills to ensure I was correctly following what they were telling me. I used restatement frequently to ensure

I had heard their words correctly and this proved invaluable when transcribing. I would summarise and reframe in order to clarify and allow the participants opportunities to correct me or expand on what they had said. I felt that I established a good rapport with all the participants, through either spending time talking at the beginning of the interview and ensuring they were comfortable with the process or by talking to them over the phone beforehand.

I found that as I became more familiar with the interview schedule, the written questions acted more as prompts, allowing me to use the semi structured style of the interview to explore more freely what was important to the participants. I was at times surprised by the direction the interviews took, particularly the early ones. Carl's reflections on restrictions on his life, for instance encouraged me to think more widely about what might be relevant to the participants.

During some of the interviews it was very difficult to turn off the clinician side of me, however this may have been of value to the study. Mearns and McLeod (1987) highlight the importance of the Rogerian therapist qualities of empathy, congruence and acceptance in qualitative research. I felt it was important to ensure people did not disclose things that would leave them with difficult feelings after I left. I also found myself emphasising the strengths and coping strategies that people raised in order to leave them feeling positive. I had a sense with several participants that there were much darker elements to their experiences, particular in relation to suicidal ideation but felt it would be unethical to draw these out further for the sake of interesting research. I always spent time at the end of each interview debriefing, checking out how they planned to look after themselves over the next few days and providing

participants with the telephone numbers of Community Health Support Team professionals who could offer them support should they need it.

The venues for the interviews were always chosen by the participants as somewhere they felt comfortable with. Half were conducted in the participants' homes, so having experience of community working was an advantage. It also meant contending on occasions with interruptions from family members, visitors, telephones and pets. I was conscious that the presence of others might influence what the participants told me but ensuring they were comfortable was paramount and also I was a guest in their homes. Having others present was at times helpful, particularly if I struggled to understand what the individual was saying and also in providing some context to statements people made. Two participants chose to meet me at a community health centre and I ensured they were reimbursed for any travel costs they had met.

I used the reflective diary to record thoughts and feelings subsequent to each interview. Here is an extract, following the first interview, with Carl:

Am buzzing, really pleased with how it went. Lasted over an hour. Realise that I had been a bit worried about how much detail I would get from the interviews and how long they would last. C was brilliant, given enough time he said things that I suppose I wasn't expecting. He was very honest and open about his dark times. I was a little scared by his talk of suicide but this was in the past and he talked about protective factors and coping strategies. I had a sense during the interview that my research was really important, people need to know about this. C's experience did not feel 'qualitatively different' from the general population, was able to make links to the literature throughout, esp to social network and isolation stuff. Was careful to end on a positive note – is this more about my needs than C's though?

12 12 06

This extract demonstrates how excited I was with the project at this stage. It also shows how my thinking about the types of themes that the participants would raise

changed almost immediately. This was the first time I had acknowledged concerns about the level of detail that would be generated and I felt a little embarrassed that I had underestimated the participants. It also shows how I was already making links to the literature.

The stories the participants shared with me were often very moving. Supervision proved invaluable in enabling me to reflect on and contain some of the sadness and anger that I experienced on their behalf. My emotions were stirred not only during the interviews but whilst I prepared and read the transcripts and whilst constructing the analysis. For instance, as I discussed Adam's experience of bullying in the results section, I felt compelled to highlight how he had raised this topic unprompted, revealing how significant this was for him.

The reflective diary shows how, as I engaged more and more with the literature, having conducted the interviews, I began to reflect on aspects I could have done differently;

Maybe I should have WAIS'ed participants. The data on self reporting (McBrien 2003) highlights the differences between mild mod in abilities to self report and reflect
27 03 07

This extract demonstrates how I later questioned the decision not to obtain information about intellectual functioning. Whilst I maintain that it was not appropriate to conduct formal testing for the specific purposes of this study, having knowledge of intellectual functioning may have proved useful in reflecting on the results. Specially, it would have been useful to consider whether the findings of Douma *et al.* (2006), that people with moderate intellectual disabilities found it more

difficult to make self reports of their symptoms, were reflected in this study. There were indeed people who seemed to find this more difficult but without any data on their intellectual functioning, it was not possible to comment on the significance of this.

The cultural and ethnic diversity of the population served by the Community Health Support Teams is not represented by sample included in the study. All the participants were of white British background. One of the reasons for this could be that the participant information sheets were only produced in English for time and cost reasons. This may, however, have limited the study's appeal to people for whom English is not a first language.

Preparing the research report

IPA was a new methodology for me and although I read widely around the practical aspects and the presentation of data, I discovered quite late on that the approach I had been taking to my analysis was slightly incorrect. I had noted the individual themes emerging from each interview but had planned to look for connections between them across all the interviews as a whole. This was slightly out of step with the idiographic approach of IPA which suggests that such connections should be made on a case by case basis, before being combined with others to form superordinate themes. This was corrected but was again a time consuming process.

In the diary my engagement with the text at the analysis stage was often recorded as questions and statements:

- *Contributory factors are not always linked by participants to anxiety and depression.*
- *Where do 'breakdown's' fit?*
- *Should 'what if I can't cope' be a category?*

22 05 07

This extract demonstrates how I began to grapple with the structure of the results, deciding on relationships between themes and deciding which contained the essence of the experience of anxiety and depression.

One of the key concerns for any researcher is getting it wrong and particularly misinterpreting the data. I found that it was difficult to manage eight individual cases within the IPA framework. Whilst Smith and Osborn (2003) recommend five or six as satisfactory sample, the university required that a minimum of eight participants were interviewed for a qualitative research study. I was concerned that the individual stories of the participants would be lost as I searched for connections between the themes. In order to ensure this did not happen, I paused in my analysis before making the connections and took time out to re-read all the transcripts and note down points of particular relevance to each participant.

Throughout the process of analysis the support of the qualitative group at the university has been invaluable. They provided ideas and validation of the early emerging themes and later the superordinate themes. I recall how, having felt swamped by the sheer number of themes, a structure for the results emerged from talking to members of the group and I am aware that other group members shared similar feelings.

Of the themes that the participants raised, one of the factors that interested me most was the way that they tended to describe the same experiences and symptoms for both anxiety and depression. Whilst I felt this was relevant, I was unsure of how it related to the literature and wondered whether it a phenomena specific to people with intellectual disabilities. I started to consider that it reflected some of the difficulties in labelling feelings and self reporting that were discussed in the literature review. I was not particularly comfortable with this idea as I felt that it underestimated the participants and their stories. Very late on in the write up I was pointed towards research into the 'Tripartite' model of anxiety and depression (Clark & Watson, 1991). This model accounted clearly for what the participants described in that the symptoms of Negative Affect are common to both anxiety and depression. It is possible that a number of my worries, with regards to trying to differentiate between anxiety and depression in the interview and analysis stages, would have been reduced had I been aware of the research around Negative Affect earlier.

Issues of quality within the research

Attempts were made to follow the guidelines set out by Elliot *et al.* (1999) in terms of quality and publishability. This included giving details about the backgrounds of the participants and of the researcher and demonstrating the development of themes by using quotes. The interpretative nature of IPA investigation was emphasised throughout the report and attempts were made to demonstrate to the reader how the themes discussed emerged from the data. The themes and concepts that emerged from the analysis were those which were of the most relevance to the participants.

However, IPA acknowledges that the researcher's role in the process is an active one

(Smith & Osborn, 2003) and they draw their own values and preconceptions into the interpretation and presentation of results. It is possible that the prevalence of accounts of thoughts, behaviours and emotions was influenced by my cognitive behavioural background. The interview schedule broke experiences down into these factors and I may have looked for the links between them in analysis. This is not to say that they were merely a product of my interpretation but it may have been an influence.

