People with Intellectual Disabilities (ID) Experience of Detention under the Mental Health Act (1983)

Submitted by

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Thesis for the degree of Doctor of Clinical Psychology, to the Department of Psychology, University of Sheffield.

DECLARATION

This work has not been submitted to any other institution or for any other qualification

SECTION ONE: Literature Review

SUMMARY:

Background: *Mental health (MH) problems are considered to be relatively common for people with intellectual disability (ID), but tools for assessing such difficulties have only recently emerged.(1). To provide critical evaluation of measures currently used to assess MH difficulties in adults with mild and moderate ID. (2). To determine the standard of psychometric sophistication in such scales and (3). To alert clinicians and researchers to the range of measures now available.*

Method: *55 papers and 18 scales were reviewed which were grouped according to (1) behaviour rating scales (2). mental health scales (3) multi-trait scales and (4) interpersonal scales. The psychometric basis of each of the scales, in terms of reliability and validity issues are considered and compared.*

Results: *Of the scales currently available only the ABC and Reiss have independent published studies, providing sufficient evidence for a sound psychometric foundation.*

Conclusions: *In terms of available evidence, with regards to current clinical practice, effective assessment should be led by use of the Reiss Screen, in the context of client and informant interviews. Recommendations for further research concerning measure development and evaluation across the field are provided.*

SECTION TWO: Research Report

ABSTRACT:

BACKGROUND: Fundamental to the development of research knowledge are studies establishing user views and experiences of service delivery. However, currently there are no published studies providing insight into the experience of detention for people with intellectual disability.

SPECIFIC AIMS: This study explores the experiences of people with intellectual disability of detention under the Mental Health Act (1983). The study seeks to provide insight into their perceptions of the act of detention and associated emotional responses.

METHOD: Transcripts of semi-structured one to one interviews (N=7) were analysed using Interpretative Phenomenological Analysis. Participants had mild-moderate ID and been detained under the Mental Health Act. All particpant5s had been detained in the 2-year period, prior to the study.

FINDINGS: Four themes common across participants were identified: (a). 'perception of self in the world'; (b). 'a negative event', (c). emotional response to the act of detention; and finally (d). family relationships. A number of valuable insights emerged including: the impact of perceived lack of control over self and experiences of vulnerability, powerlessness and victimisation, both prior to, and following the act of detention; participants' sense of care Vs punishment; the development of 'role' within the system and attribution of blame.

DISCUSSION: This study expands the current literature regarding the experiences of people with intellectual disabilities from their perspective, the emotional impact of traumatic experiences and differences in coping styles. Ideas for future research are also provided.

SECTION THREE: Critical Appraisal

A critical appraisal of the process of the research study will be presented in this section outlining the project from its initial conception through to its current stage of completion. Appraisal comprises of four main sections, namely: (1) Project Origins, (2) Implementation, including: initial planning and approaching of supervisors; acquisition of ethical and clinical governance approval(s); recruitment process and barriers to recruitment; supervision; personal motivation; consideration of methodological limitations and strengths, clinical implications and further research. (3) Learning and Development and (4) Final Considerations of Research Process Overall.

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WORD COUNT

Foreword

Total	1361

Section 1. Literature Review

Journal of Applied Research in Intellectual Disabilities

Article	6992
References	2654
Total	9646

Section 2. Research Report (Option B)

Journal of Policy and Practice in Intellectual Disabilities

Article	6304
References	998
Total	7302

Section3: Critical Appraisal

Article	4573
References	385
Total	4958

Section 4: Appendices

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SECTION ONE:

CONSIDERATION OF THE PSYCHOMETRIC FOUNDATIONS OF ASSESSMENTS OF MENTAL HEALTH IN ADULTS WITH INTELLECTUAL DISABILITY (ID): A LITERATURE REVIEW

INTENDED JOURNAL FOR SUBMISSION: JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES

Summary:

Background: *Mental health (MH) problems are considered to be relatively common for people with intellectual disability (ID), but tools for assessing such difficulties have only recently emerged. The aims of this literature review are therefore as follows: (1). To provide critical evaluation of measures currently used to assess MH difficulties in adults with mild and moderate ID. (2). To determine the standard of psychometric sophistication in such scales and (3). To alert clinicians and researchers to the range of measures now available.*

Method: *55 papers and 18 scales were reviewed which were grouped according to (1) behaviour rating scales (2). mental health scales (3) multi-trait scales and (4) interpersonal scales. The psychometric basis of each of the scales, in terms of reliability and validity issues are considered and compared.*

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Background

Mental health (MH) problems in adults with intellectual disability (ID) began to receive attention in the 1980's (Sturmey & Sevin, 1993), with the field developing from that point. Literature pertaining to assessment of people with ID is historically laden with instruments solely measuring skills or behaviour. Corresponding research specifically investigating assessment of MH problems is scarce in comparison. There are several problems posed when assessing psychological disorders or diagnosing MH problems in people with ID including: (a) widely held assumptions that people with ID are generally unable to give accurate account of their mental/internal state; (b) the application of classification schemes developed with non-ID populations, (Sturmey *et al*, 1991); (c) the frequent necessity to use informant information, and finally (d) difficulties encountered in distinguishing psychiatric symptoms from other behavioural traits or problems experienced by people with ID (Bouras & Drummond, 1992).

Clinicians and researchers are increasingly likely to initiate work attempting to gain insight and understanding into individuals' perceptions of their ID (Johnson *et al* 2003), and have much to offer to change the lives of people with ID and MH problems for the better (Hatton *et al* 1999; Beail, 2003; Willner 2005). A variety of instruments and techniques are utilised by clinicians and researchers to determine the MH status of people with ID. However clinical instruments can only be considered worthy of the task of assessment if they have satisfied various, and hopefully rigorous, aspects of reliability and validity (Kellett *et al* 2004). Moss (1999) stated that 'case recognition' is a crucial step, with regards to meeting the MH needs of people with ID. Unfortunately there appears to be a general paucity of fully evaluated psychometric indices of MH for clinical use with people with ID (Aman, 1994; Beail 2004). This further heightens the challenge of accurately detecting, diagnosing and formulating the MH difficulties of people with ID (Kellett *et al.* 2004) and evaluating treatment outcomes (Beail, 1994).

Prevalence

MH problems are considered common among adults with ID, although a definitive large-scale epidemiological study has yet to be undertaken (Cooper, 2003). Studies estimating prevalence of MH difficulties in people with ID indicate rates varying from 10% to 80% (Borthwick-Duffy, 1994), depending on definitions of disorders, methods of case identification and populations studied (Caine & Hatton, 1998). Studies indicate that people with ID are consistently at higher risk of MH problems, than individuals without ID (Deb *et al* 2001), suggesting raised prevalence of psychiatric disorder (Melville, 2003; Deb *et al*, 2001) but lower risk of affective and neurotic disorders (Moss, 1999). It has been suggested that apparently lower rates of some problems may not be an accurate indication of morbidity, but an indication that people with ID may have increased likelihood of having an undiagnosed psychiatric disorder (Prosser, 1999). Indeed people with ID are more likely to experience risk factors for affective disorders, such as stigmatisation, poor social skills and lack of support (Sturmey *et al* 1991) and can therefore be considered as an 'at risk' group for experiencing depression and anxiety. It is likely that many individuals with ID have MH problems that remain undetected, and therefore go untreated (Reiss, 1990). One possible reason for under-diagnosis is the deficiencies in the assessment tools available to detect 'caseness' (Caine & Hatton, 1998).

Approaches to assessment:

Reliability and validity of diagnosis of psychiatric disorder in general psychiatry, has been improved by the introduction of standard classification systems of psychiatric disorders (Caine, & Hatton, 1998); namely Diagnostic and Statistical Manual of Mental Disorders -DSM (APA, 1994) and International Classification of Diseases-ICD (WHO, 1993). However, the validity of applying such criteria to people with ID is problematic, as DSM/ICD criteria were developed on general child and adult populations, raising questions as to whether such criteria need to be modified for people with ID (Sturmey & Sevin 1993). Currently some consensus guidance has been developed on the use of these manuals with people with ID, but these have not been empirically evaluated.

Standardised interviews and checklists of MH problems specifically designed for people with ID are a rarity (Sturmey *et al.* 1991; Sturmey, 1993) and research on ID and dual diagnosis relies heavily on general population studies (Esbenson *et al.* 2003). Between-studies comparisons of existing research is made difficult because of widely differing assessment and diagnostic approaches (Sturmey, 1993). A few screening instruments have been developed, including the PAS-ADD schedules (Moss, *et al.* 1996; Prosser *et al.* 1997), Assessment for Dual Diagnosis – ADD (Matson and Bamburg, 1998); the Psychopathology Instrument for Mentally Retarded Adults – PIMRA (Matson *et al.* 1984) and the Reiss Screen for Maladaptive Behavior (Reiss, 1988). The majority are informant-based rather than self-report, yet such information provided by informants has been found to be of questionable reliability and validity (Powell, 2003).

Clinicians and researchers assessing MH problems in people with ID have turned to utilising single and multi-trait measures, many of which are extant scales adapted for use with individuals with ID, including the Beck Depression Inventory (BDI), Brief

Symptom Inventory (BSI) and The Inventory of Interpersonal Problems-32 (IIP-32). Scales are typically administered in an assisted completion format, involving rewording items for ease of understanding, removing items and redesigning response formats. Although these changes make self-report measures more accessible for use with people with ID, such changes may impact upon the reliability and validity of the instruments, with adapted measures still requiring full psychometric evaluation.

Aims:

Although previous reviews have been conducted (Sturmey *et al*, 1991; Aman, 1994; Caine & Hatton, 1998) many measures have emerged in recent years. The aims of this review are threefold:

(1) To provide critical evaluation of measures currently used to assess MH difficulties in adults with mild and moderate ID

(2) To determine the standard of psychometric sophistication

(3) To alert clinicians and researchers to the range of measures now available

METHOD

Rationale for exclusions:

This review focuses on psychometrically based scales used with adults with mild to moderate ID. Scales only utilised with people who have severe and profound ID have been excluded. Scales used to assess dementias have been excluded, as the focus of the review is MH, as opposed to organic deterioration. Clinical interview based approaches such as Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation - DC-LD (Royal College of Psychiatrists, 2001) and PAS-ADD-10 Schedules have been excluded as they are not psychometrically based. Anger scales have been excluded as they have recently been reviewed (Taylor, 2002; Rose & West, 1999).

Search Strategy

Papers were identified using two search strategies, namely:

(1). PsycINFO; Web of Science and MEDLINE databases were searched with a combination of the terms "intellectual disability"; "developmental disability"; "mental retardation"; learning disabilities"; "mental health assessment"; "reliability" and "validity". Only papers published in peer review journals, in English were selected.

(2). References from published studies

Including only papers published in English, describing assessment measures used with people with ID in relation to reliability and validity.

Definitions of Reliability and Validity:

Reliability refers to the degree of reproducibility of the measurement, or the consistency with which any scale assesses a trait or attribute (Barker *et al.* 2002), the more consistent the measurement, the greater the reliability. Three measures of reliability have been selected and are presented in Table 1 (Barker *et al.* 2002).

Table 1 Measures of Reliability

Criterion	Definition
Test-retest	Considers whether the measure is reliable over time and has temporal stability
Internal consistency	Standard way of assessing the inter-item reliability of a scale that is composed of multiple similar items. E.g. measuring whether the items of a scale are measuring the same thing (high consistency) or different things (low consistency). A scale is internally consistent when items are highly correlated with each other, suggesting that all items are measuring a common construct
Inter-rater	Used in observational rather than self-report measures in order to check the reliability of rater observations. Inter-rater reliability is the extent to which ratings "agree".

Validity is defined as "whether the measure measures what it is supposed to measure" (Barker *et al.* 2002). Five validity measures have been selected: see Table 2 (Barker *et al.* 2002).

Table 2: Measures of Validity

Criterion	Definition
Content Validity	Assesses whether a measure adequately covers different aspects of the construct that are specified in the definition
Construct Validity	Examines the validity of a construct rather than the individual methods of measuring it. Asks if the pattern of relationships between measures of that construct and measures of other constructs is consistent with theoretical expectations
Criterion Validity	Considers how well the measure correlates with an established criterion or indicator of the construct it is measuring. Implies an empirical association between an item or scale and a 'gold standard' criterion.
Face Validity	Assesses whether a measure looks right at face value e.g. self evidently measures what it claims to measure
Sensitivity/discriminant validity	An index of how well the measure picks out people who have a target condition (e.g. how few false negatives there are

For purposes of psychometric evaluation suggested reliability (Anastasi & Urbina 1997) and validity (Barker & Pistrang, 2002) standards are used:

Table 3 Reliability and Validity standards

	Reliability	Validity
Good	0.80	0.50
Moderate/acceptable	0.60	0.30
Low	0.40	0.10

Review Structure:

For the purposes of review, assessment measures have been divided into four categories namely; (1) behaviour rating scales; (2) mental health scales (anxiety; depression and anxiety + depression) (3) multi trait scales, and (4) interpersonal functioning scales.

RESULTS

Behaviour Rating Scales

A number of behavioural scales have been developed for ID populations (Aman, 1994), but only three have paid any significant attention to psychometric foundations (reliability data Table 4 and validity Table 5).

*The Aberrant Behaviour Checklist (*ABC; Aman & Singh, 1986).

This instrument was devised by compiling items from New Zealand based populations, which were then pooled and factor analysed, using a cross-validation procedure, to produce a five subscale instrument (Aman *et al.* 1985a.). The scales are titled Irritability, Lethargy, Stereotypy, Hyperactivity and Inappropriate Speech. The factor structure of the ABC has been replicated in a number of analyses using principal factoring methods, including comparison of American, British and Japanese populations (Aman *et al.* 1987; Newton & Sturmey, 1987; Bihm & Poindexter, 1991; Ono, 1996). Test-retest reliability of the ABC has been reported as excellent (Aman *et al.* 1985b.; Ono, 1996) and internal consistency found to be high for all subscales (Aman *et al.* 1985b.). Bihm & Poindexter, (1991) cross-validated the scales internal consistency and concluded that the ABC was factorially a sound instrument but that interrater reliabilities were moderate. Ono (1996) assessed factor validity using the principle factoring method and found essentially the same structure as the original scale.

Walsh & Shenouda (1999) concluded that ABC predicted Reiss Screen total scores, indicating criterion validity and Aman *et al.* (1985b.) found low-moderate relationships between the Vineland and the Adaptive Behaviour Scales indicating concurrent validity.

Evidence of discriminant validity and convergent validity was found (Aman *et al.* (1985b: Aman *et al,* 1994). Rojahn *et al.* (2003) found evidence of convergent and divergent validity when cross validating the ABC with the Behavior Problem Inventory. Aman (1994) concluded that psychometric characteristics have been examined both by the authors and independent researchers and appear to be robust. However, people with mild ID were excluded from the validation studies and numbers of participants with moderate ID are not described. The applicability of the ABC with people with mild/moderate ID needs further research.

Behavior Problem Inventory (BPI-01; Rojahn, 2001).

The BPI is a 52-item, respondent-based behavior rating scale designed for ID populations covering three subscales (Self-injury, Stereotypy & Aggressive/Destructive

Behaviour). The BPI has been translated into 11 different languages as part of a standard battery of outcome measures (Rojahn *et al.* 2001).

The BPI was designed as a treatment outcome measure and has been subject to several factor analyses (Rojahn, 1984; Widman *et al.* 1987) The BPI-01 is the latest version and was derived from the original BPI. The reliability and validity of the original scale is well established. Rojahn *et al.* (2001) completed confirmatory factor analysis and found it to be reasonable, with moderate-good test-retest reliability and good mean internal consistency. Criterion validity was also good, established through concurrent validity when compared with Pervasive Developmental Disorder. However 84% of participants had severe/profound levels of ID, thus its application with people with mild or moderate ID requires further research.

The Reiss Screen for Maladaptive Behavior (Reiss, 1988)

The Reiss Screen is a 36-item informant style scale that yields eight scales (aggressive behavior; autism; psychosis; paranoia; depression (behavioural signs); depression (physical signs); dependent personality disorder and avoidant personality disorder), from which a 38-item total score is calculated (Reiss, 1988). Reiss (1988) discussed the concept of factor content validity, concluding that the screen has face validity and evaluated reliability and validity on a sample of 205 people (Reiss, 1990). Reiss (1997) argues that concurrent validity is best highlighted by consistency of significant correlation with psychiatric case file diagnosis, indicating criterion validity. However no specific description of the psychiatric diagnoses, or how they were reached was provided.

The Reiss has been subject to exploratory factor analyses (Benson & Reiss, 1988; Reiss 1988), and confirmatory factor analysis (Havercamp & Reiss, 1997) showing good replication of the eight factor structures (Reiss, 1988) There are several independent exploratory replication studies (Chitty *et al.* 1993; Rojahn & Warren 1994; Minnen *et al* (1995); Sturmey *et al.* 1995; Gustaffsson & Sonnander, 2002), providing evidence of reasonable replication. Sturmey & Bertman (1994) found moderate to good test-retest, inter-rater reliability and internal consistencies. However Sturmey *et al.* (1995) found low-moderate test-retest, internal consistency and interrater reliability.

Sturmey *et al* (1996) found a moderate correlation between Reiss autism scores and the ABC Irritability subscale, and high correlation between Reiss Depression subscale and ABC Lethargy subscale indicating concurrent validity. Sturmey *et al* (1996) also found moderate to good concurrent validity for PIMRA total scores but following exploratory principle components analysis reported that the validity of the 8 sub-scales is questionable. Reiss (1997) responded, concluding that Sturmey had not provided "a fair test of the issue of robustness and was heavily biased against replication of the Reiss factors" (1997). Walsh & Shenouda (1999) concluded that ABC predicted Reiss total scores well indicating concurrent validity, concluding that the Reiss provides a quick, efficient clinical instrument.

Versions have also been used in Holland, India and Sweden. Rojahn & Warren (1994) evaluated the Dutch version and found that subscales could successfully differentiate between people with ID with a psychiatric diagnosis and those without. They also found adequate test-retest reliability, but low convergent validity levels of agreement between the Reiss, a psychiatric interview and a self-report measure. Gustafasson & Sonnader (2003) evaluated the Swedish version finding high internal consistency but low-moderate inter-rater reliability. Kishore, *et al.* (2004) evaluated use of the Reiss in India and found agreement between clinical diagnosis with ICD-10 and Reiss screen scores was 82%, indicating concurrent validity.

Table 4: Reliability of Behaviour Rating Scales:

Criterion **Scale**	**Test-retest**	**Internal Consistency**	**Inter-rater**
ABC	Aman *et al* (1985b.) **0.98** Ono (1996) **0.86**	Aman *et al* (1985b.) **0.86-0.94** Aman *et al* (1986) **0.90** Newton & Sturmey (1987) **0.64** Bihm & Poindexter (1991) **0.84-0.95** Sturmey & Bertman (1994) **0.87** Aman (1994) Ono (1996) **0.92** Minnen *et al* (1995)	Aman & Singh (1985) **0.63** Newton & Sturmey (1987) Bihm & Poindexter (1991) **0.63** Ono (1996) **0.66**
BPI-01	Rojahn *et al* (2001) x = **0.76**	Rojahn *et al* (2001) x = **0.83**	Rojahn *et al* (2001) **0.92**
Reiss Screen	Reiss (1990) Rojahn (1994) Reiss (1997) Chitty *et al* (1993) Sturmey& Bertman (1994) Rojahn & Warren (1994) Sturmey *et al* (1995) **0.31**	Reiss (1988) **0.54-0.85** Sturmey & Bertman (1994) **(0.58)** Sturmey *et al* (1995) **0.33** Havercamp & Reiss (1997) Gustafsson& Sonnader (2002) x = **0.60**	Reiss (1988) x = **0.54** Sturmey & Bertman (1994) Sturmey *et al* (1995) **0.56** Gustafsson & Sonnader (2002) **0.60**

Table 5: Validity of Behaviour Rating Scales:

Criterion **Scale**	**Content validity**	**Construct validity**	**Criterion validity**	**Face validity**	**Sensitivity**
ABC	Aman *et al* (1985)	Aman *et al* (1985a.) **(0.58)** Aman *et al* (1986) Aman *et al* (1987) **(0.90)** Newton & Sturmey (1987) **(0.83-.88)** Bihm & Poindexter, (1991) **(0.84-0.95)** Ono (1996) Walsh & Shenouda (1999) Rojahn *et al* (2003)	Aman *et al* (1986) Sturmey & Bertman (1994) **(0.69)** Walsh & Shenouda (1999) **0.00-0.74**	Aman *et al* (1985a)	Aman *et al* (1985a) Rojahn *et al* (2003)
BPI-01		Rojahn *et al* (2003)	Rojahn *et al* (2001))		Rojahn *et al* (2001) **(0.88)**
Reiss Screen	Reiss (1988)	Reiss (1988); Benson & Reiss (1988); Rojahn & Warren (1994) Sturmey *et al* (1996) **(0.33-0.87)** Havercamp & Reiss (1997) Johns & McDaniel (1998) Walsh & Shenouda (1999) Gustafsson & Sonnander (2002) **(0.60)**	Reiss, (1990) Sturmey & Bertman (1994) **0.541-0.604)** Sturmey *e t l* (1996) Walsh & Shenouda (1999) **0.58** Gustafsson & Sonnander (2002) Kishore *et al* (2004)	Reiss (1988)	Rojahn & Warren (1994) Minnen *et al* (1995) Gustafsson & Sonnander (2002)

Mental Health Scales:

Measures have been developed specifically for use with people with ID whom are suspected to have MH problems. The majority are informant based and the most commonly used are separated into 3 categories:

1. anxiety scales (Tables 6 & 7)
2. depression scales (Tables 8 & 9)
3. anxiety and depression scales (Tables 10 &11)

Anxiety Scales

Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-AD: Mindham & Espie, 2003).

As the GAD-ID was constructed specifically for use with ID populations through a process of consultation with people with ID, clinicians and researchers and consideration of appropriate literature, it is argued that it has reasonable content validity (Mindham & Espie, 2003). Test-retest reliability was good at one month suggesting stability in measurement. Internal consistency was found to be high (Mindham & Espie, 2003). The correlation of the measure with the Beck Anxiety Inventory (BAI) provides preliminary evidence of acceptable criterion validity (Mindham & Espie, 2003). No validity data for the BAI with people with ID has been published.

Zung Self-Rating Anxiety Scale (Zung, 1971)

Masi *et al* (2002) investigated the concurrent validity of the PIMRA and other general measurement instruments with the Zung Scales and found that the Anxiety Scale correlated highly with the PIMRA anxiety subscale.

Table 6: Reliability of Mental Health Scales (anxiety)

Criterion	Test-retest	Internal Consistency	Inter-rater
Scale			
GAS-AD	Mindham & Espie (2003) **0.93**	Mindham & Espie (2003) **0.96**	Mindham & Espie (2003)
Zung-A			

Table 7: Papers reporting the validity of Mental Health Scales (anxiety):

Criterion	Content	Construct	Criterion	Face	Sensitivity
Scale					
GAS-AD	Mindham & Espie (2003)		Mindham & Espie (2003)		
Zung-A			Masi, *et al* (2002)		

Depression Scales

Beck Depression Inventory (BDI; Beck & Steer, 1993)

The BDI is a 21-item instrument measuring cognitive, behavioural, motivational and vegetative states of depression. Prout and Schaeffer (1985) found that people with ID scored higher using the BDI than the general population. Following confirmatory factor analysis, Powell (2003) concluded that the BDI has clinical validity and found good internal consistency of the sample when compared with other research in the field. However, Helsel & Matson (1988) found the mean internal consistency to be moderate. Kazdin *et al.* (1983) compared the BDI with various measures of depression with the correlations, suggestive of concurrent validity. Beck *et al.* (1987) found that the BDI had good correlation with psychiatric diagnosis of depression indicating good concurrent validity. Factor analysis also suggested that the instrument is valid for use in intellectually disabled populations and Powell (2003) concludes that the BDI is a better instrument than the Zung, as it shows similar psychometric properties across general and ID populations. The BDI-II has now been published but no data pertaining to people with ID is available.

Glasgow Depression Scale for People with a Learning Disability (GDS-LD) and Carer supplement (GDS-CS; Cuthill et al, 2003)

Cuthill, Espie and Cooper (2003) stated that face and content validity of the GDS-LD and the GDS-CS were acceptable. The scales were found to discriminate effectively between depressed and non-depressed groups, when based on Mini-PASADD assessment. The GDS-LD scale also correlated highly with the BDI-II scores of people with depression, but without ID, suggesting that the same construct was being measured (Cuthill *et al.* 2003). The scales demonstrate internal consistency and have good test-retest reliability. Inter-test reliability was also demonstrated between the GDS-LD and the GDS-CS suggesting that the GDS-LD may be clinically useful in assessing non-compliant individuals. Sensitivity of 96% was achieved by using a cut-off score of 13.

Self-Report Depression Questionnaire (SRDQ; Reynolds, 1989)

The SRDQ is an orally administered scale designed to assess depressive symptomology using DSM criteria (Reynolds, 1989), as a screening tool for use with adolescents and adults with mild or borderline ID. It contains a pre-test, comprising 15 items and the scale itself comprises of 32 items. Good test-retest reliability after 11 weeks has been found (Reynolds & Baker, 1988) and good test-retest and internal consistency (Aman, 1991). Aman (1991) also reports some congruence between other indexes of depression indicating concurrent validity. Evidently psychometric data remains limited regarding the SRDQ.

Zung Self-Rating Depression Scale **(Zung, 1965)**

The Zung has been adapted for use with people with ID (Prout & Schaffer, 1985; Lindsay & Michie, 1988). Prout & Schaffer(1985) found internal consistency to be moderate. Powell (2003) found internal consistency measures of the Depression Scale to be low and factor analysis did not allow reliable interpretation of loadings. Powell (2003) therefore argued that further research of this instrument regarding its utilisation across all populations, not purely ID, is necessary.

Masi *et al.* (2002) investigated the concurrent validity of the PIMRA and other general measurement instruments with the Zung Scales and found the Depression Scale had no significant correlation, suggesting a lack of convergent validity.

Table 8: Reliability of Mental Health Scales (depression)

Criterion	**Test-retest**	**Internal Consistency**	**Inter-rater**
Scale			
BDI		Helsel & Matson (1988) **0.59** Powell (2003) **0.86**	N/A
GDS-LD	Cuthill & Espie (2003)	Cuthill & Espie (2003)	
SRDQ	Reynolds & Baker (1988) **0.79** Aman (1991)	Reynolds & Baker (1988) **0.93** Aman (1991)	N/A
Zung –D		Prout & Schaffer (1985) Helsel & Matson (1988) **0.54** Powell (2003) **0.58**	N/A

Table 9: Validity of Mental Health Scales (depression)

Criterion	**Content**	**Construct**	**Criterion**	**Face**	**Sensitivity**
Scale					
BDI		Powell (2003)	Kazdin *et al* (1983) Prout & Schaffer (1985) Beck *et al* (1987) Powell (2003)		
GDS-LD	Cuthill *et al* (2003)	Cuthill *et al* (2003)	Cuthill *et al* (2003)	Cuthill *et al* (2003)	Cuthill *et al* (2003)
SRDQ			Aman (1991)		
Zung – D		Powell (2003)	Powell (2003) **0.59**		

Anxiety and Depression Scales

Anxiety, Depression and Mood Scale (ADAMS; Esbenson, et al, 2003)

The ADAMS is a 28-item behaviour-based informant instrument that is non-reliant on DSM criteria. It is described as the first instrument to successfully obtain empirically derived factors of both anxiety and depression with one sample of subjects (Esbenson *et al.*2003). At the item level there was variability among test-retest correlations; but total scale and subscale retest correlation were good, whilst interrater reliability values were low. Esbenson *et al.* 2003 found factor structure to be internally consistent with reasonable model fit and purported that the ADAMS proved to be a valid instrument for screening for bipolar disorder, clinical depression and OCD. Further research is necessary to determine cut-off scores and assess convergent and discriminant validity.

Table 10: Reliability of combined scales (anxiety+depression)

Criterion Scale	Test-retest	Internal Consistency	Inter-rater
ADAMS	Esbenson *et al* (2003) **0.78**	Esbenson *et al* (2003)	Esbenson *et al* (2003) **0.48**

Table 11: Validity of combined scales (anxiety+depression)

Criterion Scale	Content	Construct	Criterion	Face	Sensitivity
ADAMS		Esbenson *et al* (2003)			

Psychiatric Symptom Rating Scales (Tables 12& 13)

Assessment for Dual Diagnosis (ADD; Matson & Bamburg, 1998)

The ADD was developed as a measure for symptoms typically reported as problematic with individuals with mild and moderate ID (Matson & Bamburg, 1998) and items were primarily derived from DSM-IV criteria. The ADD is an informant based, 79-item MH screening instrument containing 13 subscales. Overall test-retest and subscale test-retest scores, internal consistency and inter-rater reliability were good (Matson & Bamburg, 1998). However there is currently no published validity data on the ADD.

Brief Symptom Inventory (BSI; Derogatis, 1993).

The BSI is a 53-item self-report inventory designed to reflect the typical symptomatology of people with psychiatric problems. It has been subject to extensive reliability and validity testing in non-ID populations (Derogatis, 1993) and is a multi-trait measure.

The instructions of the BSI state that 'retarded' individuals break the inventory premise and cannot be assessed with the measure. However examinations of the psychometric underpinnings of the BSI with people with ID (Kellett *et al.* 2003) indicate that the BSI effectively discriminates between clinical and community populations, with moderate internal consistency, when using assisted completion format. Kellett *et al.* (2004) conducted exploratory factor analysis, illustrating that the BSI retains the majority of the extant subscale structure when applied to people with mild ID. The eight-factor solution that emerged had high face validity in terms of basic construction (Kellett *et al.* 2004). Findings suggested that people with mild ID respond to a large proportion of items in a similar manner to general adult populations.

The Mini Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Mini PAS-ADD;Moss, 2002b.)

The Mini PAS-ADD is an instrument comprising of 86 psychiatric symptoms generating a series of subscores (depression; anxiety and phobias; mania; obsessive-compulsive disorder; psychosis; unspecified disorder (including dementia) and pervasive developmental disorder (autism) (Prosser, *et al.* 1998).

Findings concerning reliability and validity are encouraging (Moss *et al,* 1998). Prosser *et al.* (1998) found mean internal consistency to be moderate. However, mean internal consistency across all scale items was found to be moderate to very good, whilst inter-rater reliability was low. Criterion validity was encouraging and there was high correlation between clinical opinion and Mini PAS-ADD scores. 81% of cases were correctly identified indicating sensitivity.

Minnesota Multiphasic Personality Instrument – 168 (L) – (MMPI-168; McDaniel, 1997).

Overall and Gomez-Mont (1974) provided evidence that the first 168 items of the Minnesota Multiphasic Personality Instrument (MMPI) serve as valid predictors of the profiles obtained from the entire MMPI. McDaniel (1997) modified the MMPI-168 for use with people with mild/moderate ID. The original 168 were expanded to contain 173 items and the measure labelled as the MMPI-168 (L).

Test-retest correlations were consistent with those observed in general population MMPI scores and found to be high approximately one year later for some scales (McDaniel, 1997). Substantial consistency across assessments was seen on scales sensitive to serious disabling MH problems. Scales sensitive to sociopathic tendencies also proved consistent over time. Statistically significant test-retest correlations were achieved on all three scales.

McDaniel (1997) concluded that overall, in the hands of a practitioner familiar with administration of MMPI, important information about MH problems in people with mild and moderate ID can be determined by the MMPI-168 (L). McDaniel *et al.* (1997) found that the MMPI-168 (L) demonstrated construct validity with respect to ratings of behavioural and/or psychological disturbance in ID adults and adolescents.

However McDaniel *et al* (2002) cross validated the MMPI-168 with the ADD and failed to show convergence of scales, indicating a possible threat to construct validity.

The Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD Checklist; Moss et al, 2002a.).

The PAS-ADD Checklist was developed from ICD-10, as a screening measure to detect and assess MH problems on 7 dimensions. It has 29 symptom items scored on a four-point scale, combined to provide three threshold scores. Crossing a threshold indicates the need for fuller assessment. Moss *et al.* (1998) found internal consistency to be moderate, however inter-rater reliability was low. Validity in relation to clinical opinion was found to be acceptable, demonstrating criterion validity. Taylor *et al.* (2004) found that the PAS-ADD was a sensitive tool for identifying MH caseness in ID populations.

Sturmey *et al.* (2005) completed independent replication of the PAS-ADD's psychometric properties finding moderate internal consistency scores. The majority of scores were similar to those reported by Moss *et al* (1998). The checklist was sensitive to differences between groups, with overall sensitivity of 66 per cent.

The Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson, 1988)

The PIMRA is an extensively researched 56-item measure divided into 7 subscales, (Schizophrenic Disorder; Affective Disorders; Psychosexual Disorders; Adjustment Disorder; Anxiety Disorders; Somatoform Disorders; Personality Disorders and Inappropriate Mental Adjustment). Items comprising the scale are derived from DSM criteria and thereby it is argued that test items have face validity (Senatore *et al.* 1985). The PIMRA has self- report and informant versions. Senatore *et al.* (1985) initially reported that both versions have good internal consistency. However Sturmey & Bertman (1994) found internal consistency to be moderate. Test-retest results indicated statistically significant correlations in the moderate to good range. Iverson & Fox (1989) reported inter-rater reliability varying from 70-95 per cent..