Validation

One of the participants, Belinda, had expressed an interest in discussing with me the findings of the study and this presented a useful opportunity to gain some validation of the themes. However, this did not happen as planned as it proved impossible to find a date to suit both Belinda and myself within the time scale of the project. With hindsight this could have been done through written correspondence but preparing an accessible document would have taken more time than I had allowed for and unfortunately did not happen. Belinda did bring with her to the interview a booklet that she had written for the study about anxiety and depression. This highlights some of the issues that are relevant to her experiences. The booklet is included in Appendix O. Whilst the themes were not shared with participants, early drafts of the results were shared with the clinical field supervisor who felt that they 'resonated' (Elliot *et al.*, 1999) with her experiences of working clinically with people with intellectual disabilities who have anxiety and depression.

Reflexivity

When exploring qualitative methodologies, a researcher quickly attunes to the importance of reflexivity. It is mentioned even in the introductory texts (e.g. Willig, 2001) that IPA has a reflexive epistemology. When embarking on this study, I

believed that I should keep a diary and include a statement about the potential influences of my personal and professional background on the findings. With less than three weeks to go I had failed to find a concise and consistent definition of reflexivity to include in the research report. At this stage I realised that it was not just my definition that was lacking, but my understanding. Searching for answers, I allowed myself the time to read a couple of chapters from Etherington (2004).

Etherington demonstrates how the role of the researcher can be located within the text, rather than standing outside, perhaps as my statement did. She achieves this by weaving her voice and her personal story through the research and alongside the participants. She acknowledges however, that her academic standing and confidence allow her to 'break the rules' as to the acceptable structure and level of self-disclosure. This is not a position I feel I have reached. I reflected on my own disclosure, of personal experiences of anxiety and realised how tentatively and inconspicuously I have placed this into the text.

I feel that it has been difficult to use my voice within the research report but I have a growing self awareness of what I bring as an individual to the research. Etherington describes reflexivity as 'having an awareness in the moment of my thoughts, feelings, bodily responses and my reactions to what I'm hearing' (p46). I believe I have begun to explore this, and using the diary as been helpful in this process. I am aware that this description may appeal to me as it resonates with CBT approaches to self awareness, to which I currently have a clinical affiliation. The next challenges for me are to develop more of a sense of myself in relation to the theoretical side of research and to demonstrate my voice within a research report.

Maintaining motivation

I felt it would be important from the start to choose a topic that would maintain my interest and believe I achieved this. I was also fortunate in being able to pursue my clinical interests in this field with the hosting trust, which made my research feel more relevant and more a part of my working life than something I just had to do to pass my doctorate. On placement days I was working with clinicians who were enthusiastic not only about my project but also about their own research with people with intellectual disabilities. I found that witnessing people publish their work and present at international conferences was quite motivating.

I often felt that my research was a long and lonely journey and found that I was actually much more productive when I remained in regular contact with peers, friends and family. Taking time out from the study allowed me to return to it with a fresh perspective, although there were several points when I needed reminding of how beneficial this could be. Breaking the study into sections and setting mini 'deadlines' for the completion of these helped me to feel in control. Finally, I was again reminded to attend to the practicalities and organise the binding of my thesis in a timely fashion. I was thankful for this advice as there were a couple of complicating issues that could have led to a late submission if unforeseen.

A factor which I feel has impacted on the production of my thesis and through discussions I am aware has similarly affected my peers, is the current employment situation for clinical psychologists in the NHS. Increased numbers of final year trainees are applying for a decreased number of positions. For many of us this has led

to trying to achieve a difficult balance between preparing the thesis and applying for and preparing for job interviews, a position many previous cohorts have avoided. However, I do not feel this has had a detrimental effect on the work I produced, as the time away gave me the opportunities for perspective I described earlier and provided me with solace and distraction following unsuccessful applications.

Key learning points

Throughout the research process there have been several key areas of learning which I believe will influence me as a researcher and as a clinical psychologist.

1) Understanding the process and planning accordingly

Not being fully aware of the university and NHS protocols for research governance and ethical approval caused me several avoidable hold ups. In future I would be sure to have a thorough understanding of such processes and allow time for each stage in my planning. Before submitting a proposal I would think more widely around any practical issues that could arise and try to plan for them. In this project, having to resubmit to the Research Ethics Committee to widen my recruitment and to have the interviews transcribed, again caused me unnecessary delays.

I have learnt to allow time for details that could easily be over looked but add considerable value to a study, such as pilot interviews and participant validation. However, I am also more aware of the need to be flexible with scheduling and to respond calmly to unforeseen circumstances. In future I would allow extra time for elements such as recruiting participants and analysing data as such things invariably take longer than predicted. I would be certain of how to put my methodological approach to analysis into practice in order to avoid causing myself additional work. I would also try to consider how decisions made at an early stage could influence the results produced, for instance I feel that the decision not to gather any data regarding participants' intellectual functioning has somewhat limited what can be concluded from my findings.

2) Accessing and asking for support

I feel that I was fortunate in having so many people around me who were enthusiastic about my project and about research with people with intellectual disabilities in general. In planning another project I would again seek to do so in an environment where people are familiar with and excited about research as I feel this played a major part in motivating me through the research process and encourages me to disseminate my findings.

Through this project I have learnt the value of talking through various aspects of the research. Talking to my supervisors, peers and colleagues proved invaluable in working through practical problems and dilemmas with analysis and presentation that would have seemed insurmountable on my own. Supervision is essential to working safely and effectively with clients in a clinical environment and I have discovered that this is equally true in a research capacity. It was necessary for me to discuss the emotional impact of the research and check out issues regarding the well-being of the participants on a number of occasions. I also learnt the need to ensure that you have the emotional support of friends and family throughout a project of this nature. Contracting to maintain regular contact through texting, phoning and emailing, helped me manage a difficult time when I felt isolated from university peers and I would have struggled without the practical support and understanding of my family.

3) Application of clinical skills

During this project it has become increasingly apparent that my clinical skills as a clinical psychologist are relevant to research and vice versa. Ethical issues around informed consent and confidentiality needed to be addressed in much the same way as

they would in a clinical setting and I used the same skills to establish rapport with participants and ensure they felt comfortable to talk. The time I spent debriefing with participants reminded me of the need to spend time at the end of clinical sessions (particularly assessments) ensuring that clients will be safe and supported when they go home. There can be difficulties in accessing support when people are placed on waiting lists after assessments as they often do not have the ongoing professional support my participants had. As a result of this project I try to ensure that I provide clients who will have to wait for therapy with information about local organisations who could offer support.

Finally, I believe the project has strengthened my ability to make theory-practice links. Through my analysis of the interviews I was able to see how the participants' descriptions of their experiences would directly relate to or reflect the literature around anxiety and depression. As a skill this will be vital to my future career, enabling me to develop theory-based formulations and intervention plans. The study has also taught me how to look critically at the evidence and reminded me of the need to consider the uniqueness of the individual.

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Appendices

Appendix A

List of journals searched manually

- Disability and Society 1996 – June 2005
- Journal of Applied Research in Intellectual Disabilities 2000 – Aug 2006
- Mental Retardation and Developmental Disabilities Reviews 2000 – June 2005
- British Journal of Intellectual Disabilities 2000 – Aug 2006
- Journal of Intellectual disability Research 2002 – Aug 2005
- Journal of Psychiatric and Mental Health Nursing Jan 2005 – Aug 2005
- Clinical Psychology Forum 1998 – August 2006

Appendix B Standard Criteria for anxiety and depression

ICD 10 Criteria

F32 Depressive episode

G1. The depressive episode should last for at least 2 weeks.

G2. There have been no hypomanic or manic symptoms sufficient to meet the criteria for hypomanic or manic episode (F30.-) at any time in the individual's life.

G3. Most commonly used exclusion clause. The episode is not attributable to psychoactive substance use (F10-F19) or to any organic mental disorder (in the sense of F00-F09).

Somatic syndrome

Some depressive symptoms are widely regarded as having special clinical significance and are here called "somatic". (Terms such as biological, vital, melancholic, or endogenomorphic are used for this syndrome in other classification.). A fifth character (as indicated in F31.3; F32.0 and F32.1; F33.0 and F33.1) may be used to specify the presence or absence of the somatic syndrome. To qualify for the somatic syndrome, four of the following symptoms should be present:

- (1) marked loss of interest or pleasure in activities that are normally pleasurable;
- (2) lack of emotional reactions to events or activities that normally produce an emotional response;
- (3) waking in the morning 2 hours or more before the usual time;
- (4) depression worse in the morning;
- (5) objective evidence of marked psychomotor retardation or agitation (remarked on or reported by other people);
- (6) marked loss of appetite;
- (7) weight loss (5% or more of body weight in the past month);
- (8) marked loss of libido.

In *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical descriptions and diagnostic guidelines*, the presence or absence of the somatic syndrome is not specified for severe depressive episode, since it is presumed to be present in most cases. For research purposes, however, it may be advisable to allow for the coding of the absence of the somatic syndrome in severe depressive episode.

F32.0 Mild depressive episode

A. The general criteria for depressive episode (F32) must be met.

B. At least two of the following three symptoms must be present:

- (1) depressed mood to a degree that is definitely abnormal for the individual, present for most of the day and almost every day, largely uninfluenced by circumstances, and sustained for at least 2 weeks.
- (2) loss of interest or pleasure in activities that are normally pleasurable;
- (3) decreased energy or increased fatigability.

C. An additional symptom or symptoms from the following list should be present, to give a total of at least four:

- (1) loss of confidence and self-esteem;
 - (2) unreasonable feelings of self-reproach or excessive and inappropriate guilt;
 - (3) recurrent thoughts of death or suicide, or any suicidal behaviour;
 - (4) complaints or evidence of diminished ability to think or concentrate, such as indecisiveness or vacillation;
 - (5) change in psychomotor activity, with agitation or retardation (either subjective or objective);
 - (6) sleep disturbance of any type;
 - (7) change in appetite (decrease or increase) with corresponding weight change).
- A fifth character may be used to specify the presence or absence of the "somatic syndrome" (defined on page xx):

F32.00 Without somatic syndrome

F32.01 With somatic syndrome

F32.1 Moderate depressive episode

- A. The general criteria for depressive episode (F32) must be met.
- B. At least two of the three symptoms listed for F32.0, criterion B, must be present.
- C. Additional symptoms from F32.0, criterion C, must be present, to give a total of at least six. A fifth character may be used to specify the presence or absence of the "somatic syndrome" as defined on page xx:

F32.10 Without somatic syndrome

F32.11 With somatic syndrome

F32.2 Severe depressive episode without psychotic symptoms

Note: If important symptoms such as agitation or retardation are marked, the patient may be unwilling or unable to describe many symptoms in detail. An overall grading of severe episode may still be justified in such a case.

- A. The general criteria for depressive episode (F32) must be met.
- B. All three of the symptoms in criterion B, F32.0, must be present.
- C. Additional symptoms from F32.0, criterion C, must be present, to give a total of at least eight.
- D. There must be no hallucinations, delusions, or depressive stupor.

F41 OTHER ANXIETY DISORDERS

F41.0 Panic disorder [episodic paroxysmal anxiety]

- A. Recurrent panic attacks, that are not consistently associated with a specific situation or object, and often occurring spontaneously (i.e. the episodes are

unpredictable). The panic attacks are not associated with marked exertion or with exposure to dangerous or life-threatening situations.

B. A panic attack is characterized by all of the following:

- (a) it is a discrete episode of intense fear or discomfort;
- (b) it starts abruptly;
- (c) it reaches a crescendo within a few minutes and lasts at least some minutes;
- (d) at least four symptoms must be present from the list below, one of which must be from items (1) to (4):

Autonomic arousal symptoms

- (1) Palpitations or pounding heart, or accelerated heart rate.
- (2) Sweating.
- (3) Trembling or shaking.
- (4) Dry mouth (not due to medication or dehydration).

Symptoms concerning chest and abdomen

- (5) Difficulty breathing.
- (6) Feeling of choking.
- (7) Chest pain or discomfort.
- (8) Nausea or abdominal distress (e.g. churning in stomach).

Symptoms concerning brain and mind

- (9) Feeling dizzy, unsteady, faint or light-headed.
- (10) Feelings that objects are unreal (derealization), or that one's self is distant or "not really here" (depersonalization).
- (11) Fear of losing control, going crazy, or passing out.
- (12) Fear of dying.

General symptoms

- (13) Hot flushes or cold chills.
- (14) Numbness or tingling sensations.

C. Most commonly used exclusion criteria: not due to a physical disorder, organic mental disorder (F0), or other mental disorders such as schizophrenia and related disorders, (F20-29), affective disorders (F30-39), or somatoform disorders (F45). The range of individual variation of both content and severity is so great that two grades, moderate and severe, may be specified, if desired, with a fifth character:

F41.00 Panic disorder - moderate: at least four panic attacks in a four week period.

F41.01 Panic disorder - severe: at least four panic attacks per week over a four-week period.

F41.1 Generalized anxiety disorder

Note: For children different criteria may be applied (see F93.80).

A. A period of at least six months with prominent tension, worry and feelings of apprehension, about every-day events and problems.

B. At least four symptoms out of the following list of items must be present, of which at least one from items

(1) to (4).

Autonomic arousal symptoms

(1) Palpitations or pounding heart, or accelerated heart rate.

(2) Sweating.

(3) Trembling or shaking.

(4) Dry mouth (not due to medication or dehydration).

Symptoms concerning chest and abdomen

(5) Difficulty breathing.

(6) Feeling of choking.

(7) Chest pain or discomfort.

(8) Nausea or abdominal distress (e.g. churning in stomach).

Symptoms concerning brain and mind

(9) Feeling dizzy, unsteady, faint or light-headed.

(10) Feelings that objects are unreal (derealization), or that one's self is distant or "not really here" (depersonalization).

(11) Fear of losing control, going crazy, or passing out.

(12) Fear of dying.

General symptoms

(13) Hot flushes or cold chills.

(14) Numbness or tingling sensations.

Symptoms of tension

(15) Muscle tension or aches and pains.

(16) Restlessness and inability to relax.

(17) Feeling keyed up, or on edge, or of mental tension.

(18) A sensation of a lump in the throat, or difficulty with swallowing.

Other non-specific symptoms

(19) Exaggerated response to minor surprises or being startled.

(21) Persistent irritability.

(22) Difficulty getting to sleep because of worrying.

C. The disorder does not meet the criteria for panic disorder (F41.0), phobic anxiety disorders (F40.-), obsessive-compulsive disorder (F42.-) or hypochondriacal disorder (F45.2).

D. Most commonly used exclusion criteria: not sustained by a physical disorder, such as hyperthyroidism, an organic mental disorder (F0) or psychoactive substance-related disorder (F1), such as excess consumption of amphetamine-like substances, or withdrawal from benzodiazepines.

F41.2 Mixed anxiety and depressive disorder

There are so many possible combinations of comparatively mild symptoms for these disorders that specific criteria are not given, other than those already in the diagnostic guidelines. It is suggested that researchers wishing to study patients with these disorders should arrive at their own criteria within the guidelines, depending upon the setting and purpose of their study.