The PIMRA has been found to be less psychometrically robust than the Reiss and the validity of the subscales called into question (Sturmey *et al.*, 1991; Sturmey & Bertman, 1994). Criterion validity investigation indicated low-moderate concurrent validity for the affective (Kazdin *et al.* 1983; Matson *et al*, 1984) and schizophrenia subscales (Sturmey & Ley, 1990; Swiezy *et al.* 1995), and further research failed to replicate the seven-scale factor structure (Aman *et al.* 1986; Sturmey & Ley, 1990; Watson *et al.* 1988). Matson *et al* (1984) found only moderate-good convergence between the self-and-other report versions.

An independent study by Watson *et al.* (1988) concluded that the PIMRA's psychometric characteristics were not as convincing as in previous studies, finding moderate-good internal consistency, low test-retest results, and suggesting that the self-report version may be psychometrically unacceptable.

Linaker & Helle (1994) assessed the diagnostic precision of the PIMRA schizophrenia criteria in a non-ID population from a psychiatric hospital and demonstrated the sensitivity of the scale (71.7%.).

The Symptom Checklist (SCL-90-R; Derogatis, 1983)

The SCL-90-R is a 90-item symptom inventory initially designed to reflect the symptom patterns of psychiatric and medical patients. The SCL-90-R has been subject to extensive reliability and validity analysis (Derogatis, 1983) within general mental health populations. Kellett *et al* (1999) examined the utility of using the SCL-90-R with people with ID and established its basic psychometric properties when used in ID and found high internal reliability and consistency across symptom dimensions. Furthermore the SCL-90 demonstrated discriminant validity between clinical and community samples (Kellett *et al* 1999).

Table 12: Reliability of Psychiatric Symptom Scales:

Criterion	**Test-retest**	**Internal Consistency**	**Inter-rater**
Scale			
ADD	Matson & Bamburg (1998) **0.93**	Matson & Bamburg (1998) **0.93**	Matson & Bamburg (1998) **0.98**
BSI		Kellett *et al* (2003) range **0.63-0.78**	N/A
Mini PAS-ADD	Moss *et al* (1998)	Prosser *et al* (1998) **0.6-0.95**	Prosser, *et al* (1998) **0.44**
MMPI-168	McDaniel (1997)	McDaniel (1997) McDaniel *et al* (2003)	
PAS-ADD	Moss *et al* (1998)	Moss, *et al* (1998) Sturmey *et al* (2005)	Moss, *et al* (1998) **0.42**
PIMRA	Matson & Senatore (1984) **0.56** Watson *et al* (1988) 0.31 Swiezy *et al* (1995)	Matson & Senatore (1984) **0.85** (self-report) **0.83** (informant) Watson *et al* (1988) **0.64** (self-report) **0.66** (informant) Sturmey & Bertman (1994) **0.699**	Iverson & Fox (1989)
SCL-90		Kellet *et al* (1999) **0.75-0.86**	N/A

Table 13: Validity of Psychiatric Symptom Scales:

Criterion	Content	Construct	Criterion	Face	Sensitivity
Scale					
ADD		Matson & Bamburg (1998)			
BSI		Kellett *et al* (2004)	Kellett *et al* (2004)	Kellett *et al* (2004)	Kellett *et al* (2004)
Mini PAS-ADD			Prosser *et al* (1998)		Prosser *et al* (1998)
MMPI-168		McDaniel *et al* (1997) Johns & McDaniel (1998)	McDaniel *et al* (2003)		
PAS-ADD		Moss *et al* (1998) Sturmey *et al* (2005)	Moss *et al* (1998)		Sturmey *et al* (2005)
PIMRA		Matson & Senatore(1984) **0.58-0.70** Watson *et al* (1986)	Kazdin *et al* (1983) Matson & Senatore (1984) Sturmey & Ley (1990) Sturmey *et al* (1991) Swiezy *et al* (1995)**0.43-0.58** (2 subscales only) Masi *et al* (2002) **0.62-0.76**	Matson & Senatore (1984)	Matson & Senatore (1984) Linaker & Helle (1994)
SCL-90		Kellet *et al* (1999)			

Interpersonal Functioning Scales (Data presented in Tables 14 & 15)

The Inventory of Interpersonal Problems-32 (IIP-32) (Barkham et al. 1996)

Interpersonal problems are common in people who are experiencing MH difficulties. The IIP-32 is a psychometrically robust self-report measure of interpersonal problems in adult populations (Barkham, et al) and has 4 sub-scales. Beail and Warden (1996) reported that the IIP-32 could be used in an interview format with people with mild ID. Kellett *et al.* (2005) report on aspects of reliability and validity of the IIP-32 with adults with mild ID. The IIP-32 was completed alongside the Brief Symptom Inventory (BSI; Derogatis, 1993), which has an 'interpersonal sensitivity scale' that the IIP-32 subscales significantly correlated with, indicating concurrent validity. The IIP-32 retained internal and external criterion validity and the factor structure was perfectly replicated on 3 of the 8 sub-scales. Kellett *et al.* 2005, conclude that the full scale IIP-32 can be used with a degree of confidence in its reliability and validity.

Table 14: Reliability of Interpersonal Functioning Scales

Criterion **Scale**	**Test-retest**	**Internal Consistency**	**Inter-rater**
IIP-32	Kellett *et al* (2005) **(0.84)**	Kellett *et al* (2005)	N/A

Table 15: Validity of Interpersonal Functioning Scales

Criterion Scale	Content	Construct	Criterion	Face	Sensitivity
IIP-32		Kellett *et al* (2005)	Kellett *et al* (2005) **(0.12-0.74)**		

Discussion

The properties of reliability and validity of any given instrument is of paramount clinical significance. For example, if instruments with very limited proven reliability or validity are utilised in clinical practice, it is possible that people will be mistakenly assessed as experiencing a particular difficulty, or conversely that people who *are* experiencing a particular difficulty will not be identified. Furthermore potentially life changing and/or detrimental decisions regarding treatment may be based on these 'mistaken' assessments, and may have far reaching consequences for the individuals involved.

Taken as a whole, there are now an increasing number of instruments pertaining to assessment of possible dual diagnosis in ID. This review has attempted to provide clinicians and researchers with an overview of evidence regarding the psychometric robustness of such measures. The review indicates a "curates egg" situation, with some measures attaining sound psychometric bases, whilst others do not (as yet) meet minimum requirements. Evidence for meeting all selected reliability and validity criteria has been indicated for the Reiss, ABC and GDS-LD. The PIMRA has been researched on all criteria except content validity, though consideration has been given to its face validity, which is a similar concept (Barker *et al.* 2002). Overall, the Reiss, ABC and PIMRA emerge as the best independently validated scales.

Although there are a reasonable number of measures currently available, there continues to be a general paucity of fully evaluated psychometric indices of MH for clinical use with people with ID (Aman, 1994; Beail 2004). Sturmey *et al* (1991) concluded that although research was expanding regarding reliability of measures, validity tended to be overlooked or ignored, and current evidence suggest that this trend continues. Although reliability has been investigated for the majority of measures, over the four categories of assessment, there is very little published evidence regarding analyses of content or face validity and sensitivity. The most commonly investigated validity measures are criterion and construct respectively.

Methodological Weaknesses

An issue of methodological concern is the lack of independent evaluation of measures assessing MH problems in ID. Aman (1991) states that independent studies are essential if instruments are to be seen as psychometrically robust with independent reviews of the validity of measures may reducing any methodological flaws. The current evidence highlights the lack of published research specifically addressing analysis of content and face-validity. Content validity assesses whether a measure adequately covers the different aspects of the construct specified in its definition (Barker *et al.* 2002). Face validity is similar to content validity and assesses whether the measure self-evidently measures what it claims to measure (Barker *et al.* 2002). Evidence of content and face validity would seem a basic, yet fundamental assessment of validity of any measure. Face validity would appear particularly relevant in use of self-report symptom-checklists, and analysis of whether or not a self-report measure holds face validity for ID populations appears crucial. Currently there appears little evidence of consideration of such issues in published literature.

A further threat to validity arises from the provision of research-based evidence of criterion validity through cross-validation with other 'established' measures. This review indicates that a number of measures are interdependent in terms of validity. There is a danger of methodologically unsound cross-validation, via comparison with data from measures, which themselves have not been subject to robust assessment of validity. In order to provide evidence of criterion validity the measurement being used as the criterion must be well established, (Barker *et al,* 2002) and of unquestionable validity (Barker *et al,* 2002), which none of the measures reviewed would appear to be, with the possible exception of the ABC. The Reiss and the PIMRA have both been subject to question regarding their validity, and therefore do not appear to be of unquestionable validity, subsequently indicating that they may not be an appropriate criterion by which to measure the validity of other scales.

Cross-validation weaknesses also arise from the diffuse nature of the methodologies employed across studies. The key variables differing across measures include age range; residential circumstances; criteria for assessment; assessment technique used to identify symptoms and (where appropriate) specification of appropriateness of informant. None of the measures appear to be culturally or ethnically sensitive. Clinicians assessing people from different ethnic backgrounds and/or cultures should be cautious in the interpretation of assessment findings.

Concurrent validity is further evidenced through comparison with psychiatric diagnosis or case mote analysis. There is very limited reporting across studies of what those 'diagnoses' were, the professionals making such 'diagnoses' and even less information provided as to the basis upon which 'diagnoses' were made. Caine and Hatton (1998) state that research in general psychiatry has demonstrated that clinical judgement may be unreliable and subject to biases, which further reduce the validity of diagnoses (Sandifer, Hordern & Green, 1970). Furthermore Moss (1995) reports that the validity of clinical judgement is likely to be additionally reduced even further when an inexperienced or untrained clinician attempts to gain information from a person with ID. This review indicates that standard methodological practice should be use of psychiatric case notes/diagnoses as a measure to validate assessments of MH, therefore reducing threats to criterion validity.

Further complications arise from using DSM/ICD criteria to provide diagnosis by clinicians and researchers, who have not been appropriately trained. As discussed earlier, there are clear issues regarding the applicability of these criteria to ID populations, and it would seem apparent that there are methodological difficulties, and subsequent threats to validity, arising from establishing criterion validity on this basis. Therefore evidence for criterion validity provided by concurrence between a measure and DSM/ICD criteria, possibly reveals nothing other than that, DSM/ICD and the measure concur. This concurrence would be possible for two reason (1) measures such as the SRDQ and ADD are derived from DSM/ICD criteria and therefore it would be expected that they would concur at some level and (2) DSM/ICD criteria and reviewed measures identify characteristics of MH, but there is no empirical evidence to suggest that either are sensitive to MH problems in people with ID. Therefore where evidence of criterion validity has been established on this basis and sensitivity has not been established or evidenced, clinicians and researchers should remain cautious.

Conclusions

The "gold standard" for assessments of dual diagnosis can be considered as information drawn from multiple sources, including, clinical interviews , informant information and psychometric assessment. A major methodological advance would be for researchers to triangulate sources of data from each measure between the person-referred, clinician ratings, ratings from key significant others in the persons life, and a detailed working knowledge of core means of relating (Kellett *et al.* 2005).

This review has demonstrated that two of the assessment measures (ABC and Reiss) developed have independent, published research studies providing exploration of, or evidence for, all measures for reliability *AND* validity. However, the evidence of the reliability and validity of the ABC with mild and moderate ID is currently unknown. In terms of clinical psychological assessment, it is recommended that where appropriate the Reiss is completed and used in conjunction with an additionally appropriate and case specific self report measure, interview with client and informant(s). A further recommendation is that clinicians involved in assessment of MH in people with ID have experience in working specifically with this population. Assessments conducted by potentially ID inexperienced professionals must carefully consider validity issues via the supervisory process.

A further area for research development is the sensitivity of measures in detecting change due to intervention. Although test-retest has been explored for some measures, little attention is paid to their utility as outcome measures. Mental health difficulties can be episodic and sporadic in frequency, and may (or may not) respond to intervention. Measures that provide pre and post-intervention mean, standard deviation and test-retest scores, can be utilised to identify clinically significant post intervention change (Jacobson & Truax, 1991; Roy *et al*, 2002). Anger scales have been used to evaluate treatment outcomes (Taylor, 2002) and it is possible that comparison of reliability and validity of scales used in this review, with anger scales may be useful in the future.

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SECTION TWO:

Research Report:

People with Intellectual Disabilities (ID) Experience of Detention under the Mental Health Act (1983)

OPTION B –INTENDED JOURNAL FOR SUBMISSION: JOURNAL OF POLICY AND PRACTICE IN INTELLECTUAL DISABILITIES

ABSTRACT

BACKGROUND: Fundamental to the development of research knowledge are studies establishing user views and experiences of service delivery. However, currently there are no published studies providing insight into the experience of detention for people with intellectual disability.

SPECIFIC AIMS: This study explores the experiences of people with intellectual disability of detention under the Mental Health Act (1983). The study seeks to provide insight into their perceptions of the act of detention and associated emotional responses.

METHOD: Transcripts of semi-structured one to one interviews (N=7) were analysed using Interpretative Phenomenological Analysis. Participants had mild-moderate ID and been detained under the Mental Health Act. All particpant5s had been detained in the 2-year period, prior to the study.

FINDINGS: Four themes common across participants were identified: (a). 'perception of self in the world'; (b). 'a negative event', (c). emotional response to the act of detention; and finally (d). family relationships. A number of valuable insights emerged including: the impact of perceived lack of control over self and experiences of vulnerability, powerlessness and victimisation, both prior to, and following the act of detention; participants' sense of care Vs punishment; the development of 'role' within the system and attribution of blame.

DISCUSSION: This study expands the current literature regarding the experiences of people with intellectual disabilities from their perspective, the emotional impact of traumatic experiences and differences in coping styles. Ideas for future research are also provided.

BACKGROUND

Rogers, *et al* (1993) observed an increasing interest in the views of people using hospital services and the gradual development of recognition of the value of service user perspectives in the development of healthcare policies. The Griffiths Report (HMSO, 1990), previously championed the importance of health services being accountable to patients and in recent years the role of users of services has attracted more research attention (Bowl, 1996; Campbell, 1996; Repper, 1999). Although there appears a clear acceptance within health organisations that more credence and authority should be given to service user perspectives, the views of psychiatric patients detained under the Mental Health Act (MHA; 1983), are often neglected and excluded from health service satisfaction research (Rogers, *et al,* 1993).

The MHA (1983) is a unique instrument enabling the compulsory detention and treatment in hospital of individuals defined as having a 'mental disorder'. Under the Act, people do not have to have appeared in court, or indeed committed a criminal offence in order to be detained. Central to understanding the use of the MHA is an understanding of the term 'mental disorder'. The four subcategories of mental disorder are Severe Mental Impairment; Mental Impairment; Psychopathic Disorder and Mental Illness (Holland, 1998). 'Mental Illness' is defined in psychiatric manuals such as, the International Classification of Mental Disorders (ICD-10) and the American Diagnostic and statistical Manual (DSM-IV; APA, 1994). The MHA defines 'Mental Impairment' as arrested or incomplete development of mind, including significant impairment in intellectual and social functioning, associated with abnormally aggressive or seriously irresponsible conduct. People with ID can only be detained under the Act if there is a history of developmental delay and evidence of significant social and intellectual impairment AND evidence of behavioural difficulties (Holland, 1998).

There appears to be a vast potential for negative effects associated with becoming a compulsory psychiatric patient (e.g. stigma; loss; trauma). A minimum requirement on the part of service providers and policy makers is that efforts are made to ascertain and hopefully comply with patient's views/experiences of services (Rogers, *et al,* 1993).

People with ID are among the most socially excluded and vulnerable groups, however professionals and planners have been reluctant to seek and pay due credence to their views (Stalker, 1998). People with ID also experience detention as psychiatric patients, and as a group are unlikely to have had any influence over policies and planning of services (McConkey *et al,* 2004) Given that they already encounter general day-to-day negative effects and difficulties with issues of consent (Holland, 1998) and communication (Remington, 1998) the added complexity of being a psychiatric patient with an ID potentially increases the likelihood of lack of consultation, and increased susceptibility to receipt of services that are not accountable or compliant with their views and experience.

The bulk of research regarding people with ID and psychiatric difficulties can be found in forensic areas (Clare & Murphy, 1998) where the main focus appears to be treatment/intervention strategies and the development of practice based evidence within this client group (Newman *et al* 2003), as opposed to consultation with users and consumer satisfaction. It would seem fundamental to service development requirements that the views of people with dual diagnosis are explored and listened to, in an attempt to understand their perspectives on their experiences.

No previous studies have been conducted with people with ID, regarding the experience of detention. However investigations have been completed in non-ID populations.

(Rogers, *et al,* 1993; Campbell, 1996; Read, 1996). Rogers et al (1993) conducted a quantitative study into psychiatric patients' experience of compulsory detention and treatment and found that 63% of their participants reported that the reason for their admission had not been adequately explained to them, with 68% considering that they had not been given enough information regarding their condition. A further finding was that the power of detention in hospital, and its ability to take away people's status in the outside world, was a factor deeply resented by participants, they reported feelings of being degraded or 'down graded' from society. Such findings mirror aspects of the 'degradation ceremony' described by Goffman (1961), following the loss of civil liberties.