Appendix B Continued

DSM IV – TR Criteria

Panic Disorder

People with panic disorder have feelings of terror that strike suddenly and repeatedly with no warning. They cannot predict when an attack will occur, and many develop intense anxiety between episodes, worrying when and where the next attack will strike.

Panic disorder is often accompanied by other conditions such as depression or alcoholism, and may spawn phobias, which can develop in places or situations where panic attacks have occurred. For example, if a panic attack strikes while you're riding an elevator, you may develop a fear of elevators and perhaps start avoiding them.

Panic Attack

The person suddenly develops a severe fear or discomfort that peaks within 10 minutes.

During this discrete episode, 4 or more of the following symptoms occur:

- Chest pain or other chest discomfort
- Chills or hot flashes
- Choking sensation
- Derealization (feeling unreal) or depersonalization (feeling detached from self)
- Dizzy, lightheaded, faint or unsteady
- Fear of dying
- Fears of loss of control or becoming insane
- Heart pounds, races or skips beats
- Nausea or other abdominal discomfort
- Numbness or tingling
- Sweating
- Shortness of breath or smothering sensation
- Trembling

Panic Disorder With Agoraphobia

The person has recurrent panic attacks that are not expected.

For a month or more after at least 1 of these attacks, the person has had 1 or more of:

- Ongoing concern that there will be more attacks.
- Worry as to the significance of the attack or its consequences.
- Material change in behavior, such as doing something to avoidance.
- The patient also has agoraphobia.

The panic attacks are not directly caused by a general medical condition or by substance use, including medications and drugs of abuse.

The panic attacks are not better explained by another Anxiety or Mental Disorder.

Panic Disorder Without Agoraphobia

The person has recurrent panic attacks that are not expected.

For a month or more after at least 1 of these attacks, the patient has had 1 or more of:

Ongoing concern that there will be more attacks.

Worry as to the significance of the attack or its consequences.

Material change in behavior, such as avoidance.

The person does not have agoraphobia.

The panic attacks are not directly caused by a general medical condition or by substance use, including medications and drugs of abuse.

The panic attacks are not better explained by another Anxiety or Mental Disorder.

Generalised Anxiety Disorder

Generalized anxiety disorder (GAD) is a relatively common anxiety problem, affecting 3 - 4% of the population, Generalized anxiety disorder is much more than the normal anxiety people experience day to day. It's chronic and exaggerated worry and tension, even though nothing seems to provoke it. Having this disorder means always anticipating disaster, often worrying excessively about health, money, family, or work. Sometimes, though, the source of the worry is hard to pinpoint. Simply the thought of getting through the day provokes anxiety. The diagnostic criteria for GAD is as follows:

For more than half the days in at least 6 months, the patient experiences excessive anxiety and worry about several events or activities.

The person has trouble controlling these feelings.

Associated with this anxiety and worry, the patient has 3 or more of the following symptoms, some of which are present for over half the days in the past 6 months:

Feels restless, edgy, keyed up.

Tires easily.

Trouble concentrating.

Irritability.

Increased muscle tension.

Trouble sleeping (initial insomnia or restless, unrefreshing sleep).

The symptoms cause clinically important distress or impair work, social or personal functioning.

The disorder is not directly caused by a general medical condition or by substance use, including medications and drugs of abuse.

It does not occur only during a Mood Disorder, Psychotic Disorder, Posttraumatic Stress Disorder or Pervasive Developmental Disorder.

Associated Features:

Depressed Mood

Somatic or Sexual Dysfunction

Anxious or Fearful or Dependent Personality



Sheffield Care Trust

Mental Health and Wellbeing

**Disabilities Joint Service
South Community Learning Disability Team**
Lightwood House
Lightwood Lane
Sheffield
S8 8BG

Tel: 0114 2716551
Fax: 0114 271 6550
louise.rodgers@sct.nhs.uk

Dear

In the Health Support Team we have a 3rd year trainee clinical psychologist. Her name is Helen Frain. She is training at the University of Leicester. Helen is doing a research project. The project is about what it is like for people with learning disabilities to have anxiety and depression. She would like to interview people who have had anxiety or depression, but now feel better. I wondered if you would be interested in talking to Helen about your experiences. There is an information sheet with this letter that will tell you more about Helen's project. You do not have to take part in the project if you do not want to. If you think you would like to meet with Helen to find out more please let me know and I will arrange for her to contact you.

Yours sincerely

Community Nurse / Clinical Psychologist

BEST COPY NOTE

**THE FOLLOWING PAGES
ARE STUCK IN SUCH A
MANNER THAT
FILMING IS IMPEDED**

Lots of people have anxiety and depression. It can be a very scary and upsetting time. Psychologists know a little about what it is like for people with learning disabilities to have anxiety and depression. So that they can help people get better they need to know more about it.



Why am I doing this research?

I am doing this research for two reasons,

important

- 1) I think it is important and interesting,
- 2) I have to do research in order to pass my training.



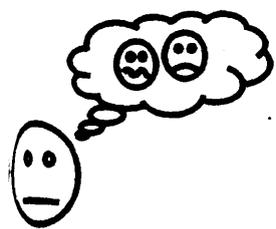
What will you have to do?

I will come and talk to you for about an hour. You can bring somebody with you if you want to. I will use a tape recorder so I can remember our conversation.



What sort of questions will I ask you?

I will ask you to tell me what you can remember about having anxiety or depression. I just want to know what it was like for you. There are no right or wrong answers to my questions. You don't have to tell me anything you don't want to.



Who will know what you have told me?

I won't tell anyone what we talked about unless I think you or someone you know is going to be hurt. Then I will tell someone who will help you. Our conversation on the tape will then be typed up. The person who types it up has agreed to keep it

confidential. This means they won't tell anyone what we talked about. They won't know who you are from listening to the tape. When it has been typed up only my supervisors and I will look at this. I might use things that you say when I write the research up but nobody will know that it was you.

What will happen to the tape?



Nobody but me and the person who types up the conversation will be allowed to hear the tape. The tape will be locked away when I am not using it. I will destroy the tape when the research is finished in about a year.

What will happen when the research is finished?



I will write up what I have learnt in a report. I will share it with other psychologists so that they can learn too. I will also write you a letter so that you know what I have learnt.

Do I have to take part?

No, you do not have to take part. Nothing will happen if you say no. If you do say yes, you can change your mind at any time.

What if you have more questions?



If you would like to talk to me more about taking part in this research you can call me on 2716939.

Thank you for taking the time to read my leaflet.

Helen Frain
Trainee Clinical Psychologist

Appendix E **‘Am I making myself clear?’ Mencap’s Guidelines for accessible writing (an extract)**

Key points

Many people find reading difficult. They may prefer to get information on audio tape or face to face. If you have to provide written material there are ways to make it easier to understand. You can:



Use clear and simple text (plain English) with short sentences, simple punctuation and no jargon.



Use larger print (at least 12 point), a clear typeface and plenty of spacing.



Use bullet points or story boxes and fact boxes to make the main points clear.



Use images such as photos, drawings or symbols to support your text. Aim to make the subject of your material clear at a glance, even to a non-reader.



Do not rely heavily on abstract symbols unless you know your readers are confident symbol users. Choose one or two simple, pictorial symbols and put them to the side of the words.



Sheffield Care Trust



Mental Health and Community

PSYCHOLOGICAL HEALTH SHEFFIELD

Learning Disability Service
 Psychology Department
 St George's Community Health Centre
 Winter Street
 Sheffield
 S3 7ND
 Tel: 0114 271 6939
 Fax: 0114 271 8932
 E-mail: Debbie.rhodes@scst.nhs.uk

Consent form

 I agree to take part in an interview for Helen Frain's research project

 I understand that this research is about anxiety and depression

 I agree that the interview can be typed up. The person who types it up will keep the information confidential. They will not discuss it with other people. They will not know who I am from listening to the tape.