It has been suggested (HMSO, 2001) that if admission to an assessment or treatment resource is unavoidable, specialist staff should support the patient in understanding and co-operating with treatment. Understanding the experience and impact of the detention itself, and how people with ID perceive themselves and what is happening to them, may aid development of service understanding of how best to support people. Fundamental to the development of research knowledge are studies establishing user views and experiences (Ramcharan & Grant, 2001) of service delivery As there are currently no published studies providing insight into the experience and process of detention for people with ID, this will be the aim of the current research project.

SPECIFIC AIMS

(1) to explore the perceptions of people with ID of being detained under the Mental Health Act (1983)

(2) to explore the emotional experience of detention for people with ID

METHOD

Participants: Interviews were conducted with seven people with ID, five men and two women, whose ages ranged from 19-57. Four participants had been detained due to deterioration in mental health alone. Three participants had also committed offences. All participants were English speaking and white. Prior to interview the length of detention across participants ranged from three to twenty months. The average length of detention prior to interview was approximately 10 months.

Design: Research was exploratory and aimed to seek insight into people's experiences, therefore the selection of an inquiry position was pivotal (Bryman, 1988). A number of qualitative research strategies were considered and, due to the lack of previous research in this area, and the aim to generate themes by which to understand the nature of experience, rather than development of theory, Interpretative Phenomenological Analysis (IPA) was selected as the research strategy. IPA is a revealing analytic technique providing an in-depth understanding of both the idiosyncratic and culturally constructed aspects of a persons' being-in-the-world (Shaw, 2001). Criterion sampling was used as the study specifically aimed to explore the experience of detention for people who have ID.

Recruitment: RMO's for each locality provided details of people with mild-moderate ID, detained within a two-year period, whom they believed had the capacity to provide informed consent and respond in verbal interview. Potential participants were contacted and an initial interview arranged during which the purposes of research were explained and consent sought. Due to research interest into the actual experience of detention, all levels of detention were included. The most important criteria were (1) that people had been detained within the last two years. (2) had mild/moderate ID and (3) had the verbal capacity to respond in interview. Using these criterion 13 people were identified and approached as potential participants. Of those people, five were experiencing significant difficulties with their mental health, and as a result were deemed to be too ill by their medical practitioner to interview, and one person refused to participate.

Ethical Considerations: Ethical approval was obtained, as was research governance approval for the three districts involved in the research, prior to approaching potential participants. Although there are no established measures of capacity to consent to participate in research for people with ID (Freedman, 2001), throughout the process of interviewing, issues concerning participants' competence to give informed consent were considered (BPS, 2001). Guidance was initially taken from RMO's, combined with a qualitative assessment by the researcher, during the initial meeting with potential participants. Prior to the commencement of interviews the information sheet was read through with participants and written consent to participate was obtained in the presence of a person selected by the participant, following which consent to audiotape was also obtained. It was made clear that participants were under no obligation to participate and made explicit that participation would in no way affect their detention status. Limitations of confidentiality were discussed prior to commencement of interview, with respect to disclosure of risk to participants or others. Participants' rights to withdraw at any stage prior to completion of write up were explained and a copy of the procedure for complaints provided. As a transcriber was to be used, a confidentiality agreement was signed prior to undertaking transcription and participants were made aware that the transcriber would hear what they said, but that this would still remain confidential.

Consent was obtained for extracts of interviews to be published, following removal of identifying information. Pseudonyms have been used where necessary in the extracts.

Interview: The interviewer was a 30 year-old white woman without ID, with 12 years experience of working with people with ID, who also had clinical experience of conducting sensitive interviews with people with ID. A semi-structured interview schedule was devised which provided a framework for interviews. Questions were devised following careful consideration of the prior clinical experience of the interviewer, discussion with service providers and guidance from supervisors. Consistent with IPA the schedule did not dictate the direction of the interview and was used flexibly allowing issues to be raised, which had not been previously thought of by the researchers (Hunt & Smith, 2004). The interview schedule covered 6 broad areas including (1). Circumstances surrounding detention; (2). People involved in the act of detention; (3). What happened after the act of detention; (4). What participants wanted to say about the act of detention; (5). What participants felt about what had happened to them in retrospect and (6). Anything else participants felt they would like to say. All interviews were audiotaped and length of interview ranged between 15 minutes to 1 hour. All interviews took placed in appropriate rooms, in private sector or state hospital provision.

Data analysis: The assumption in IPA is that the analyst is interested in learning something about the respondents psychological world (Smith & Osborne 2003). Following each interview, field notes were made and each interview audiotape was transcribed verbatim. The first interview was transcribed by the researcher in order to allow experience of the data first hand, following which a professional transcriber was employed to transcribe the remaining data. Transcripts were analysed using IPA (Smith, *et al*, 1995) with the aim of trying to understand the content and complexity of the data through sustained engagement with the text and a process of interpretation (Smith &

Osborn, 2003). The first transcript was read through a number of times, whilst listening to the audiotape. At each reading notes were made of things the participant was saying which appeared to be of importance. These initial notes included preliminary summaries and interpretations of the material. The transcript was then re-read and an initial list of preliminary themes identified, which were subsequently analysed more analytically or theoretically (Smith & Osborne, 2003) and translated into emerging themes. Following further analysis "clusters of themes" were listed from which a number of superordinate themes emerged. This process was then repeated with all the transcripts, resulting in a list of superordinate themes for each participant. Themes emerged both within individual interviews and across interviews and repetition of the emergent themes (across individual transcripts) were taken as indicative of their status as recurrent themes that reflected shared understandings (Flowers, et al, 2003). The emergence of a theme in the majority of transcripts was considered as appropriate for inclusion on a list of master themes across participants. Analysis was primarily conducted by the first author, following which a fellow trainee clinical psychologist critically examined interpretation of the links between the interview transcripts and the development of recurrent themes. Subsequently some minor changes in interpretations were made.

Validity: As the research emerged from consideration of current government and health policies, (e.g. 'Valuing People' (2001)), it demonstrates sensitivity to the context within which the research is situated (Yardley, 2000). Transparency of the process was demonstrated by the provision of information regarding participant selection, construction of the interview schedule and format for conduction of interview. (Smith & Osborn, 2003). This is further demonstrated by the provision of verbatim extracts from the corpus of the data, allowing the reader to judge the strength of claims being made (Yardley, 2000). A semi-structured interview schedule, using open questions, was devised to reduce response bias, in particular acquiescence (Prosser & Bromley, 1998) and in line with IPA. A successful pilot interview was conducted in order to check the validity and usability of the semi-structured interview schedule, showing it to be a useful guide for interview purposes. The pilot account was included due to the absence of alteration to the schedule, and also the limited number of potential participants' at that stage. To increase face validity careful consideration was given to the wording of information sheets, consent forms and the semi-structured interview schedule, with respect to promoting participants' understanding. Each transcript was read through whilst listening to each audiotaped interview, to ensure that possible transcriber interpretations had not contaminated the data and reduce the risk of errors in transcription (Smith & Osborn 2003). The process of sustained engagement with the topic and immersion in the data demonstrates commitment, and the completeness of the data transcription, analysis and interpretation demonstrates rigour (Yardley, 2000). Throughout the process of analysis the researcher returned to participants' accounts in order to remain faithful to them (Shaw, 2001) and reduce researcher bias. The research process was monitored through the completion of a research journal and the maintenance of the site file. These were discussed with both academic and NHS supervisors at regular intervals. An audit trail was kept to monitor the process of the research and the development of themes. A fellow trainee clinical psychologist was involved in the auditing of the data. Unfortunately it wasn't possible within the time framework to re-contact potential participants' and clarify the validity of emergent themes in order to establish 'testimonial validity' (Stiles, 1993).

FINDINGS:

This section presents the central themes emergent from participant accounts (Figure 1). The central issues reported were the sense of self in the world (prior to detention) the experience of the detention and emotional responses to detention. The themes are not entirely independent and do interconnect at points. Each theme will be discussed and demonstrated through the use of extracts from participants' accounts. The extracts presented were selected as they represent the essence of recurrent themes (Flowers, et al, 2003). Booth (1996) argues that where people have given very brief responses to individual prompts, it is legitimate to 'run together' a number of their responses, and present these almost as one piece of text. This strategy was utilised and a number of extracts representing instances of the same theme is provided at points.

Figure 1: Table of master and sub-themes arising from participants' accounts

(1) **Perception of 'self in the world'**
    Lack of control over self
    Vulnerability/victimisation/powerlessness in the world
(2) **Experience of 'detained self'**
    Care Vs. Punishment
    Role within the system
(3) **Emotional response to the act of detention**
(4). **Family Relationships**
    Sense of rejection
    Attribution of blame
    Support Vs 'aloneness'

THEME 1: PERCEPTION OF 'SELF IN THE WORLD'

Negative views of 'self in the world' prior to the act of detention emerged for the majority of participants, including sub-themes of perceived lack of control and a sense of vulnerability and powerlessness:

Lack of control over self

Some participants attributed their negative behaviour and/or detention to their lack of self-control, apparently allowing them to allocate blame externally to their peers. Participant 1 felt that he would not have committed an offence had he not been told to do so, and felt that he was unable to control his own behaviour under peer pressure.

> **P1:** They told me to light[the] fires, I wouldn't have done it otherwise

Similarly, participant 5 felt that his peer group caused him to 'get into trouble', affirming this attribution by identifying that during his detention (and subsequent separation from his friends), he had not been 'in trouble'.

> **P5:** Yeah [I get] in trouble with the Police....mixing with my mates'....they get me into trouble. [I] don't get into trouble in here

Participant 6 attributed the extension of his detention, following a violent assault upon another patient, primarily to the other patient.

> **.P6:** [it's] been bad since he came in.....he winds me up.....so I brayed [assaulted] him....now I have to stop here...[I]...would have been ok if he wasn't in here.....

A perceived lack of control over participants' own internal emotional states was also described as contributing to their previous behaviour or detention. Lack of control over anger, mood swings and loss of temper were all experienced by participants and attributed as causative in their detention

P1: I didn't mean to do, and I am very sorry and all, but I was mad [angry]...and I got sectioned [detained]

P3: You know, [I'm] up and down, up and down with my mood swings

P6 [It's] because of my temper and beating people up...[I] wouldn't have done it if I'd not been [drunk]

Sense of powerlessness vulnerability and victimisation 'in the world'

This sub-theme captures the impact of negative sense of self in the world in terms of powerlessness and vulnerability. It is clear from the reports of all participants that this has caused them distress. Participants 1 and 2 conveyed their vulnerability and powerlessness through disclosure of offences against them, prior to detention. Both participants experienced a sense of victimisation and provided accounts of physical and sexual abuse.

P1: It happened before... when I used to be outside and I got sexually assaulted.........I got beat up that day as well and I hadn't done anything then either....

P2: Well I was just walking up the road and I went into a bar and these kids started hitting me for nothing......

For others the sense of vulnerability and powerlessness is expressed as a sense of injustice, of not being listened to and victimised by the system.

P4: "I didn't do anything!"

P6: "they wouldn't listen and sent me here"

Participant 1 expressed the overwhelming impact and fear of leaving hospital following detention. Indicating the development of a fear of the "badness" in the world and engendered dependence on hospital services.

> **P1:** "I don't want to leave.......... there is lots of mixing with bad people..."

Vulnerability was also apparent in the account by participant 3 where an example of absolute dependency upon others, prior to detention was recounted.

> **P3:** "Yeah...because I couldn't do anything for myself .I couldn't even get bathed or anything like that

THEME 2: 'A NEGATIVE EVENT'

This theme captures the individual impact upon participants of the experience of detention. There are two subthemes namely 'Care Vs Punishment' and 'role within the system'.

Most of the participants experienced detention overall as a negative event, characterised for some by a sense of rejection. Attributions for detention were closely allied to the experienced negative 'sense of self' in the world and the lack of self control, vulnerability and powerlessness described earlier. Participant 2 felt uninformed regarding detention, powerfully describing feeling 'thrown down' and attributing detention to the fact that he was in some way 'faulty'.

> **P2** [detention felt] bad.......Nobody told me about it [detention]
> [I felt] mad.....thrown down I don't even like it here......I want to go home........My mum put me in here because she doesn't want me to

live with her anymore

P2: Something Bob was saying ....[I] forgot what it was.......but I've got something wrong with me....

Participant 4 experienced feelings of abandonment by her mother and feeling disbelieved and unheard.

P4: Me mum took me......then she left me and that doctor said I was coming in here... He [psychiatrist] didn't believe me [he].wasn't even listening [which] made me more mad.....I was mad.....I didn't do anything

Participant 6 expressed his powerlessness and distress during the act of detention and his subsequent perception of the withdrawal of his adult rights, resulting in feelings of resentment and anger. He attributed detention partly to his mothers' inability to cope.

P6: No...[I]....didn't want to come [in].....but it wasn't up to me...I had to come......I was really upset.....but Alison said to me that my mum can't cope anymore. I hate it here [people] thinking they're telling me what to do [they] wouldn't even let me go out on my own, I'm 24, man....and they treat me like a kid.....

For participant 7 the event of detention was totally overwhelming, becoming visibly tearful during interview and describing the detention as

P7 [It] was bad ......just awful

Positive Aspects

However some participants described positive experiences of detention and a sub-theme emerged from accounts. In retrospect participant 1 seemed to experience a sense of settling in, making a home and gathering his things around him apparently experiencing a "sense of belonging".

> **P1:** I've settled down now [I've got] my own TV Yeah....I've got me coffee table, me kettle...me new kettle... me err...me hi-fi stand.....28 inch television
>
> [There are] nice staff and you get extra things like Christmas presents
>
> I don't want to leave here

However although participant 1 had a retrospective positive view of his detention the act of detention itself engendered a powerful negative emotional experience:

> **P1:** I was upset, .I was angry and just confused...
>
> I felt really angry...

By contrast participant 3 exceptionally described her experiences of detention in positive terms. Similarly to Participant 1 she took great pride in having her belongings around her and settling in, in fact wishing to break from interview to show the researcher her room. This feeling of settling in appeared to have arisen from a sense that she was dependent on the system and would otherwise be alone in the world.

> **P3** I like it here.....I love it in fact...come and see my bedroom...come on have you got time?

I feel a lot happier now.....They've really helped me here [without a] hospital anywhere I'd have had nowhere to go I haven't got anyone left anymore more.....you know?

Care Vs Punishment

There was a sense, and general awareness, expressed by some of the participants who provided positive experiences of detention of some distinction between care Vs punishment. Participant 3 described her reaction to admission to hospital as opposed to remaining in custodial care.

P3: I was in the Police station for a week... in Bradford...then they put me here....that was a relief

Whilst participant 5, who had committed an offence prior to detention, clearly viewed hospitalisation as a preferable alternative to being sent to prison:

P5: Well [it's] better....better than going to prison! You get freedom here!!..........I feel alright....[I].don't get into trouble in here.....[I] was in trouble a lot before [detention]
It's ten times better [than prison]..I don't get hassle....

Upon admission participant 6 felt that the indication that the police would be involved if his behaviour was problematic on the ward served as a deterrent.

P6: They said you're here now... you are with us, in our care....any trouble from you and you will be arrested and taken back.. taken back to the police station.... And I wasn't very happy....I didn't want that to happen

'Role within the system'

Of those participants who provided positive accounts of detention it emerged that they had developed some sense of a positive 'role' within the system separate to that of patient. Examples of emerging roles were 'advisor'; 'carer of the other patients' and 'helper of staff'.

Participant 1 felt that he would like to help other patients. However his perspective was to use his own experiences to help his peers and identifying his sense of self as separate or different from staff.

> **P1:** and [I would say]....I'm here .... I'm here to help you...things like .... I've gone through it [detention] as you went through it...
>
> I'd say the nice staff..if you treat them nice they treat you right...and you get extra things...things like Christmas presents and things like that....

Participant 3, allied herself with the staff and apparently experienced a sense of difference from other patients, even using negative language to describe them seemingly to enhance the distance between herself and them.

> **P3:** we don't know what we'll get in ... we get some right psycho's in here ..what I mean....
>
> I had to shove [push] him everywhere...everywhere I went, he went as well...I help with [the] patients

Participant 5 whilst describing a positive relationship with a member of staff, apparently proudly disclosed that he helps:

P5: She's nice is Bev, I help her when she's on [duty]

In fact all participants, including those who had a negative experience of the act of detention reported they had felt adequately informed and supported by unit/ward staff upon admission.

P3 He [Staff}had a talk with me about how I [was] feeling and that...about hospitals and things......

P5: Bev told me where stuff [things] were when she booked me in

THEME 3: EMOTIONAL RESPONSE TO THE ACT OF DETENTION

Although almost some participants experienced positive aspects of detention, the majority described experiencing negative emotions following detention. Only one participant provided positive emotional responses to the actual act of detention, describing appreciation and happiness. The most commonly occurring emotions experienced are presented in Figure 2.

Figure 2: Emotions experienced by participants in response to detention:

Anger
Resentment
Rejection
Vulnerability
Powerlessness
Defensiveness
Victimisation

THEME 4: IMPACT OF FAMILY

During interviews, all participants reported details of their families, even though there were no specific questions relating to this on the interview schedule. Following further analysis the significance of these relationships emerged as a theme in its own right. Most of the participants appeared to feel rejected or abandoned by their family, in some instances blaming family members, in particular their mothers for detention. Perceived inability of family members to cope with participants behaviours was attributed as causative in detention.

Participant 2 felt that he had been detained because his mother did not want him to live with her anymore. When asked if he had had contact with his mother since his detention he replied, "No, I'm on me own now" and became tearful. Participant 4 described how her mum took her to the doctors and left her, later on saying that her mother still visited her but "she doesn't want me home". When asked how that felt she said "I don't want to talk about her". Participant 6 revealed his fears for the future as his mother did not feel she could cope with his behaviour. However he does not appear to be disclosing feelings of rejection, providing "other kids" as a reason and considering options for his future.

P6 "my mum can't cope with my temper.......not with [the] others kids"
"[I] don't know what is going to happen after [detention]... she [mother] won't have me [at] home". [I] suppose I'll have to get council flat or something"

Participant 3 talked at great length about her family apparently needing 'to tell her story" poignantly discussing family members who had died, highlighting her feelings of aloneness in the world

> **P3:** And as soon as my mum had cancer...I went down to my mums' and lived with my mum all the time.. while [until]she died
>
> And I was married and my husband got killed in the car, coming back from someplace... He got... He got killed.. my husband and the dog...
>
> And he [dad] died.... a long time back [ago] because me mum was only about 36 [years old] then

Similarly participant 1 described his losses in terms of his family but also described the support he received from his sister, apparently needing to emphasise that someone, somewhere cared for him.

> **P1:** My sister was there........ and she helped.......
>
> Yeah...[I've] got me dad's watch....[it was the] second one he had when he retired.... my dad...he's dead now.... and my mum....
>
> I've got two sisters in London... Yeah she [one sister] came...she came to court
>
> I need some...I....I needed somebody around to help me....

DISCUSSION

This study has demonstrated the value of using a qualitative approach to explore the perceptions of people with ID to detention under the Mental Health Act (MHA; 1983), resulting in the emergence of a number of themes. The theoretical underpinnings of the study are phenomenological in its attempts to gain an understanding of the perspective of people (Smith, 2003) with ID who have been detained, through their description of their experience. However there are several theoretical implications indicating that a number of psychological models can be used to understand the processes involved in experiencing detention when people have ID. Themes and theoretical implications will now be considered further:

Perception of 'self in the world'

An emergent theme recurring throughout transcripts concerned participants 'sense of self in the world'. Participants described a lack of control over various aspects of self and a vulnerability and powerlessness in the world from which emerged a sense of victimisation in the 'world'. Research has indicated high rates of victimization experienced by people with ID (Davis, 2000) and the perception or belief of participants in the current study that they have been victimised supports this literature.

'A Negative Event'

The majority of participants in this study experienced detention as a negative event, reflecting studies of general psychiatric populations (Rogers, *et al,* 1993; Campbell, 1996; Read, 1996). Similarly some participants appeared to resent the power of detention and its ability to take away their status in the outside world, with one participant describing feeling "thrown down", echoing the experience of being "down graded" (Rogers, *et al,* 1993). However unlike the study by Rogers *et al* (1993) the majority of participants were not confused regarding the reason for their admission. Participants who were able to describe positive experiences appeared to be coping better with the experience than people who only held negative perceptions of their experience. Participants with a positive perception appeared to have developed positive 'roles' for themselves within the system, possibly enabling them to cope more positively with the experience. Interest in the concept of coping style and its relationship to psychological distress has grown rapidly over the past few years (Zeidner & Endler, 1996). As a result there is now a considerable body of evidence demonstrating that coping style is related to an individual's level of adjustment to a broad range of problems including traumatic events (Dunmore, *et al*, 1997; Morgan, *et al*, 1995).

Emotional response to the act of detention

The majority of emotional responses to detention were negative. Research suggests that providing psychological consultation and training, to staff responsible for the care and support of people with ID facilitates emotional development, improves staff-client relationships, decreases symptomatic behaviour and increases quality of life (Arthur, 1999). This in combination with the development of ways to access the emotional experience for the person with ID, would probably facilitate the most effective support.

Impact of family

All participants talked about their families, even though this was not a specific area identified on the interview schedule. Some participants allocated blame to their families and described anger and resentment towards them. In the schema proposed by attachment theorists (Bowlby, 1973; Ainsworth, 1978; Kobak, 1999) periods of separation, and perceived threat of separation or abandonment, are seen as arousing both anxious and angry behaviour in susceptible people. Other participants talked about family members who had died, or whom they no longer had contact with, providing poignant accounts highlighting their sense of aloneness in the world, and apparently making a 'statement ' of past belonging, perhaps indicating the significance of theories of loss, bereavement and trauma in relation to people with ID.

Methodological Limitations and Strengths

The selection of IPA as the research strategy may have resulted in methodological limitations, in that IPA as a strategy does not take into account the sequential and temporal nature of the data, as effectively as other strategies, and the selection of, for example, a narrative approach, may have expanded further on these aspects of the data.

Due to the mixed gender and wide age range of participants it is possible that some comparability with other groups of detained people with ID is possible. However the scope of comparability is restricted by the lack of representation of participants from different cultural/ethnic backgrounds. It is likely that the fact that the researcher did not have ID and may have appeared to be 'staff', or part of the system will have provoked a 'power imbalance' (Walmsley, 2004), affecting the nature and extent of participants accounts. All interviews were conducted with people currently subject to detention and as such were conducted on wards/units where people were detained which is likely to have impacted upon participant responses. However most participants were still apparently able to speak candidly about the nature of their experiences.

The data obtained interviewing people with ID was probably not as rich as that which could be obtained from interviewing people in the general population. Participants tended to answer with short statements, which many of them found difficult to elaborate on. The participants may have experienced difficulty in describing subjective feelings and internal emotional states due to their ID. However people with ID should be accorded the right and opportunity to articulate their needs and express their opinions on issues, and interviewing the person with ID themselves, maximises the likelihood of obtaining valid information about their needs (Prosser & Bromley, 1998). Time constraints imposed by the research timetable, and difficulties encountered in recruitment resulted in termination of data collection sooner than desirable. Further recruitment may have resulted in the emergence of other themes. The time constraints also prevented opportunity to go back to participants and discuss themes with them in order to establish 'testimonial validity' (Stiles, 1993), which would potentially have increased the validity of the themes.

Strengths of the current study include the fact that people with ID have not previously been asked about their experiences, and therefore completion of this research begins to address the lack of investigations of this nature. Also studies of user views and experiences in isolation have the potential to ignore the complex interactions amongst people with ID and those in their family, services and communities who affect there lives in important ways (Dunst *et al,* 1993). This research goes someway to provide some information about people with ID's experience of interactions with their families, services and communities.

Clinical Implications

Most participants experienced detention as a negative event giving rise to negative emotions and a sense of powerlessness and abandonment. It is important to note that this study was conducted over a large geographical area and that the number of people with ID detained was found to be quite small. This could suggest that mental health professionals use powers of detention sparingly with this client group. However, it is hoped that these findings will inform clinical practice in such circumstances. Clinicians need to take into account and address the clients' feelings of being alone in the world and powerless with a range of negative emotions.

There are indications within research findings that if people are supported appropriately from the outset of their contact with services, then their potential for engagement with services may increase. As such, there would seem to be an immediate need to provide the detained person with opportunities to form warm, empathic and non-judgemental relationships with people who have time to listen to them. The detained patient needs to establish a sense of being valued and to regain a sense of self worth. Thus opportunities need to be provided that facilitate the development of a valued social role.

The emergence of a theme around family also suggests that such links need to be pursued, encouraged and facilitated.

Further Research

Further investigation of the impact of 'positive role' development or 'positive sense of self' would be useful in respect informing the trauma and coping styles literature. It is also apparent that further research into the complex interactions amongst people with ID, and those in their family, services and communities, who affect their lives in important ways (Dunst *et al,* 1993) is necessary. Attachment theory draws on psychoanalytic theory, ethology, biological control theory, cognitive psychology and systems concepts (Howe, 1995) and may provide a useful framework from which to develop an understanding of the 'internal world' of people with ID. Further investigation of the impact of perceived rejection by, or removal from caregivers, when people with ID are detained may inform this literature.

Caine & Hatton (1998) noted that people with ID have an increased risk of developing mental health problems, suggesting that life experiences common to people with ID, including stigmatisation and loss may play an important role in the aetiology of some mental health problems and continued research into this area is important. Future research into the experience of victimisation for people with ID, prior to detention, detained under the MHA (1983) would inform the victimisation literature further.

Finally comparing and contrasting the experiences of general psychiatric patients with the finding of this study, attempting to evaluate positive and negative aspects of the different services between client-group, would potentially inform service development.

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SECTION THREE:

CRITICAL APPRAISAL

CRITICAL APPRAISAL

INTRODUCTION

A critical appraisal of the process of the research study will be presented in this section outlining the project from its initial conception through to its current stage of completion. Appraisal comprises of four main sections, namely: (1) Project Origins, (2) Implementation, including: initial planning and approaching of supervisors; acquisition of ethical and clinical governance approval(s); recruitment process and barriers to recruitment; supervision; personal motivation; consideration of methodological limitations and strengths, clinical implications and further research. (3) Learning and Development and (4) Final Considerations of Research Process Overall

PROJECT ORIGINS

I have worked in various roles with people with intellectual disabilities (ID) for 12 years. Prior to commencing clinical training, I worked in a low secure unit for people with ID and became interested in the responses of people upon admission to the unit. I found that people's responses to detention appeared to differ broadly, and I became interested in how they viewed the experience. At around the same time The White Paper: Valuing people (HMSO; 2001) was released, purporting that mainstream mental health services and specialist ID services need to be more responsive to the needs of people with ID, and provide facilitation and support with mental health issues. I had always been sure that I would wish to work with people with ID upon qualification, and during my first year of training my conviction remained and developed. During the process of formulating ideas for my 3rd year research I completed an initial literature search, and it became apparent that there was no existing published research considering ID service user views of the experience of detention, and I became keen to complete a third year research project.

IMPLEMENTATION

Initial planning and approaching supervisors

I arranged a meeting with Professor Nigel Beail, Consultant Clinical Psychologist, specialising in ID, in June 2003, during which it was agreed that there was indeed a need to examine the experience of people with ID detained under the Mental Health Act (MHA; HMSO:1983), and that this was currently a unique area within which to complete my research. I also approached Dr. Steve Kellett, Consultant Clinical Psychologist, to act as my NHS supervisor (see Supervision section).

Research Proposal Approval and Research Insurance

The completion of the proposal itself was time consuming, and it was difficult to identify how long the actual proposal should be due to inaccurate guidance in the course handbook. I therefore consulted with my academic supervisor who clarified this issue. During the development of the proposal I worked in close consultation with my research supervisors and was given intensive support in altering a number of drafts, resulting in the final proposal.

In April 2004 I submitted the completed proposal to the University of Sheffield Research Sub-Committee. I feel that this went smoothly for me, particularly considering the difficulties that this process presented for a number of my peers. The Sub-Committee primarily suggested that I included a clearer theoretical implications section, considering trauma and coping skills, attachment and stigmatisation theories and slightly modified recruitment procedures and some aspects of design. I resubmitted the proposal with the appropriate amendments in May and received approval. I was then able to apply for Non Clinical Trials Insurance from the university, which I received in August 2004. Following university approval I contacted the Responsible Medical

Officers (RMO's) for each district and sent them a copy of the completed proposal. This allowed me to obtain their support for the completion of my research, and for the approach to clinical governance for each of their districts. I then began the process of obtaining ethical approval.

Ethical Approval

Due to the potential for encountering difficulties with recruitment and the potential for involving a number of sites, it was suggested by my supervisors that I applied for MREC (Multi-Centre Research Ethics Committee) approval. The completion of the MREC form was very intensive, quite laborious and more elongated than I had considered it would be. However upon completion of relevant paperwork the actual process itself was very smooth.

I applied in August 2004 and my application was considered in September, following which I received notification of a number of necessary amendments. MREC concerns were primarily concerned with recruitment procedures and some discrepancies on the form. Appropriate changes were made where possible. However one of the main recommendations was that only people detained 'recently' were included, due to concerns regarding people with ID's ability to recall the event. Following subsequent discussion with my supervisors, we provided the MREC with references of published research pertaining to the recall abilities of people with ID for autobiographical event memory and asked for extended permission to approach people detained within the last two years. This request was subsequently granted and confirmation of ethical approval provided in October 2004.

Clinical Governance Approval

There was a lot of confusion regarding when and how to obtain clinical governance approval for each site, and it became somewhat of a parallel process, running alongside application for MREC approval. I contacted each clinical governance department at each site and was given clear information and helpful guidance. I gathered together the necessary information for all sites (again a laborious and time consuming venture) and sent it off in August 2004. For one of the three sites the response was very prompt and approval provided in September 2004. However receipt of clinical governance approval from the other two sites was considerably slower. One of the sites had a backlog of applications, with approval finally arriving in November 2004. The third site was involved in its own process of change, and it was very difficult to get information regarding the progress of my application. This resulted in me having to make numerous phone calls and send a number of e-mails all of which received no response. However I finally received clinical governance from this site in December 2004. During this delay I was conscious of the necessity to keep the RMO, for that site, informed. He was thankfully very understanding and supportive and when I finally obtained all the necessary documentation his secretary (whom I had spoken to on numerous occasions by this point!) was able to help me very quickly and efficiently at gaining access to potential participants.

The Recruitment Process and Barriers to Recruitment

Although the recruitment process was difficult in terms of numbers of people available, this process was made much better than it might otherwise have been, due to the support and help I received from all the RMO's involved; their secretaries; staff on the wards; the participants who I did manage to recruit relatively early in the process and my supervisors. However throughout the process I did encounter some difficulties, which I will now consider.

The main obstacle to recruitment resulted from attempting to complete a research study of this nature within such a limited time frame. The majority of the people that I was attempting to recruit had extremely complex difficulties, due to the nature of their dual diagnosis of ID and mental health problems. On three occasions I travelled to conduct research interviews, with people who had consented to participate. However although the person had been well when the interview had been scheduled, they were experiencing difficulties and distress when I arrived. Therefore it was necessary to revisit these people. This provoked a dilemma for me, in that if people had consented to participate, but they remained unwell within the time frame available to me, I would be unlikely to return and complete the interview. I felt that this was unfair to them and represented a missed opportunity to talk about their experiences, especially in light of their obtained consent. Had the time frame not been as pivotal it would have been possible to wait until people's psychological well being improved. However, I was able to complete my final interview with a participant in this situation, and therefore did not need to consider this further in relation to this research, although it is something that I will be very aware of in the course of any subsequent research.

I also experienced some organisational difficulties in approaching a medium secure hospital, providing a service for two potential participants. Due to a change in personnel structure at the organisational level, I was unknowingly attempting to contact an RMO who was no longer responsible for the people involved. When I finally clarified whom I needed to contact there was again a long delay in receiving the necessary information. This issue was ultimately resolved by Professor Beail and one of the interviews made possible. However this had again taken much longer than expected and caused me increasing anxiety as to whether I would be able to recruit the necessary number of participants to make the research worthwhile.

Supervision

I am incredibly grateful for the patient and supportive supervision I have received from both my supervisors. Prior to the development of my initial ideas, I had known Professor Beail, both from his role at university and from the completion of my first year placements in the department where he was based clinically. I was also aware of his knowledge of both clinical practice and research with people with ID. Early in my first year of training I had requested and subsequently completed a second year core placement with Professor Beail, followed by a third year specialist placement. This allowed the cultivation of a really good working relationship.

I had approached Dr Kellett to act as my NHS supervisor, even though ID was not an area of specialist interest to him and he was less familiar with qualitative approaches than quantitative, because I had completed a core 1st year placement with him, and he had always provided me with a very supportive approach to my learning. I trusted that he would be able to keep me motivated and provide deadlines for completion of the work, helping me to ensure that the research process remained as contained as possible. I also completed a third year specialist placement with Dr Kellett. As a result of being clinically supervised by both my research supervisors I had constant access to guidance and support, and although clinical supervision was always protected time, the feasibility of arranging a research meeting whenever it was necessary was incredibly helpful.

Upon reflection I think that the selection of supervisors who I already had really positive experiences of working with was the key to the relatively smooth progression of my research to date. Both supervisors returned drafts of completed sections promptly, and helpful and constructive advice was provided. Both my supervisors are skilled and confident clinicians and researchers, and at times I was a little in awe of their knowledge base. However they were both able to maintain my confidence in my own ability, whilst making me feel comfortable asking any question, no matter how naïve I suspected it may be.

Personal motivation

In some respects I have viewed the completion of this research in the same way that I have viewed the completion of the rest of my training, namely, as part of a process that will lead me to a job that I have always wanted to do. I have been privileged with the support of my partner, family and friends who have maintained my sense of confidence, reminding me at times of decreased motivation, of the ultimate goal, whilst accepting without complaint, that they would see very little of me, during its completion.