 I understand that Helen will keep the tape safe. Helen will destroy the tape when the research is finished.

 I understand that Helen will not put my name on the typed up interview. This will be kept safely at the University of Leicester when the research is finished.

I understand that Helen might use something I have said when she writes up the research. She will make sure that nobody will know that I have said it.

I understand that if I do not want to be included in the research I can say so at any time.

Signed by

Name _____

Signature _____

Date

Supported by

Name _____

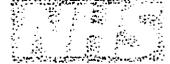
Signature _____

Date



Sheffield Care Trust

Mental Health and Wellbeing



PSYCHOLOGICAL HEALTH SHEFFIELD

**Learning Disability Service
Psychology Department
St George's Community Health Centre
Winter Street
Sheffield
S3 7ND**

Tel: 0114 271 6939

Fax: 0114 271 8932

E-mail: Debbie.modes@sct.nhs.uk

Confidentiality agreement

Transcription of research interview tapes for Helen Frain

I agree to keep the information I am transcribing from the tapes strictly confidential.

I will not discuss the contents of the tapes with anyone other than Helen Frain.

If I believe I recognise the person on the tape I will cease immediately and tell Helen that I cannot continue with the particular tape.

I will not make copies of any of the tapes.

I will keep the tapes safely.

Nobody else will be allowed access to the tapes during the transcription process.

Signed:

Name:

Date:

Countersigned by:

Date:



Sheffield Care Trust

Improving health and wellbeing



PSYCHOLOGICAL HEALTH SHEFFIELD

Learning Disability Service
Psychology Department
St George's Community Health Centre
Winter Street
Sheffield
S3 7ND
Tel: 0114 271 6939
Fax: 0114 271 8932
E-mail: Debbie.hodges@sheffield.ac.uk

Dear _____,



Thank you for taking part in my research about anxiety and depression.



If you have any more questions about my research please give me a call on _____.



If you feel very sad or worried because of something you talked about during the interview please call _____ (a clinical psychologist) on _____.

Many Thanks



Helen Frain
Trainee Clinical Psychologist

Appendix I Confirmation of Ethical Approval



North Sheffield Ethics Office

1st Floor Vickers Corridor

Direct Line: 0114 271 4894 or 271 4011

Fax: 0114 256 2469

Email: sue.rose@sth.nhs.uk

Northern General Hospital

Herries Road

Sheffield

S5 7AU

CM/SR

11 September 2006

Mrs Helen Frain
Trainee Clinical Psychologist
Leicestershire NHS Partnership Trust
104 Regent Rd
Department of Clinical Psychology
University of Leicester
LE1 7RH

Dear Mrs Frain

Full title of study: Understanding anxiety and depression: the subjective experience of people with learning disabilities.

REC reference number: 06/Q2308/130
experience of people with learning disabilities.

Thank you for your letter of 31 August 2006, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The Chairman considered the further information.

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].

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

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>
Application	1	31 July 2006
Investigator CV	Student	31 July 2006
Protocol	2	31 August 2006
Covering Letter	1	05 September 2006
Summary/Synopsis	1	25 July 2006
Letter from Sponsor	1	24 July 2006
Peer Review	1	02 June 2006
Interview Schedules/Topic Guides	1	25 July 2006
Participant Information Sheet	2	31 August 2006
Participant Consent Form	2	31 August 2006
Response to Request for Further Information		31 August 2006
Intro letter from Clinical Psychologist	1	31 August 2006
First contact letter	2	31 August 2006
CV - supervisor		31 July 2006
Applicant's checklist	1	31 July 2006
Accompanying letter	1	31 July 2006

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

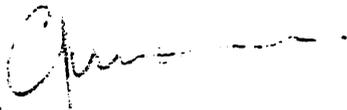
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q2308/130

Please quote this number on all correspondence

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

Yours sincerely



C Moore
Chair

Email: sue.rose@sth.nhs.uk

Copy to: Leicestershire NHS Partnership trust, R&D Office, Daisy Peake Building, Towers Hospital, Leicester

R & D Consortium

Dr S Allen (Supervisor)

Appendix J

**Confirmation of Approval of Amendments from
North Sheffield REC**



North Sheffield Ethics Office

1st Floor Vickers Corridor

Direct Line: 0114 271 4894 or 271 4011

Fax: 0114 256 2469

Email: sue.rose@sth.nhs.uk

Northern General Hospital

Herries Road

Sheffield

S5 7AU

SR

31 January 2007

Mrs Helen Frain
Trainee Clinical Psychologist
104 Regent Rd
Department of Clinical Psychology
University of Leicester
LE1 7RH

Dear Mrs Frain

Study title: Understanding anxiety and depression: the subjective experience of people with learning disabilities.

REC reference: 06/Q2308/130

Amendment number: 1

Amendment date: 27 January 2007

Thank you for submitting the above amendment, which was received on 29 January 2007. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

Documents received

The documents to be reviewed are as follows:

Document	Version	Date
Protocol	3	27 January 2007
Participant Information Sheet	3	27 January 2007
Participant Consent Form	3	27 January 2007
Confidentiality agreement	1	27 January 2007
Notice of Substantial Amendment (non-CTIMPs)	1	27 January 2007
Covering Letter	1	29 January 2007

Notification of the Committee's decision

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

Research governance approval

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects research governance approval for the research.

06/Q2308/130: Please quote this number on all correspondence

Yours sincerely



Ms Sue Rose
Committee Co-ordinator

E-mail: sue.rose@sth.nhs.uk

Copy to: Leicestershire NHS Partnership trust

Appendix K

Interview Schedule

- Can you remember when you saw [psychologist]?
- Can you remember why you saw him/her?
- What was that like [the problem]
- Can you remember how [psychologist] explained that to you?
- Did [psychologist] use any special words?
- What does anxiety / depression mean?
- Are they different?
- Can you have both at the same time?
- Is anxiety different from feeling scared because of a loud noise outside?
- Is depression different from feeling sad because you saw something sad on the TV?
- What kind of things would make somebody feel anxious / depressed?
- How would you know if some one had anxiety /depression?
 - What would they do?
 - What would they look like?
 - How would they feel?
 - What kinds of things would they think about when they felt anxious/ depressed?
- What did you do when you felt anxious / depressed?
 - What did you look like?
 - How did you feel?
 - What kinds of things did you think about when you felt anxious/ depressed?
 - What was the worst thing about feeling anxious / depressed?
 - Did it stop you doing things you enjoy?
- Did people know that you felt anxious / depressed?
- How did they know?
- What made you feel better?
- How would you know if you felt anxious /depressed again?
- What would you do?

Appendix L Worked example of IPA analysis

The following provides an example of how the researcher followed the procedures for IPA analysis as outlined by Smith and Osborn (2003) and Willig (2001).

Stage 1) Initial engagement with the text.

Having listened to the tape of the interview and read the transcript several times, initial thoughts were recorded in the left-hand margin. These included the main points raised and tentative interpretations. These are illustrated in the left-hand column of Table 1.

Table 1 Worked example of stage 1 and 2 analysis of Sarah's text

Stage 1	Transcript	Stage 2
<i>Had to avoid the stressor</i>	10 P it was. And it was for all us all. And it really, and then it got to the stage when he got a bit better so I stayed at home a couple of days cos I couldn't go up and then I went and it got a bit easier to go. And then, and then I used to I had, I was, I had me first	<i>Coping- Avoidance of stressors</i>
<i>Break down, life long difficulties, life got too much, bogged down, can't cope, pressure</i>	breakdown in, when I was about 13, and then that was through, pe, er, college, er school work really because it used to get that mush and I used to get bogged down and I couldn't cope with the pressure, I can't cope with a lot	<i>Understanding Levels of mental health problems BREAKDOWN Time - life long difficulties Reaction to everyday stressors</i>
<i>Breakdown - different levels of difficulty</i>	of pressure. And so then I had a little mini breakdown then and then I had a bad one then	<i>Coping Can't cope</i>
<i>Time period of difficulty</i>	I were off and then I left school when I were 16 and then I were a long time, about a month,	<i>Understanding Levels of mental health problem BREAKDOWN</i>
<i>Couldn't get a job</i>	about 3 or 4 month then before that I could get a job really, so I was, then I was going up to job centre and signing on and that and then	<i>importance of employment</i>
<i>Employment - they didn't explain properly - no good</i>	er, I went to this place at [place], er [place], er, [place] and I was there about a year. And I did all, things like, they weren't like explaining,	<i>anxiety as a reaction - not understanding</i>
<i>Expectations</i>	like it weren't right good for me cos they did explain really what it were I were gonna do so I were like chucked in the deep end. So they	<i>anxiety as a reaction - expectations</i>
<i>Couldn't do the work</i>	didn't explain where I were gonna be cos I were making these umbrella which I couldn't do.	<i>Failure</i>
<i>Couldn't do it - Learning Disability?</i>	They were like clips on your umbrellas, and you'd got to put them in a whole but I hadn't got much co-ordination, problem. So I hadn't got much co-ordination and they didn't always go in	<i>Learning Disability connected to failure?</i>
	<i>Sarah</i>	

Stage 2) Identification of themes

On subsequent readings preliminary themes were identified and noted in the right-hand margin, as illustrated in the right-hand column of Table 1. Possible connections between themes were also noted. Those that later emerged as super-ordinate themes are underlined.

Stage 3) Clustering of themes

A list of all the themes that emerged in the transcript was produced, simply as they appeared in the text. This allowed the researcher to consider the clusters and relationships between themes. Next, a table of all the clusters with quotes and identifying details was produced. Quotes were cut and pasted into a table directly from the original transcript to ensure the participants exact words were used. This allowed for the source of the theme to be easily traced. At this stage there were still a large number of themes and no data was omitted. The relationships between the themes were still developing and one theme might consist of several sub-themes, reflecting different aspects of the experience of negative affect, for instance behavioural and emotional indicators. An example is given from Belinda's extract in Table 2. The researcher was continually referring back to the original text to ensure the themes were grounded in the data.

Table 2)

Example of clustering themes within Belinda's text

Understanding Anxiety			
	A Worries	<i>Even the slightest little thing</i>	32
	A Levels of mental health problems	Depression as worse; <i>But in depression sometimes you've gone to pieces</i> <i>With depression, you feel more psychiatric level</i> It feels a lot worse depression? <i>It does</i>	52 58 64
	A Related to LD / disability	<i>Because when you have a disability that I've had it can actually make you more anxious</i> <i>Because its linked to a disability as well</i>	32 248
	A Different / similar to depression?	<i>I think in some ways they can be linked</i> <i>Similar I think but sometimes different</i> Emotions; <i>They can both make you a bit sad, a bit fed up and angry</i> <i>Fear; I suppose afraid goes with both</i> <i>At the same time? You can but not necessarily</i>	52 58 66 74 108

Stage 4) Production of a summary table

Through examination of the lists of themes at this stage and discussions within the qualitative support group, the four super-ordinate themes were identified. The lists were organised into summary tables to reflect the four super ordinate themes and subordinate themes within these emerged. Sub-themes that were very limited or that did not fit with these aspects of the experience were excluded at this point. An example of the development of the 'Describing' super-ordinate theme from Gemma's text is illustrated in table three

A in the table refers to anxiety, D refers to depression.

Table 3

Development of the 'Describing' super-ordinate theme from Gemma's text

Superordinate theme	Subordinate themes	Aspects of subordinate themes	Key words / quotes	Line numbers
1) concrete descriptions of behaviours / symptoms				
		ABehaviours	<ul style="list-style-type: none"> • <i>Pace up and down</i> • <i>Having a smoke</i> • <i>Phone an ambulance</i> • <i>Avoidance; I don't go to town ... in case I bump into him</i> 	GEM 226 GEM 226 GEM 260 GEM 332
		DBehaviour	<ul style="list-style-type: none"> - <i>Self harm; I took an overdose</i> - <i>Avoid social contact;</i> - <i>you just don't want to see anybody</i> - <i>I weren't bothered about seeing any body</i> - <i>You don't want ot join in with anything</i> - <i>You want to go out for walks</i> - <i>Loss of interest in appearance;</i> - <i>I weren't bothered about me self</i> - <i>You don't want to have a have</i> - <i>Lack of motivation; I didn't want to do anything</i> - <i>Self harm; I take overdoses</i> 	GEM 26, 111 GEM 32 GEM 172 GEM 402 GEM 402 GEM 172 GEM 402 GEM 172 GEM 172
		AAsk for help	<i>I had to phone police and ambulance</i>	GEM 448
		APhysiological	<i>Palpitations</i>	GEM 230
		Self harm	<i>That's another reason I took an over dose</i> <i>Took me medication with me</i>	GEM 401 GEM 450
2) Describing Thoughts				

		D Thoughts	Of the past; <i>everything comes flooding back</i>	GEM 62, 64
		A Thoughts	Not able to cope alone; <i>wish that somebody was here to sort things out</i> What's wrong with me? <i>I don't know whether it were summat to do with a cold</i> <i>It might have been a tumour</i> Safety; <i>I worry about leaving t'flat</i> <i>I don't want anyone getting in</i> <i>Somebody getting in</i> <i>Bumping into somebody I don't know</i>	GEM 234 GEM 264 GEM 270 GEM 280 GEM 282 GEM 332
		DCoping thoughts	- Positive thoughts; <i>I think of good times</i> - Pets; <i>I look at those two</i>	GEM 364 GEM 364
		DBereavement	<i>Well I think about him</i>	GEM 350
		DThoughts are different to non depressed times	But when you've got depression that feels true? <i>Hmmm</i>	GEM 180
3) Metaphors and Descriptors		DSuicide	<i>Everybody's better off without me</i>	GEM 174
		ADescriptors (metaphors)	<i>I shall end up cracking up</i>	GEM 310
		AOther descriptors	<i>Terrible</i>	GEM 224
		DDescriptors	- <i>You're in a world of your own</i> - <i>Gloomy</i> - <i>Got me down</i> - <i>I just got fed up with people</i>	GEM 32, 402 GEM 84 GEM 142 GEM 450
		DMetaphors	<i>Big black cloud</i>	GEM 36, 346
4) Unable to Describe				
5) Describing emotions				
		D Emotions	<i>Not very happy. It means you're sad</i> <i>Upset</i>	GEM 56 GEM 66
		A Feelings	- <i>Upset</i> - <i>frightened</i>	GEM 224 GEM 264
		DEmotions	<i>Angry; you don't just get down you get angry</i>	GEM 424

Integrating the cases

In order to integrate the eight cases the researcher at this point reverted back to pen and paper. Four large sheets of paper were used, at the top of each were one of the four super-ordinate themes. The associated subordinate themes from each text were then written on the sheets of paper in turn to produce lists. By examining these lists and referring back to the original text the researcher produced the final sub ordinate themes within the super-ordinate themes. Some of the subordinate themes were combined to reflect a broader element of an experience. For instance, the following themes were combined to produce the ‘what is the problem’ sub ordinate theme within the ‘Understanding’ super ordinate theme;

- Differentiating between anxiety and depression
- The problem fluctuates
- Illness model
- Metaphors
- Explanations from professionals
- The spectrum of mental health problems.