The biggest effect upon my motivation has been the overall impact of the write up, on my life. However I have engaged in a similar process in the past, during completion of my MSc thesis and have been able to remind myself that once it is done, I can do all the things that I have had to put on hold.

I have a firm commitment to working with people with ID and fundamentally believe that this research is valuable, which has also maintained my motivation. Although the final stages have at times felt frustrating I recently obtained confirmation of my first qualified post, working with people with ID, who will be returning to district from secure accommodation. This has not only provided a 'gleaming light at the end of the tunnel', but also increased motivation to complete this study, as I believe it will provide me with a good base from which to commence my new post.

Personally I feel that I have achieved something by providing the participants in this research with an opportunity to be heard. This research represents to me all the people who have ID, who I have worked with over the years, who have managed to live in a world which often pays no respect to them or their views, and yet somehow they maintain a strength of spirit, which I feel very few people are privileged enough to encounter.

Methodological Limitations & Strengths

As part of the implementation, RMO's were contacted and provided details of people whom they believed had capacity to provide informed consent, and respond verbally in interview, although they did not agree on behalf of participants, it was evident that professionals tended to assume that individuals would be agreeable to taking part. It is also possible that professionals nominated specific individuals whom they considered likely to agree (Stalker, 1998). This provides a possible threat to validity in that access may not have been provided for some people, potentially affecting the nature of obtained data.

Another methodological limitation and potential threat to validity arises from the lack of established measures of capacity to consent to participate in research for people with ID (Freedman, 2001). As a result BPS (2001) guidance was used, which may, or may not have been adequate for people with ID. However I reconciled this with the fact that taking part in the research demanded not one decision, but a whole series of decisions

(Rodgers, 1999). Participants chose to meet with me and listen to the research information; consented to participate and consented to audiotape the interview and they subsequently completed interviews, perhaps indicating that consent to participate had in fact been obtained. However it remains with me that decision-making does not take place in a vacuum, and people were no doubt influenced by the attitudes of carers, and by the chance to spend time with someone doing something a bit different from usual routine.

There have been concerns about the validity of data arising from direct interviews with people with ID (Rodgers, 1999), particularly regarding tendencies to acquiesce and the phenomenon of recency (where a person chooses the last in a series of given options) (Siegelman, *et al*, 1982). These concerns were negotiated in part by the use of a semi-structured interview, and by my own careful consideration of how to progress through interviews whilst guarding against opportunities for recency or acquiescence.

Due to the practicalities of involving another researcher, different methods of data collection or analysis, "triangulation" of data was not completed. This may have strengthened the validity of findings.

The time constraints, in combination with the difficulties encountered in recruitment made it necessary for me to stop data collection sooner than I would have, had I not been restricted. This may (or may not) have resulted in the emergence of other themes. Time constraints also impacted upon my ability to go back to participants and discuss themes with them in order to establish 'testimonial validity' (Stiles, 1993). This would potentially have increased the validity of the themes.

A particular strength of this research is that people with ID have not previously been asked about their experiences, and therefore it begins to address the lack of investigations of this nature. Studies of user views and experiences in isolation have the potential to ignore the complex interactions amongst people with ID and those in their family, services and communities who affect their lives in important ways (Dunst *et al,* 1993). This research goes someway to provide some information about people with ID's experience of interactions with their families, services and communities.

Clinical Implications

Clinical psychologists are increasingly likely to find themselves initiating psychological work that attempts to gain insight and understanding into individuals' perceptions of their ID, to support them in making the most of their living experience (Johnson, *et al* 2003). This study generates phenomenological research to continue to inform the profession and clinicians working with this population of people. People with ID are vulnerable to structural inequalities across all areas of their lives, and as such it would seem that they are potentially more vulnerable to not being heard within the confines of systems such as adult mental health services. People with ID continue to be one of the most ignored and underprivileged groups in terms of mental health services and psychological research (Read, 1996) and although there is some existing research into the experience of social inequality in adult mental health (Penfold & Walker, 1984; Williams, 1997) it remains apparent that the experiences and views of people with ID are underrepresented. Thomas and Leck (1997) argue that it is important to question how we provide a good psychology service and continue to work for clients <u>within</u> the system even though at times the needs of the two do not appear to fit together. This research provides a forum for recognition of the difficulties encountered by people with ID through attaching value to their experiences; hearing their voices; bringing them to the attention of the psychological community and potentially informing services on bridging existing divides.

Furthermore Chadwick (1997) states that rehabilitation begins upon admission and identifies a 'gaping hole' in current hospital training procedures for provision of support upon admission. As such I believe this research provides a unique insight into people with ID's perception of compulsory admission and the potential influence that this may have over their views of services, allowing insight into the necessity of staff training which is driven by an understanding of service user need. There are indications within research findings that if people are supported appropriately from the outset of their contact with services, then their potential for engagement with services may increase. This research has begun to address the lack of research knowledge, and potentially serves as the building block for a generation of new research projects exploring people with ID's experience of using psychiatric services.

Indeed, the overarching clinical implications is the provision of an insight into people's experiences, perhaps allowing a greater understanding from which to generate information which can be developed, potentially leading to the development of more empathic and effective delivery of care.

Further Research

One of the most surprising things I learnt in completion of this study was the lack of reliability and validity checks made, prior to release of measures to the public domain. Therefore further exploration of the reliability and validity of measures used to assess people with ID is necessary.

Participants in the current study described experiences of rejection, following detention and also experiencing a lack of control over self, or self-regulation. Baumeister *et al* (2005) found that self-regulation is substantially impaired amongst people who have just received news of social rejection or future exclusion. Rejected people are less likely to act in prosocial ways, such as cooperating with someone or providing help (Twenge *et al;* 2002), thus potentially evoking a 'vicious circle', which may impact upon engagement with treatment following detention. Therefore the impact of negative sense of self and the impact of rejection should be further evaluated with people both with and without ID, detained under the MHA (1983).

Although the majority of participants reported distressing experiences and emotions related to the act of detention, the ways that people chose to cope during the detention differed significantly. It was apparent that the formation of a 'positive role' within the system, or 'positive sense of self' seemed to influence people's perception of their detention and allow them to find positive aspects. Therefore consideration of the impact of trauma, coping styles and positive role formation would be useful in the future.

Further research into the complex interactions amongst people with ID and those in their family, services and communities (Dunst *et al,* 1993) is necessary. All participants talked about their families, even though this was not a specific area identified on the interview schedule, and the significance of these relationships was used to highlight sense of 'self in the world' for a number of participants. Attachment theory draws on psychoanalytic theory, ethology, biological control theory, cognitive psychology and systems concepts (Howe, 1995) and may provide a useful framework from which to develop an understanding of the 'internal world' of people with ID. Further investigation of the impact of perceived rejection by, or removal from care givers, when people with ID are detained may further inform this literature.

It would also be useful to perhaps compare and contrast the experiences of general psychiatric patients with the experiences of participants in this study, in an attempt to evaluate positive and negative aspects of each service, with a view to identifying any differences in provision between client groups.

Finally, further consideration of the impact of people's view of self in the world, in comparison to their view of self within the system may provide further illumination of the experience of having ID, both 'in the world' and in the 'system', allowing consideration of the social forces and the social contexts at work, prior to and during detention.

LEARNING AND DEVELOPMENT

During the process of completing this research I at times experienced an uncomfortable paradox between fundamentally believing that this research was worthwhile and would perhaps benefit people with ID, and a heightened awareness that it was a necessary 'exercise' in order to benefit me. I read an extract from Barnes (1996) stating that 'the researcher is either on the side of disabled people or one of the oppressors'. This resonated with my discomfort and is something, which I have not yet reconciled and awareness of this, and attempts at reconciliation have greatly influenced my learning and development.

One of the key professional skills I have worked on developing during clinical training is the ability to extract the meaningful and significant from client accounts. Prior to training I had to be careful not to become absorbed in absolutely everything that people were saying. Therefore the process of emersion in the data was particularly difficult for me. However the process of another trainee auditing my themes was particularly useful, and overall I think the qualitative process has strengthened a skill that I have endeavoured to cultivate during my training.

Also in terms of professional development it seems appropriate at this stage to discuss my considerable exposure to the previously terrifying world of psychometrics, involved in the production of the literature review. I previously had very limited knowledge of measures of reliability and validity. However both my supervisors were very experienced in this area, and able to give me guidance whenever necessary. I also bought a university recommended text and threw myself into a process of intensive learning. Although at times I felt overwhelmed by the psychometrics and incapable of ever grasping a real understanding of them, over time and following the reading of many articles, I began to develop some semblance of understanding. However at times this experience left me bewildered, deskilled and lacking in motivation, and I feel that my over arching interest and desire to work to the best of my ability with this client group, and the constant support from my partner and supervisors provided my with the motivation to keep going. I gradually began to recognise that I didn't need to understand absolutely everything I read e.g. the complexities of factor analysis, to provide a credible review of the literature. This research has really brought home to me the fact that just because a measure is situated in the public domain, does not mean that it is necessarily reliable and valid, and as an ongoing process throughout my clinical career I will check what the established psychometric evidence is for measures I use.

Following on from the supervision section, is how much the completion of this project has highlighted the importance of good supervision, and I feel that I have completed this process to date, with relatively low levels of stress (in comparison to some of my peers), as the result of the excellent supervision I received. I started to plan my research relatively early and believe that this allowed me the time to think about who would best meet my supervisory needs, prior to commencement of the project, which has been invaluable. Upon commencement of training I had felt very strongly about the role of *clinician* as opposed to *researcher.* However the experiences I have had of completing this research have made me realise the importance of both skills. Indeed I am hoping to maintain research links with both Professor Beail and Dr. Kellett, having been left with a desire to complete further research in the future and develop my ideas with their support.

Finally, both personally and professionally the completion of this project marks for me the beginning of the end of training, and the opportunity to now concentrate on my career in a profession that I have worked very hard to be a part of, with a client group which I have always wanted to work with.

FINAL CONSIDERATIONS OF RESEARCH PROCESS OVERALL

This process has been for me, a very positive experience, with only minimal difficulties encountered to date. The main difficulties, as has been discussed earlier, arose from the time constraints imposed by the process of training and the difficulties obtaining the necessary research and clinical governance approvals. Although I am fully aware of the necessity of stringent ethical approval procedures, the impact of these upon the completion of this project has been problematic. Although I believe procedures for these approvals are once again being evaluated and amended, it is possible that unless there is a reduction in the length of time it takes to receive these, completion of short-term research projects, such as this, will become impossible. This could ultimately have implications for the current structure of Doctoral Training programmes.

Furthermore, the process of completing this research has highlighted to me the overall significance of time constraints upon the potential 'quality' of completed research. I feel that in the 'real' world, it would have been possible to complete the study over a longer period of time ensuring a greater number of participants, potentially resulting in more in-depth information and increased validity of findings.

I am also currently considering the best way in which to disseminate the research. I feel strongly that findings should be discussed with participants as well as services who have supported my research. However I am also aware that I will encounter difficulties regaining access to, or contact with, the people who participated, some of whom have been discharged or moved to out of district placements. The feasibility of this remains to be seen, which leaves me feeling that the current research process, with very vulnerable groups, can ultimately continue to cast people in the respondent role as opposed to 'active participant'.

In conclusion, I am privileged to be able to say that I have enjoyed the experience of completing this study. However its all-encompassing nature leaves me with no real sadness at its end, and I will savour its final completion and reward myself with the prize of getting my life back!

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Williams, J. (1997) Mental health services that empower women: the challenge to clinical psychology. *Clinical psychology Forum, 100,* 11-18

SECTION FOUR: APPENDICES:

FORMATS

ETHICAL APPROVALS

MEASURES

OTHER

APPENDIX ONE

THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology
Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
Clinical supervision training and NHS research training and consultancy

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK
Unit Director: Prof Graham Turpin
Assistant Director : Prof Pauline Slade
Prof Gillian Hardy

Telephone: ++44 (0)114 22 26632
Fax: ++44 (0)114 22 26610
Email: dclinpsy@sheffield.ac.uk

Clinical Practice Director: Ms Joyce Scaife
Course Administrator: Carole Gillespie
Prof Nigel Beail

To: Research Governance Office

RESEARCH THESIS

Approval of Research Project

Trainee name Carolyn McNally

University Research Supervisor Nigel Beail

Title of Research Project
People with learning disabilities experience of detention under the Mental Health Act (1983)

I confirm that this research project has been reviewed by two independent reviewers appointed by the Clinical Psychology Unit Research Sub-committee. Any necessary amendments have been made and the project therefore receives full approval from the Clinical Psychology Course.

Signed N. A. Beail Date 4/6/04
(University Research Supervisor)

Signed Date 28/5/04
(Course Research Tutor)

APPENDIX TWO

THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology
Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
Clinical supervision training and NHS research training and consultancy

Clinical Psychology Unit
Department of Psychology
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Sheffield S10 2TP UK
Unit Director: Prof Graham Turpin
Assistant Director : Prof Pauline Slade
Prof Gillian Hardy

Telephone: 0114 2226570
Fax: 0114 2226610
Email: dclinpsy@sheffield.ac.uk

Clinical Practice Director: Ms Joyce Scaife
Course Administrator: Carole Gillespie
Prof Nigel Beail

11th March 2005

Carolyn McNally
Third year trainee
Clinical Psychology Unit
University of Sheffield

Dear Carolyn

I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: Journal of Applied Research in Intellectual Disabilities

Research Report: Journal of Policy and Practice in Intellectual Disabilities

Please ensure that you bind this letter and copies of the relevant Instructions to Authors into an appendix in your thesis.

Yours sincerely

Andrew Thompson
Chair, Research Sub-Committee

APPENDIX THREE

Instructions for Authors

Papers (in English) should be sent to the editors (see address on the inside front cover).

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http://www.blackwellpublishing.com/journals/jarid/submiss.htm
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Submission

One original and three copies of each typescript should be submitted to one of the editors. Papers are accepted on the understanding that they have not been and will not be published elsewhere.

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Manuscripts should be typed (with a wide margin), double spaced, on one side of standard paper (A4-30×21 cm). Authors should retain one copy of the text, tables and illustrations as the editor cannot accept responsibility for damage or loss of manuscripts. Final versions of accepted manuscripts should be accompanied by disks.

Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

Cover Page

A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and include postal address, telephone and fax numbers as well as an e-mail address and the author for correspondence should identified clearly. A suggested running title of not more than fifty characters, including spaces, and up to six key words to aid indexing should also be provided.

Main Text

All papers should be divided into a structured summary (150 words) and the main text with appropriate sub headings. A structured summary should be given at the beginning of each article, incorporating the following headings: Background, Method, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study.

The text should proceed through sections of Abstract, Introduction, Materials and Methods, Results and Discussion. Tables and figures should be submitted on separate sheets and referred to in the text together with an indication of their approximate position recorded in the text margin. The reference list should be in alphabetic order thus:

Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities.* Cambridge University Press, Cambridge.

McGill P. & Toogood A. (1993) Organizing community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232–259. Chapman and Hall, London.

Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130–145.

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

Illustrations and Tables

These should be referred to in the text as Figures using Arabic numbers, e.g. Fig. 1, Fig. 2, etc, in order of appearance. Three copies of each figure should be submitted and each figure should be marked on the back with its appropriate number, together with the name(s) of the author(s) and the title of the paper.

Line drawings should be on a separate sheet in black ink (dot matrix illustrations are not permitted). Photographs should be unmounted glossy prints and should not be retouched. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained.

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It is the policy of the *Journal of Applied Research in Intellectual Disabilities* for authors to pay the full cost for the reproduction of their colour artwork. For full instructions and to download a colour work agreement form go to http://www.blackwellpublishing.com/journals/jarid/submiss.htm.

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APPENDIX FOUR

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lbany, New York 12222
SA

mail: jppideditor@aol.com

Submissions should be brief to moderate in length, with most manu- ipts from 20–25 typed, double spaced pages. Please allow for tables, ures and references. Brief submissions of case studies or policy activi- are welcome and should be limited to 5–8 manuscript pages. All ers are referred. Please send along an accompanying letter indicating you think JPPID is appropriate for your manuscript and be sure to cate that your manuscript has not been published previously, or is under submission to another publication.

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References

The reference list should follow APA (5th Edition) standards and be in alphabetical order thus:

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Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown et al., 1977). Authors are responsible for the accuracy of their references.

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APPENDIX FIVE

UNIVERSITY OF SHEFFIELD

DEPARTMENT OF FINANCE

To Carolyn McNally **Date** 09-Aug-04

Department Clinical Psychology Unit

Certificate of Insurances (non clinical trial)

Trial Number NCT03/Z110

Department Clinical Psychology Unit

Title of Trial People with Learning Disabilities experience of detention under the mental Health Act (1983)

Name of Investigators C McNally, Prof Nigel Beail
Dr Steve Kellett

Commencement Date Aug-04

The University has in place insurance against liabilities for which it may be legally liable and this cover includes any such liabilities arising out of the above research project/study

C.F. Jackson , Financial Accountant (Insurances)

Please Note 1. If not already provided please forward a copy of the Ethics Committee Approval as soon as possible

2. A record of the names of all participants, copies of signed Consent Forms and G.P.'s approvals should be retained by the Department.