The final list of super ordinate and sub ordinate themes is presented in Table 4.

A further table was created documenting all of the contributions made by of the participants in relation to each of the super and sub ordinate themes (sub ordinate themes are underlined). This was a lengthy document and therefore is not included.

Table 4

Final list of super ordinate and sub ordinate themes

Super ordinate theme	Sub ordinate themes
Identifying	
Describing	<ul style="list-style-type: none"> • Physiological change • Behavioural change • Emotional change • Cognitive change
Understanding	<ul style="list-style-type: none"> • <u>What is the problem</u> <ul style="list-style-type: none"> - what is the difference between anxiety and depression? - are the difficulties constant? - this is an illness - using metaphors • <u>Why has this happened to me at this time in my life?</u> <ul style="list-style-type: none"> - family health and well being - bereavement and loss - past experiences - every day stresses - family / relationship difficulties - social interaction - having a disability • <u>What control do I have over the problem?</u> • <u>What impact do these difficulties have on my life?</u>
Coping	<ul style="list-style-type: none"> • <u>What can I do to manage my difficulties</u> <ul style="list-style-type: none"> - avoidance - activity - techniques from professionals - medication • <u>Who will support me through this?</u>

References

Smith, J.A. & Osborn, M. (2003). *Interpretative Phenomenological Analysis*.

J.A. Smith (Ed). *Qualitative Psychology: A practical guide to research methods*.

London: Sage Publishing.

Willig, C. (2001). *Introducing qualitative psychology: Adventures in theory and method*. London: Open University Press.

Appendix M

List of indicators of negative affect suggested

by participants

Type of Indicator	Indicator	Example from participant	Line number	Name	
Behavioural	sitting in the dark	<i>Sitting int'dark</i>	33	Carl	
	lack of motivation	<i>not wanting to do much</i>	32	Carl	
	using alcohol	<i>alcohol</i>	501	Carl	
		<i>they might drink alcohol more</i>	198	Belinda	
	smoking	<i>smoking</i>	491	Carl	
	shouting	<i>shouting</i>	579	Carl	
	avoidance of social contact	<i>just wanting to be on your own</i>	34	Carl	
			681	Carl	
		<i>stoppin in a bit more and that wanting to be alone</i>	393	Carl	
		<i>not wanting to go out</i>	397	Carl	
		<i>they won't join in with anything</i>	158	Gemma	
		uncommunicative	<i>he shuts off, its like a blank</i>	233	Sarah
			<i>I just went really quiet</i>	156	Belinda
			<i>they'd talk a lot either</i>	158	Gemma
		restless	<i>twiddling me hair</i>	201	Sarah
			<i>I can't settle</i>	201	Sarah
	<i>uncomfortable around here</i>		209	Belinda	
	sleeping	<i>sleeping all the time</i>	677	Carl	
		<i>staying in bed</i>	391	Carl	
	changes in appetite	<i>off food</i>	475	Carl	
		<i>or they wouldn't eat owt</i>	158	Gemma	
		<i>can loose a little bit, then again I might even overeat</i>	228	Belinda	
		<i>I used to snap at everybody</i>	237	Sarah	
Aggressive	<i>I give ger some right grief</i>	211	Paul		
	Coping behaviours	<i>Putting the bottles out</i>	203	Sarah	
		<i>Yoga</i>	206	Sarah	
Emotional	<i>just close me eyes</i>	206	Sarah		
	Worried	<i>Bit worried like</i>	183	Belinda	
Fear	<i>you might be a little bit afraid</i>	74	Belinda		
	<i>I were frightened</i>	30	Sarah		
Intimidated	<i>a little bit intimidated</i>	206	Belinda		
Sad	<i>He's feeling a bit sad</i>	90	Belinda		
	<i>It means you're sad</i>				
Upset	<i>you just feel upset, miserable</i>	44	Carl		
	<i>Upset</i>	28	Carl		
Frustrated	<i>you can get quite frustrated</i>	143	Belinda		
Lonely	<i>There were nobody there</i>	32	Sarah		
	<i>felt a bit lonely</i>	547	Carl		
Down	<i>feeling down</i>	407	Carl		
	Physiological				

Tearful	<i>tearful</i>	401	Carl
	<i>They'd cry a lot</i>	158	Gemma
	<i>I would be more tearful</i>	292	Belinda
Shaky	<i>shaky hands</i>	483	Carl
	<i>shaky hands</i>	193	Sarah
	<i>legs were jelly</i>	263	Sarah
stomach	<i>come up from me stomach</i>	50	Sarah
Tension	<i>Tight feelings</i>	259	Sarah
	<i>his shoulders go all tight</i>	195	Sarah
	<i>you feel really tense</i>	209	Belinda
Eyes	<i>and his eyes wrinkle up</i>	195	Sarah
	<i>sad, miserable weepy eyes</i>	220	Beverley
Face	<i>I can tell by me dads face</i>	195	Sarah
	<i>its in me face</i>	173	Adam
	<i>my face changes colour</i>	176	Belinda
	<i>their eyes, their face, how they look</i>	220	Beverley
Headaches	<i>sometimes you get pains in your head</i>	358	Paul
Nausea	<i>I was feeling sick</i>	263	Sarah
Sweating	<i>me hands went all clammy</i>	263	Sarah
Breathing difficulties	<i>I feel starved of me oxygen.</i>	206	Sarah
	<i>I can hyperventilate</i>	200	Belinda

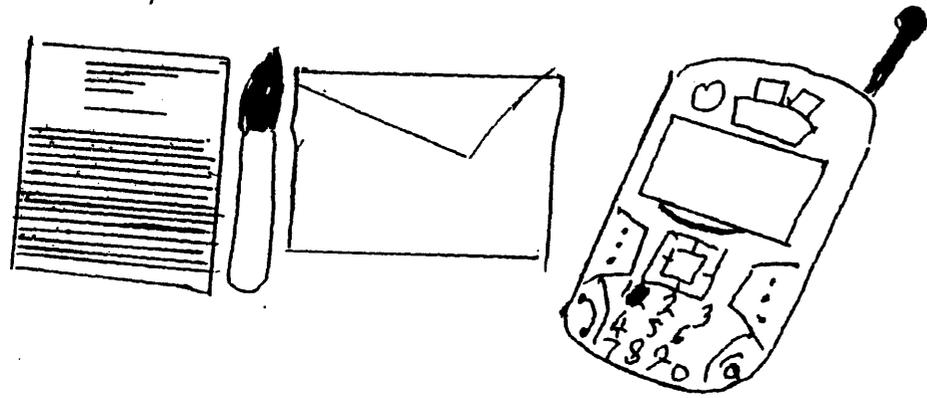
Appendix N**List of factors the participants discussed that may have contributed to their negative affect**

Contributing factor	Discussed by which participants
Social interaction (or lack of)	Carl , Sarah, Gemma, Adam, Belinda, Beverley, Paul,
Family Health worries	Carl, Sarah, Gemma, Belinda, Beverley.
Novel situations	Carl, Gemma.
Bad experiences n the past	Carl, Sarah, Gemma, Paul, Adam, Beverley,
Financial security	Carl, Gemma.
Everyday stresses	Carl, Sarah, Gemma, Adam, Beverley.
Family / relationship difficulties	Sarah, Gemma, Reginald, Belinda.
Restriction / expectations	Carl, Sarah, Gemma, Reginald.
Failure	Carl.
Being a burden	Carl .
Loss of loved ones	Carl, Sarah, Paul, Gemma, Belinda, Beverley.
Responsibility	Sarah.
Not understanding or not being understood	Sarah, Gemma, Belinda.
World as a dangerous place	Sarah, Gemma.
Intellectual disability	Carl, Sarah, Belinda.
Other peoples emotional states	Sarah.
Own health	Gemma, Paul.
Crime	Gemma, Adam, Beverley.
Weather	Gemma.
Disturbing television programmes	Reginald.
Hospitals	Paul.
Not being listened to	Belinda.
Changes in plans	Belinda.
Needles	Beverley.

CONTENTS

- 1) INTRODUCTION
- 2) ABOUT BOOK
- 3) DEPRESSION/ANXIETY
- 4) MY DISABILITY
- 5) HOW 3 & 4 ARE LINKED
- 6) COPING STRATEGIES
- 7) CBT & CAT
- 8) CAUSES OF DEPRESSION
& ANXIETY

If you want to know more about my book you can call me on [REDACTED] or write to me,

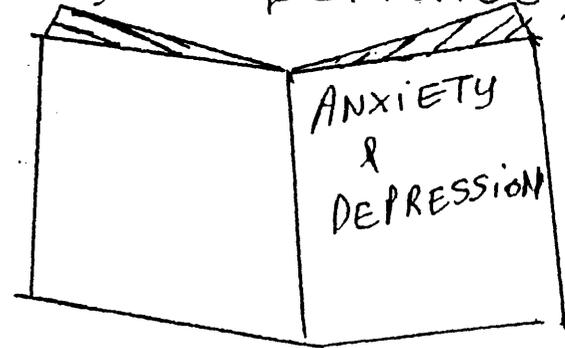


ABOUT BOOK

[REDACTED] (Learning Disability psychologist), approached me to see if I would help with some research.

I am helping Helen Frahn who is doing research about anxiety and depression.

I also decided to help Helen and anyone else who it might help by writing a book from my experience.

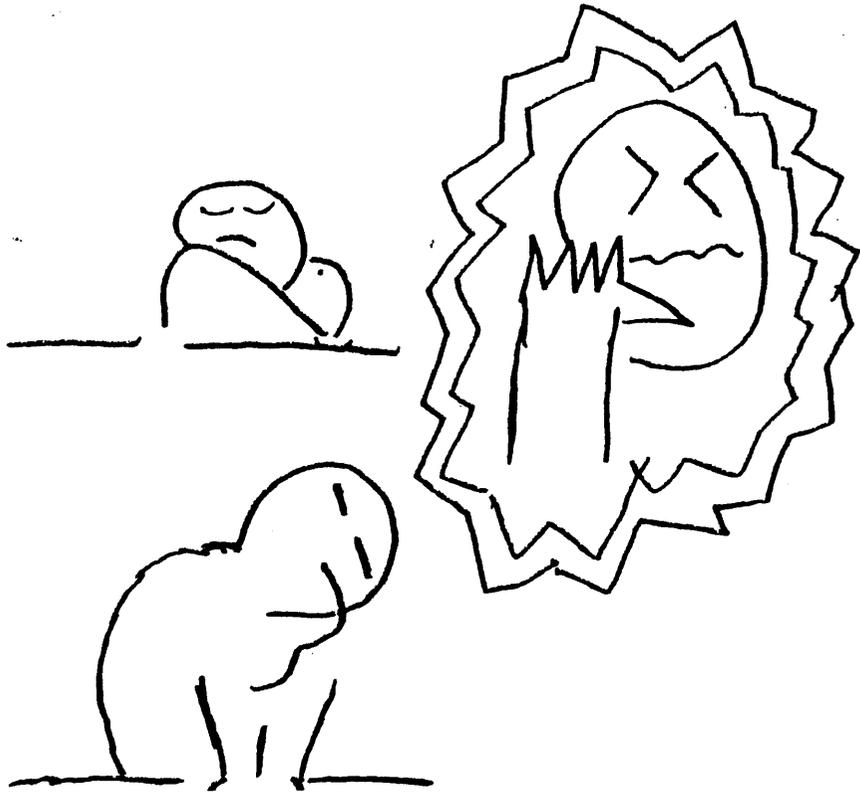


DEPRESSION/ANXIETY

Sometimes I can be anxious without being depressed and sometimes I can feel both at the same time.

I was depressed as a child too as I got bullied a lot.

This can make you feel sad, angry, afraid and timid.



MY DISABILITY

I have a mild Learning Disability and Asperger's Syndrome which is a form of Autism.

I have struggled all my life because when I was younger I did not meet the criteria for support.

I now see a psychiatrist and access some support from services

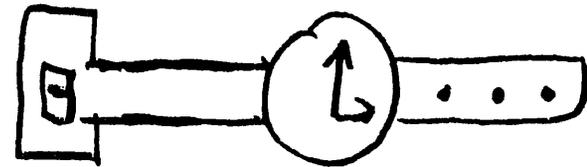
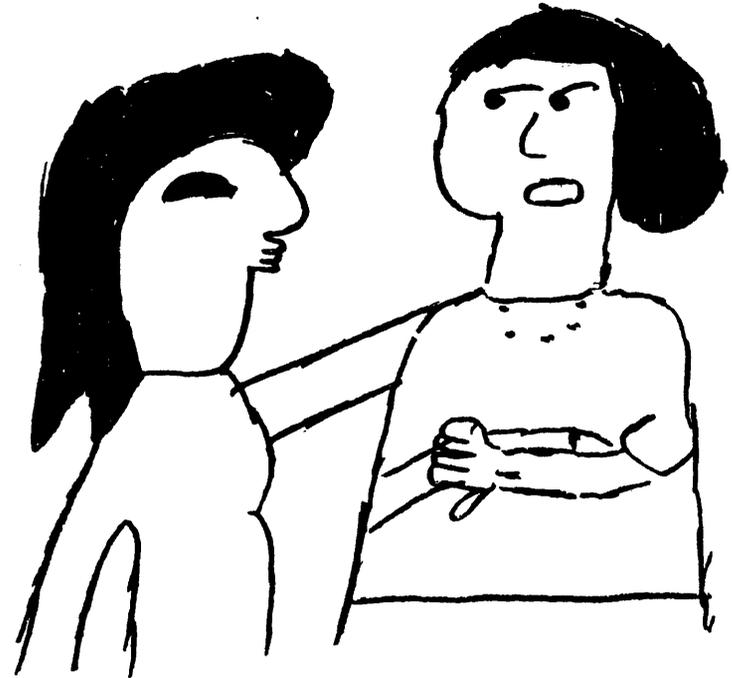


HOW 314 ARE LINKED

Autistic Spectrum Disorders can lead to depression or anxiety especially when things do not work out.



To avoid this it is important to have the right support at the right time.



COPING STRATEGIES

When I feel depressed or anxious I might miss food or overeat, I might want space, I might be unable to talk for a while as a safety net, I may ask for help or I might recap on my CBT and CAT skills.



CBT & CAT

CBT is Cognitive Behavioural Therapy when you think something is wrong with your mind.

It is about changing negative thoughts to positive.

CAT is Cognitive Analytic Therapy.

It looks at relationships and solving the problem at the time.

I have used both and got a lot out of them.

They are talking therapies.

CAUSES OF DEPRESSION & ANXIETY

Being let down.
Being misunderstood.
Being ... bullied.
Change of plan.
people being late.
Communication at times.
Not being listened to.
Splitting up with fiance.
Loosing jobs.
Bereavment

Appendix P

**Notes to contributors
(Journal of Applied Research in Intellectual
Disabilities)**

Journal of Applied Research in Intellectual Disabilities

Published on behalf of **bild** (British Institute of Learning Disabilities)

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The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, social networks, staff stress, staff training, epidemiology and service provision.

Theoretical papers are also considered, provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous peer-refereeing process.

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