NCT

APPENDIX SIX

Telephone enquiries, please contact
Cynthia M Richardson on 01924 213110
Fax 01924 213195
e-mail Cynthia.richardson@wwpct.nhs.uk

Our ref: 04/Q1204/58 – Please quote this number on ALL correspondence

Wakefield West
Primary Care Trust

NHS

White Rose House
West Parade
Wakefield
WF1 1LT

21 October 2004

Prof Nigel Beail
The University of Sheffield
Clinical Psychologist
The University of Sheffield
Clinical Psychology Unit,
Department of Psychology
Western Bank
Sheffield S10 2TP

Dear Prof Beail,

Full title of study: People with learning disabilities experience of detention under the Mental Health Act (1983)
REC reference number: 04/Q1204/58
Protocol number:

Thank you for your letter of 5th October 2004, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

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.

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 documents reviewed and approved were as those listed in our letter of 17th September 2004 and as itemised in your letter of the 5th October 2004.

Management approval

You should arrange for all relevant host 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 management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Notification of other bodies

We shall notify the research Host Organisation (the South Yorkshire Mental Health NHS Trust), that the study has a favourable ethical opinion.

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.

Yours sincerely,

C. M. Richardson

Cynthia M Richardson (Mrs)
Wakefield District REC Co-ordinator
(Signed for and on behalf of Dr Margaret L Faull, Chairman)

Enclosures **Standard approval conditions [SL-AC1 or SL-AC2]**

APPENDIX SEVEN

[illegible] SHSRC

Director: Dr Adrian Carr (adrian.carr@sct.nhs.uk)
Consortium Manager: Dr Robert Dixon (robert.dixon@sct.nhs.uk)
All project related emails to: shsrc@sct.nhs.uk

Fulwood House
Old Fulwood Road
Sheffield
S10 3TH

☎ (0114) 271 8804
(0114) 271 6736
www.shsrc.nhs.uk

11 November 2004

Ms Carolyn McNally
Clinical Psychology Unit
University of Sheffield
302 Western Bank
Sheffield, S10 2TP

Dear Ms McNally,

Re: ZD04: People with Learning Disabilities: Experience of Detention Under the Mental Health Act (1983)

You now have Research Governance approval from this Consortium to carry out research as described in documentation you have supplied to us. Please advise us of the project start date immediately you do so and at that time inform us also of the expected end date.

In order to comply with the NHS Research Governance Framework, you may be asked to report on progress as part of our monitoring or audit of projects managed by the Consortium.

We wish you every success with the project and please feel free to contact us if you need further assistance from the Consortium.

Yours sincerely

RDixon

Robert Dixon
Consortium Manager

Cc Alick Bush

A multi-agency consortium of NHS Trusts,
Universities and Social Services in Sheffield

NHS Sheffield Sheffield Hallam University

E:\Shared\Projects\ZD Files\ZD04\10.11.2004Re ZD04 RG Approval letter.doc

APPENDIX EIGHT

Barnsley NHS
Primary Care Trust

Your Ref:

Our Ref: SB/AS/ResGov/21Sep04/05

Please ask for: Sue Bentley

Kendray Hospital
Doncaster Road
Barnsley
S70 3RD

Direct dial: 01226 777029
Fax: 01226 204314

Website: www.barnsley.nhs.uk

22 September 2004

Carolyn McNally
Trainee Clinical Psychologist
Clinical Psychology Unit
University of Sheffield
Western Bank
Sheffield
S10 2TP

Dear Ms McNally

People with Learning Disabilities Experience of Detention under the Mental Health Act (1983)

Thank you for submitting the above project for approval by the Barnsley Primary Care Trust. The project was considered by the Barnsley District General Hospital NHS Trust Research Governance Sub Group on behalf of the PCT at a meeting on 21 September 2004 and I am pleased to confirm that the sub-group agreed to approve the project, subject to information governance agreement and copy of MREC/REC letter.

Please note that in agreeing to act as Principal Investigator for Barnsley on this project, you are accepting responsibility for making sure that informed consent and procedures approved by the ethics committee are adhered to.

Any changes or new information which would raise questions about the continued conduct of the research must be notified to the research office immediately.

Basic information on the project will be entered into the Trust's research database and may be submitted to the National Research Register. The research office may seek further information from time to time in order to fulfil the information requirements of the Trust or NHS Executive.

I should be grateful if you could provide a brief annual report on the progress of the research to the Research Office, including reference to any publications that have arisen from the research. This report should be submitted during March each year, so that pertinent information can be included in the Trust's Annual Research Report.

Yours sincerely

Sue Bentley

Sue Bentley
Director of Performance and Quality

Cc: Research Governance Office, BDGH

MsCMcNally 220904

APPENDIX NINE

Doncaster and South Humber NHS
Healthcare NHS Trust
Research Education Development Centre
St. Catherine's Hospital, Tickhill Road, Doncaster DN4 8QN
Tel: 01302 796214 Fax: 01302 796240

16 December 2004

Title of project : People with Learning Disabilities Experience of Detection under the Mental Health Act (1983)

Dear Carolyn McNally

Doncaster & South Humber Healthcare NHS Trust has reviewed your above project for Organisational approval. This means that it meets the requirements for Research Governance but if the protocol should change you would have to re-submit your new proposal. May we remind you that you are obliged to adhere to the Research Governance Framework for Health and Social Care and if it is found that this is not the case then your research will be terminated pending an enquiry.

May I take this opportunity to wish you well with your project. If you have any concerns please do not hesitate to contact Sue Sparks (Head of Education, Research and Development) on 01302 796480.

Yours sincerely

Sue Sparks.

Sue Sparks
Head of Education, Research and Development

APPENDIX TEN:

The Interview:

Introduction:

My name is Carolyn McNally and I am training to be a clinical psychologist. I am hoping to work with people with learning disabilities when I have finished my training.

I want to do this project because I want to help people to understand what it is like to be detained or sectioned under the Mental Health Act when people have a learning disability.

First I just need to read the information sheet again with you to make sure that everything is clear and that you have understood it and are sure you want to take part.

As it says on the form what you say will stay between you and me. Another person will listen to the tape and write down what they hear but that person will not know who you are. That means they will not know you're name or where you live. They have also signed a form promising not to talk to anybody apart from me about the things they hear. The only time I would have to talk to anybody else about the things that you tell me is if you tell me that you are thinking about hurting yourself or anybody else. If I was going to do this I would talk to you about it and tell you whom I was going to talk to before I do.

You do not have to answer any questions that you do not want to answer. If you change your mind about something you have said while we are talking you can tell me and I will stop the tape and rewind it and tape over the bit you don't want to be used. If you change your mind about something you have said after the interview you can contact me at the telephone number on the information sheet. If you change your mind about taking part in the project you just need to tell me. It will not effect your treatment or change your detention (section) status at all. You can change your mind at any time apart from after the project is finished and the report written.

If it is ok with you I am going to ask someone to come in while you sign the form? Have you got any questions before I ask you to sign the consent form?

There are no right or wrong ways of talking about what happened when you were detained/sectioned. I am interested in all your feelings and thoughts about what happened and I would just like you to tell me everything you can remember.

Have you got any questions before I start the tape recorder?

(START TAPE RECORDER)

Interview Schedule

1. **You were detained (sectioned) under the Mental Health Act; can you tell me about it?**

- Can you tell me when you were detained (sectioned)?
- What happened before that?
- What was going on for you?
- What was it like?

2. **Who told you that were going to be detained (or sectioned)?**

- Did you know the person who told you?
- What was it like, being told?
- Do you remember any feelings?
- What words would you use if you wanted to tell people how you felt?
- Do you remember anything that you didn't understand?

3. **Do you remember what happened next, after you were detained (sectioned)?**

- Do you remember any feelings you had?

- What words would you use if you wanted to tell people how you felt?
- Where were you taken to?
- Who was there?
- What was it like?

4. Looking back how do you feel about what happened?

- What do you think about what happened?
-

5. Is there anything else.....

- You would like to say?

.......Have you got any questions you would like to ask?

(TURN TAPE RECORDER OFF)

Debrief

How did you find that, I've asked lots of different questions that might have been hard to think about? Do you feel ok with the things I've asked you? How do you feel? I (enquire about mood, whether talking about the experience has been distressing if appears appropriate. Discuss any concerns or issues regarding confidentiality that may have arisen). If you feel worried about anything you've told me today and think that you don't want me to put it in my report please phone me (get someone to phone me) and I won't use it.

When I've finished talking to the other people who have agreed to take part in the project I'll get in touch and arrange to come and see you and talk about the main themes/points that people have talked about. That will probably be in March next year.

Anything that you have said that I want to put in my report I will talk to you about. (make sure the participants contact details are going to be the same in March 2005).

I'd like to say thank you for your time and patience in talking to me today

APPENDIX ELEVEN:

EXAMPLE OF DETAILED DATA ANALYSIS AT EACH LEVEL:

Please note: Levels of analysis, provided for illustration, are mainly for P2, to allow the reader to go through the whole process of analysis for one participant. Reflections upon the process are also provided, to allow the reader to further consider the process for, and interpretations of, the researcher.

Key:

P6 = Participant 6 (for example)

Int: = Interviewer

(4:86) = The page number and line number of the transcript example

Level One Analysis -

Process:

Initially reading and rereading transcript 1 a number of times. During each reading anything that initially appeared interesting was recorded, in the left hand margin. The remaining levels of analysis were completed for transcript one before considering other transcripts.

Reflections:

Initially appeared straightforward, but as more notes appeared in the margin, with each reading, it became really clear how important it was to read and re-read, allowing data to emerge. This was harder than I had naively anticipated and good practice for the remaining levels of analysis. In the exert provided I've tried to indicate how many times the transcript had been read before themes emerged on the particular page.

N.B. Identifying material has been removed

Int: "Ok…….What do you think about if you try and look back to what happened to you when you had to come into hospital

② Beaten up

R: "When I got brayed up?….[redacted]?"

Int: "Yeah, is there anything else you want to say about what happened?"

R: "Yeah… well I was just walking up [redacted] I went into [redacted] Inn……and er…….these kids started 'itting me for nowt

① 'ting me 'r nothing

Int: "Right…..was that up by the [redacted] then? Did you go up to [redacted] first and then come here or…..?

R: "I went to [redacted] and then come here…."

Int: "Right…if you think about what happened… think about when all that was happening….

R: "Yeah"

Int: "Somebody brayed you and then you came… you had to into hospital…

② Dismay ③ Tearful

R: "Yeah"

Int: "..erm, how do you feel about all that now? How d'you …did you feel about coming into hospital?"

① Angry "Thrown down"

R: "Mad……………..thrown down"

Int: "Is there anything you think people could have done to make it different for you?….. so it's the whole….having to come in…….and you just feel really mad about it….is there anything else that….you

Level Two Analysis

Process

Transcript 1 was again read from the beginning, whilst closely considering the initial notes. Where possible notes were changed into more concise phrases or potential themes and recorded in the right hand margin. I found it useful to be aware of three different aspects of analysis at this level. Firstly, direct description of feelings representing participant experience (which apparently concurred with their audiotape), were taken at face value e.g.

P:6 "I were right upset" (4:86)

P1: "angry". (2:40)

Secondly where words holding two or more meanings were used, e.g. "mad", careful consideration was given to the context of the statement e.g.:

Int: "Erm…how do you feel about all that now? How d'you …did you feel about coming into hospital?" (4: 94-95)

P2: "Mad" (4: 96)

Thirdly where a theme may be emerging, which was not explicitly spoken, I tried to consider my interpretation at a slightly higher level of analysis, using a more psychological framework.

Reflections

I was acutely aware of the necessity to check and recheck that my early stage analysis was not 'clumsily' putting words into my participants mouths and used the notes in the left hand margin and text of transcripts to make sure that I was connecting with the participant account. At this stage I began to get a sense that people were describing their lives prior to detention and also talking about their families. I began to get a sense that these would be relevant. I listed notes from the right hand margin chronologically on a piece of A3 paper and also entered a copy into the computer.

N.B. Identifying material has been removed.

Int: "Ok.......What do you think about if you try and look back to what happened to you when you had to come into hospital

② Beaten up

R: "When I got brayed up?....[redacted]?"

Abused / Attacked

Int: "Yeah, is there anything else you want to say about what happened?"

R: "Yeah... well I was just walking up [redacted], I went into [redacted] Inn......and er.......these kids started 'itting me for nowt

① 'itting me for nothing

Victimised by the outside world.

Int: "Right.....was that up by the [redacted] then? Did you go up to [redacted] first and then come here or.....?

R: "I went to [redacted] and then come here...."

Int: "Right...if you think about what happened... think about when all that was happening....

R: "Yeah"

Int: "Somebody brayed you and then you came... you had to into hospital...

R: "Yeah"

② Dismay
③ Tearful

Upset/tearful
Powerless

Int: "..erm, how do you feel about all that now? How d'you ...did you feel about coming into hospital?"

R: "Mad................thrown down"

① Angry
"Thrown down"

Angry
Abused?

Int: "Is there anything you think people could have done to make it different for you?..... so it's the whole....having to come in.......and you just feel really mad about it....is there anything else that....you

Initial List of Themes - P2

Victimised/abused
Confused
Anger
Negative experience
Feeling bad inside
Lack of self-determination
Powerlessness
Annoyance
Alone in the world
Resentful
Sadness
Shame
Victimised by the outside world
Rejected/abandoned by mum
Internalised blame
Faulty self

Level Three Analysis

Process

Connections were looked for between emergent themes identified at Level Two analysis and 'clusters' of themes began to be identified. actually said by participants. Once clusters had been identified they were again drawn out on A3 and entered into the computer.

Reflections

This was a different process for each transcript, in that some transcript themes appeared more interconnected or inter-related than in others. In order to prevent becoming so emerged in the data that it was difficult to 'see the woods for the trees' it was necessary to repeat this process a number of times. During this process I again had to keep checking and rechecking my own ideas against the original transcript to make sure that the connections represented what was in fact being drawn from the original account. At this stage of analysis I used my sense of participants descriptions of their life before detention and began to map themes which appeared to represent this into clusters. There also emerged a set of emotional responses to detention and I steadily began searching the data for themes which represented this emerging overarching theme.

Clustering of themes - P2:

Victimised
Powerless
Rejected by mum

Annoyance
Anger
Confusion
Resentment
Sadness
Shame
Feeling bad inside
Internal blame – faulty self

Alone in the world
Abused
Lack of self-determination

Negative experience!

Level Four Analysis

Process

Using the clusters, a table of themes was devised, which aimed to capture the essence of participants' experiences. Clusters were given a name, representing 'superordinate' themes for their interview and original transcripts were checked to ensure that the superordinate themes had actually present in participant accounts. A table was produced listing superordinate theme and the sub-themes accompanying them. Exerts from original transcript data were provided to enable direct communication with the part(s) of the transcript that themes had originally emerged from participant accounts.

1. Sense of self in system	
- Powerless	2. 29"my mum put me in here"
- Victimised	2. 31"because she doesn't want me to live with her"
- Abused	4. 96{feel} "thrown down"
2. Undesirable feelings/negative experience	
- Annoyance	2. 34 "Real annoying"
- Anger	4. 97 [feel] mad!
- Confusion	1. 12 "Can't really tell you because I can't remember"
- Resentment	1.7 "I got beaten up, then put in here"
- Sadness	2.38 "No...I'm on my own now"
- Shame	5.112."I've got something up with me..."
- Internal blame – faulty self	6.123 . "Yeah,,,something's up with me"
- Rejected	2.31 she doesn't want me to live with her
3. Sense of self in the world	
- Alone in the world	2.38 "No...I'm on my own now"
- Victimised	4. 85 [kids[started hitting me for nothing
4. Family?	2. 29"my mum put me in here"

Reflections

This process helped me to clearly see the emerging themes for each individual participant. I already had a clear idea re. 'sense of self in the world', emotional response to detention and detention as a 'negative event'. I also had an unclear sense of 'family'. As I wanted to start looking for themes for the group, I asked a fellow trainee to check the analysis so far. He was in agreement with existing themes identified for each individual and concurred with my sense of developing overarching themes. He felt that participants accounts contained a theme of '**impact** of the family' as opposed to the rather vague sense of some importance that I had been experiencing. Once I was sure that the themes I had identified had emerged from the data I began to look for commonalities and differences between participants' accounts, look for 'overarching' themes for the group.

In order to ensure that the superordinate themes applied to the majority of transcripts, an analysis was undertaken whereby each superordinate theme was colour coded e.g. Theme (1) = red; Theme (2) = Green; Theme (3) = Blue and Theme (4) was purple.

Audit of Superordinate Themes

(1) **Perception of 'self in the world'**
Lack of control over self
Vulnerability/victimisation/powerlessness in the world
(2) **'A Negative Event'**
Care Vs. Punishment
Role within the system
(3) **Emotional response to the act of detention**
(4). **Family Relationships**
Sense of rejection
Attribution of blame
Support and aloneness

Each level of analysis for participant one was then checked and rechecked for the appearance of themes, starting with level four, working backwards and colour coding themes where they appeared. The full analysis is included for participant one (below). This process was then repeated for all participants. Example of level four analyses for each are provided, for example:

Level Four Analysis (P:1)

1.	*Lack of Control*		
	- Lack of control over self (Self determination)	1. 6	"I didn't mean to do it I was mad"
		3. 71	"they told me to light fires"
		3. 72	"I wouldn't have done it otherwise"
	- Need for others to take control of self	2. 30	"get in trouble....my sister was there"
		8. 188	"So I didn't blow
		8. 189.	"because of them that I kept my cool
		11. 261	"See what the Dr. has to say"
	- Overwhelmed/small in the world	4. 81	"They make you feel small"
	- Behaviour attributed to anger	1. 6	"I didn't mean to do it I was mad"
		8. 198..	"I was steaming mad inside"
	- Attribution of blame to other (diffusion of personal responsibility)	3. 71	"they told me to light fires"
		3. 72	"I wouldn't have done it otherwise"
		3. 77	.."It wasn't just me"
2.	***Undesirable Feelings***		
	- Remorse/guilt	1. 6	"I'm very sorry"
	- Upset	1. 23	"upset"
	- Confused anger	2. 40	"angry....and just confused"
	- Vulnerable	9. 216	"when I used to be outside"
		9. 217	"sexually assaulted"
		11. 279	" bad people...."
3.	***Self in the outside world/out of the system***		
	- Fear of leaving/of outside world	11. 274	"don't want to leave"
	- Vulnerability to "badness in the world"	11. 276	"mixing with bad people"
		12..301	"who you mix with"
		12.302	" you're mates are"
	- Victimised by outside world...........	9. 216	"when I used to be outside"
	- Powerlessness in the world................	8. 203	"I didn't want to do it"
	- Importance of family	6.154	"got me dad's watch"
		8. 185	"needed somebody around"
4.	***Experience of Detention***		
	Negative initial response	2. 40	"angry....and just confused"
	- Care Vs Punishment.......................	4. 90	{Staff said} "you're in our care"
		4. 91	any trouble you'll be arrested"
		4. 92	"I knew I was coming here
	- Feeling safe/secure/settled in system	4. 98	"I've settled down"
	- Appreciation	6. 134	"nice staff"
		6.135	"you get extra things..."
	- Wish to be cared for		
	- Wish to share experience to help others	5.127	"I'm here to help you"
		5.128	"I gone through it...as you went
	- Respect for staff/system	6.134	"They're nice staff here
		6.135	"they treat you right"
	- Trust in system	11. 261	"see what the doctor has to say"
		11.270	"they say I'm ready"

Level Three Analysis (P:1)

Lack of control over self
Lack of self-determination
Need for others to take control of self
Overwhelmed/small in the world
Undesirable behaviour attributed to anger
Attribution of blame to other
Responsibility of self Vs other
Diffusion of responsibility

Remorse/guilt
Upset
Confused anger
Dependant
Vulnerable
Fear
Shame of disclosure
Internalised anger

Vulnerability to "badness in the world"
Fear of leaving/of outside world
Victimised by outside world
Powerlessness in the world
Care Vs Punishment
Feeling safe/secure/settled in system
Appreciation
Wish to be cared for/care for others
Wish to share experience to help others
Respect for staff/system
Need to belong
Trust in system
Feeling heard by staff

Importance of family
Need to tell story of family

Level Two Analysis (P:1)

Remorse/guilt
Lack of control over self
Undesirable behaviour ascribed to anger
Upset
Need for others to take control
Confused anger
Overwhelmed/small in the world
Attribution of blame to other
Responsibility of self Vs other
Diffusion of responsibility
Lack of self-determination
Care Vs Punishment
Need to tell story
Secure/settled/belonging in system
Consequences for self Vs others
Wish to be cared for/care for others
Wish to share experience to help others
Respect for staff/system
Importance of family –sister, mum, dad
Need to belong
Appreciation
Dependant
Vulnerable
Shame of disclosure
Internalised anger
Powerlessness in the word
Fear
Vulnerability to "badness" in world
Feeling heard by staff
Trust in system
Fear of leaving
Fear of outside world

Level Four Analysis (P:2)

1. Sense of self in system	
- Powerless	2. 29 "put me in here"
- Victimised	2. 31"doesn't want"
- Abused	4. 96 "thrown down"
2. Undesirable feelings	
- Annoyance	2. 34 "Real annoying"
- Anger	4. 96 "Mad!
- Confusion	1. 12 "Can't remember"
- Resentment	1.7 "Beaten up, then put in here"
- Sadness	2.38 "On my own now"
- Shame	5.112."Something up with me…"
- Internal blame – faulty self	6.123 . "something's up with me"
- Rejected	2.31 "she doesn't want me"
3. Sense of self in the world	
- Family	2.31 " Mum doesn't want me"
- Alone in the world	2.38 "I'm on my own now"
- Victimised	4. 84 "hitting me for nothing
- Vulnerability	1.7 "Beaten up

Level Four Analysis (P:3)

1. Sense of self in system	
- Care Vs Punishment	8.180 "that nick..awful"
- Recognition of mental health problems	1. 12 mood swings" 6.132 "hear voices…"
- Perceived improvement since hospitalisation	7. 162 "happier"
Place of safety in an unsafe world	12.296 nowhere to go
- Appreciation of services	14. 334 "they've really helped me here"
Sense of self in institution (belonging)	15. 368 "we get some [right psychos]
- (helping/carer role/ staff Vs patient)	15. 378 "we put like a bed pan underneath
	15. 379 "I help with the patients"
2. Sense of self	
- Lack of control of self/self determination	1. 12 "mood swings" 1.16 " I take fits" 6.133 "wicked voices"
- Dependency	3.69 " I couldn't do anything"
- Alone in the world	11.293 "no one left anymore"
3). Act of detention	
Relieved	8.179 "was a relief…."
3. Loss of family/need to tell story	

Level Four Analysis (P:4)

1. Feelings about detention	
- Defensive	1. 4 "Nothing happened!" 2.27 "Was alright!" 2. 54 "I'm not stupid!"
- Resentful	1. 24 "even had to go to see him!"
- Angry	2. 32 "Mad!"
- Victimised	1. 4 "Didn't do anything!"
- Attribution of blame to others	1. 13"Stupid doctor!"
2. Sense of self in the world	
- Victimised	1. 4 " didn't do anything!"
- Abandoned	2.29 "[mum]left me!"

Level Four Analysis (P:5)

1. Self in the world	
- Lack of self control	3. 58 " get into trouble"
2. Feelings about detention	
- Confusion	1.10 "Didn't really know"
- Defensive	2.28 "Doesn't bother me"
- Care Vs. Punishment	2. 43 "better than prison! 4. 101 "Freedom!"

Level Four Analysis (P:6)

1. Feelings/emotions	
- Angry	1. 9 " wound up"
- Rejected	1. 15 "she couldn't cope with me" 5.123 "doesn't want me"
- Powerless	1. 10 "sent me here"
- Resentment	1. 9 "I didn't do anything" 2.38 " Like a kid" 6.147 "out of here if…"
2. Attributions for detention	
- Justification for behaviour	2.50 "wouldn't have done it if…"
- Blaming others	5.110 "If he wasn't in here" 6.147 "I'd have been out"
3. Sense of self in the world	
- Lack of self-control	2.49 "My temper"
- Lack of self-determination	5.121 "what's going to happen"
- Resentful dependence	5.127 "don't want to stop here, but I might have to"
- Fear of unknown	5. 128 "Don't know what will happen"
- Fear of future	5.121 "What's going to happen after"

Level Four Analysis (P:7)

1. Sense of self prior to detention	
Unwell	1:17 "wasn't well"
Faulty self?	1:17 "wrong with me"
2). Support of sister	1:18 "glad my sister"
3. Feelings during detention	
Confusion	2:29 "Don't know"
Bad	1: 4 "was bad"
Awful	1:18 "felt awful"
4. Experience of detention	
Powerlessness/against will	1:13 "didn't want to

In summary, although individual participant accounts and experiences varied, the presence of the majority of superordinate themes for the group occurred in the following transcripts:

Participant **Theme**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
One	√	√	√	√	√	√	√
Two	√	√	√	√	√	√	√
Three	√	√	√	√	√	√	√
Four	√	√	√	√	√	√	√

APPENDIX TWELVE:

Research Project: People with Intellectual Disabilities experience of being detained under the Mental Health Act (1983)

Information to be used in participant recruitment interview

My name is Carolyn McNally and I am a training to become a Clinical Psychologist at Sheffield University.

As part of the qualification of Doctor of Clinical Psychology I am doing a research project into what experiences people with intellectual disabilities have when they are detained (sectioned) under the Mental Health Act.

So far there are no studies that ask people with intellectual disabilities what *they* think and feel about their experience. I think that it is important that people with learning disabilities are asked about their experiences so that people understand better what it is like.

Taking part in the project does not change what is happening for you now. It does not change your detention (section) status.

What's the project about?

1). Finding out about what happened to you when you were detained (sectioned)

- What it was like for you?
- How did you feel when it happened?
- What you think about what happened?

2). What will happen if you take part?

If you are staying in a unit/hospital I will arrange to come and see you there. If you are not in hospital I will arrange a time for you to come and see me at the hospital where I work. I will talk to/interview you for about 30 to 40 minutes. I will be using a tape recorder to record our talk. I will have some questions to guide both of us in helping you to talk about your experiences, but mostly I just want you to tell me as much as you can remember about what happened to you.

3). It's not a test...

I won't be asking you to do any tests and there are no right or wrong answers, it will just be talking about what happened to you.

4). What will I do with what you tell me?

I won't tell staff or doctors what you have said unless you tell me that you want to hurt yourself or other people. I will write up a report and your name will not be used. Things will be changed so that no one will know who you are or what you have said. Other people like your friends, family, social worker or solicitor will not find out what you have said and you do not need to tell any of these people that you are taking part, unless you want to.

5). What do you do if you want to take part?

I have a form that I need filling in that says that you consent or you want to take part. I will ask you to fill in the form before I interview you. If you need help to fill in the form we can ask someone where you live.

You can tell me today that you want to take part OR you can think about it after I have gone and I will contact you in the next couple of days to ask you.

If you do decide to take part but then decide you want to stop being part of the project at any time, you can say and you can stop being involved.

THANK YOU FOR TAKING THE TIME TO READ THIS (may be more appropriate to say "LISTEN TO WHAT I'VE HAD TO SAY")

APPENDIX THIRTEEN:

Research Information to be read to potential participants:

You are being invited to take part in a research project which is being conducted in part completion of the qualification of Doctor of Clinical Psychology (DClin Psy):

Researcher :	**Carolyn McNally, Trainee Clinical Psychologist**
Address:	**Clinical Psychology Unit, University of Sheffield, Western Bank, Sheffield S10 2HP**
Telephone:	**0114 2716602**

If you decide to take part in the project this form and the consent form will be given to you to take away.

PARTICIPATION IN THIS STUDY DOES NOT EFFECT YOUR DETENTION (SECTION) STATUS IN ANY WAY

- **What is the study about?**
  The experiences of people with learning disabilities who have been detained (sectioned), what happened, what feelings they have about it?
- **Who is taking part?**
  8-12 people with learning disabilities
- **What does it involve?**
  If you are staying in a unit/hospital I will arrange to come and see you there. If you are not in hospital I will arrange a time for you to come and see me at the hospital where I work. I will talk to/interview you for about 30 to 40 minutes. I will tape the talk/interview if you agree. I will have some questions to ask you about what happened when you were detained. I just want you to tell me as much as you can remember about what happened to you. The tapes of the talk/interview will be typed out and I will be looking for the main things that people have told me. I will come and see you again in probably in March 2005 and talk to you about the main points that the people have talked about.
- **Do you have to take part?**
  It will be your choice to decide if you want to take part. If you do want to take part you will be asked to sign a form saying so. If you choose at any time that you don't want to take part you can withdraw/stop whenever you want. You do not have to tell me why you don't want

to continue/keep taking part.

- **What are the benefits of taking part?**

  Taking part in the project does not effect your detention/section or rights. It is about people with learning disabilities being given the opportunity to talk about their experiences to try and help people understand a little better what it is like to be detained.

- **What happens if you feel worried, sad, scared, angry or upset?**

  Sometimes talking about what has happened to you might make you feel happy or better but sometimes talking about difficult times/things can be upsetting. You do not have to answer all the things I ask if you don't want to. You can also stop talking to me/end the interview when you want. If you do feel upset it is important that you let somebody know. You can ring me and leave a message. If I am not there when you ring I will ring you back (a telephone number where you can contact me is at the top of the page).

- **Will anyone know that you are taking part or know what you have said?**

  I won't tell staff or doctors what you have said unless you tell me that you want to hurt yourself or other people. If I am concerned that you or somebody else is at risk I will tell you before I talk to anyone else about it and I will tell you who I am going to talk to. I will write a report and your name will not be used. Things will be changed so that no one will know who you are or what you have said. Other people like your friends, family, social worker or solicitor will not find out what you have said and you do not need to tell any of these people that you are taking part unless you want to. The tape of the interview will only be listened to by people who are doing the project with me.

- **What if you want to complain about something to do with the project?**

  If you want to complain about something that happens during any part of the project you can contact me at the number at the top of the front page. If you do not want to talk to me or want to complain about something that I have done then you can contact Professor Nigel Beail at the University. His work address is the University of Sheffield and that means his work telephone number is the same as mine, but this does not mean that I will answer the telephone. All you need to do is ask for Professor Beail, and leave him a message if he is not there when you telephone.

  If you remain distressed after talking to Professor Beail then you can get a copy of the official NHS complaints procedure by telephoning 0114 2261000 and asking for a copy to be sent to you.

Thank for taking the time to read or listen to this information.

APPENDIX FOURTEEN:

CONSENT FORM (to be witnessed by a person chosen by the potential participant or the key worker of the person consenting to participate)

Research Project: **People with Learning Disabilities experience of being detained under the Mental Health Act (1983).**

Name of Researcher: Carolyn McNally, Trainee Clinical Psychologist, University of Sheffield. Project conducted in part completion of the qualification of Doctor of Clinical Psychology (DClin Psy)

PLEASE TICK BOX

1. I have read (or someone has read to me) the information sheet
2. I know that participation in this research study will not affect my detention status or treatment in any way ☐
3. I have been given the chance to ask any questions and these have been answered ☐
4. I know that the interview will be tape recorded ☐
5. I know that it is my choice/up to me if I take part. I can stop taking part at any time if I decide I don't want to do it anymore. I know that not taking part or withdrawing from the project will not affect my future care ☐
6. I agree/want to take part in this study ☐

______________	__________	__________
Name of Participant	Date	Signature
______________	__________	__________
Name of Witness	Date	Signature
______________	__________	__________
Name of Researcher	Date	Signature

APPENDIX FIFTEEN:

CONSENT FORM TO AUDIO TAPE INTERVIEW:

(to be witnessed by a person chosen by the potential participant or the keyworker of the person consenting to participate)

Research Project: **People with Learning Disabilities experience of being detained under the Mental Health Act (1983)**

Name of Researcher: Carolyn McNally, Trainee Clinical Psychologist, University of Sheffield

Project conducted in part completion of the qualification of Doctor of Clinical Psychology (DClin Psy)

PLEASE TICK BOX

(1). I consent to the interview being audiotaped ☐

______________	______________	______________
Name of Participant	Date	Signature
______________	______________	______________
Name of Witness	Date	Signature
______________	______________	______________
Name of Researcher	Date	Signature

APPENDIX SIXTEEN:

Confidentiality Form for Transcriber

Research Project: **People with Learning Disabilities experience of being detained under the Mental Health Act (1983)**

Name of Researcher: Carolyn McNally, Trainee Clinical Psychologist, University of Sheffield

The dialogue that you are transcribing has been collected as part of a Doctoral research project. Tapes contain information of a personal and sensitive nature and this must be kept confidential and not disclosed to another person. Confidentiality is given utmost importance by The University of Sheffield. It is therefore necessary that if you agree to transcribe any tape recordings made in connection with this project you must also agree:

- to not disclose any information heard on the tapes to others
- to keep the tape in a secure place where it cannot be heard by other people
- to only show your transcription to the researcher named at this top of this sheet
- to stop transcribing immediately if you recognise the voice of the person speaking

Declaration

I understand that:

(1). I must discuss the content of the tape only with the researcher named at the top of this sheet

(2). I will keep the tape in a safe secure place where it cannot be heard by others

(3). I will respect that the transcription of the tape is confidential information

(4). If the person being interviewed is known to me I will stop transcribing immediately and undertake no further work on the tape.

I agree to the above conditions

Your Name: ______________________

Signature: ______________________

Date: ______________________

Occasionally information contained on the tapes may be distressing. If you find any of the transcriptions of any of the tapes distressing please speak to the researcher