Examining dimensional models of psychopathology experienced by adults with intellectual disabilities

Craig Melville

B.Sc. (Hons.), M.B.Ch.B., MRCPsych.

Division of Community Based Sciences,

Faculty of Medicine,

University of Glasgow

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Author's declaration

This thesis is the work of the author unless explicitly stated otherwise.

Signed……..

Date……..

Craig Melville, B.Sc. (Hons.), M.B.Ch.B., MRCPsych.

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Summary

Background

Classification systems for use in the diagnosis of mental disorders have been developed based on a categorical model of psychopathology. Although current categorical diagnostic classification systems have been found to have good utility and reliability, studies have questioned whether these systems have adequate validity. Dimensional models of psychopathology have been examined as an alternative to categorical diagnostic classification systems and found to be more strongly related to clinical parameters, such as the severity and outcome of mental disorders.

A literature review found a small evidence base on dimensional models of psychopathology experienced by adults with intellectual disabilities. However, the findings were limited by small sample sizes, biased samples and inclusion of only a limited range of items of psychopathology. Furthermore, the methods of exploratory factor analysis used do not meet established best practice guidelines.

Informed by the existing literature, this thesis aimed to;

1. identify a dimensional model of psychopathology experienced by adults with intellectual disabilities
2. examine the associations of a dimensional model of psychopathology with measures of the severity and outcome of mental disorders
3. compare the predictive validity of dimensional and categorical models of psychopathology.

Methods

The *Psychiatric Present State- Learning Disabilities* (PPS-LD) was used as a structured instrument to collect psychopathology data. Exploratory factor analysis (EFA) following best practice guidelines was used to identify dimensions of psychopathology. Continuous measures representing the dimensions of psychopathology were calculated. Meeting criteria for the diagnosis of a mental disorder from the *Diagnostic Criteria for Psychiatric Disorders for use with Adults*

with Learning Disabilities (DC-LD) was used as the variable representing the categorical model of psychopathology.

Baseline data was collected on four measures of severity; the Health of the Nation Outcome Scales- Learning Disabilities (HoNOS-LD), Global Assessment of Functioning (GAF), Clinical Global Impression (CGI), and the Camberwell Assessment of Needs for Adults with Developmental and Intellectual Disabilities-Research version (CANDID-R) unmet needs. These measures were completed again at follow up 4-5 years later and change over time used as a measure of longitudinal outcome.

Bivariate statistics and multivariate linear regression were used to examine the associations of the dimensions of psychopathology, and DC-LD diagnosis, with the measures of the severity of and longitudinal outcome of mental disorders. Relevant socio-clinical variables, associated with psychopathology in previous population-based intellectual disabilities studies were included in the analyses: ; gender, age, living circumstances, level of intellectual disabilities, autism, Down syndrome, epilepsy, sensory impairments, mobility problems and incontinence.

Key results

A model of psychopathology with four dimensions was extracted from the EFA. This model was stable in two additional EFA using random samples. There were no significant correlations between the four dimensions which were labeled depressive, organic, behaviour-affective and anxiety.

Only the anxiety dimension of psychopathology was not associated with any of the measures of severity of mental disorders. The depression dimension was independently associated with severity on the HoNOS-LD (β=.413, p<.001), GAF (β=-.402, p<.001) and the CGI (β=.457, p<.001). The organic dimension was independently associated with severity on the HoNOS-LD (β=.205, p=.004), GAF (β=-.326 p<.001) and CGI (β=.266, p<.001). The behaviour-affective dimension was

independently associated with severity on the HoNOS-LD (β=.332, p<.001), GAF (β=-.286, p<.001), CGI (β=.253, p<.001) and CANDID-R unmet needs (β=.178, p=.018). Level of intellectual disabilities was independently associated with severity on the HoNOS-LD and CANDID-R unmet needs. Finally, younger age (β=-.208, p=.010), living independently (β=-.599, p<.001) and not having a visual impairment (β=-.191, p=.009) were associated with greater CANDID-R unmet needs.

None of the baseline measures of psychopathology were associated with longitudinal outcome on the CANDID-R unmet needs. Baseline scores on the depressive dimension were significantly associated with longitudinal outcome on the HoNOS-LD (β=.297, p=.034), GAF (β=.342, p=.002) and CGI (β=.373, p=.001). Similarly, the behaviour-affective dimension was significantly associated with longitudinal outcome on the HoNOS-LD (β=.292, p=.033), GAF (β=.244, p=.036) and CGI (β=.298, p=.009). The organic dimension was only associated with longitudinal outcome on the HoNOS-LD (β=-.382, p=.006). Individuals with mild intellectual disabilities had poorer outcomes on all four measures of longitudinal outcome. Hearing impairment was associated with poorer outcome on the GAF (β=-.483, p=.000) and CGI (β=-.331, p=.004), and poorly controlled seizures with poorer outcome on the CGI (β=-1.638, p=.004).

The variable representing the categorical model of psychopathology was only independently associated with severity on the HoNOS-LD (β=.178, p=.026), and longitudinal outcome on the GAF (β=.259, p=.045) and CGI (β=.257, p=.044). However, when categorical and dimensional models were both included in the regression analyses only the dimensional model of psychopathology was retained as independently associated with these measures of severity and outcome.

Conclusions

The description of a stable dimensional model demonstrates the value of using multivariate statistical methods to examine psychopathology experienced by adults with intellectual disabilities. Since the findings suggest that dimensional models have better validity than categorical models of psychopathology, the use of EFA, and other

multivariate methods, could contribute to the development of valid categorical diagnostic classification systems.

The presence of affective items of psychopathology across the depressive, behaviour-affective and anxiety dimensions highlights the possible relevance of a global affective model of psychopathology. Findings reported in this thesis support the potential relevance of models of affect regulation and affective arousal to developing an understanding of psychopathology experienced by persons with intellectual disabilities.

There are similarities between the dimensional model in this thesis and the tripartite model of depression and anxiety psychopathology, described in the literature- which has depressive, anxiety and general distress dimensions. Overlaps between the behaviour-affective dimension, and general distress dimension within the tripartite model, suggest that there may be an association between affective psychopathology and problem behaviours. However, it could be that this association is with affective psychopathology in the general distress dimension, rather than with depressive psychopathology, as examined in previous studies.

Confirmatory factor analyses should be considered to examine the four dimension model of psychopathology. Future studies involving individuals with intellectual disabilities should examine the relevance and validity of the tripartite model of depression and anxiety psychopathology.

Chapter 1 Background

1.1 Classification in medicine

Classification and diagnosis are closely related and central to the contemporary practice of medicine.

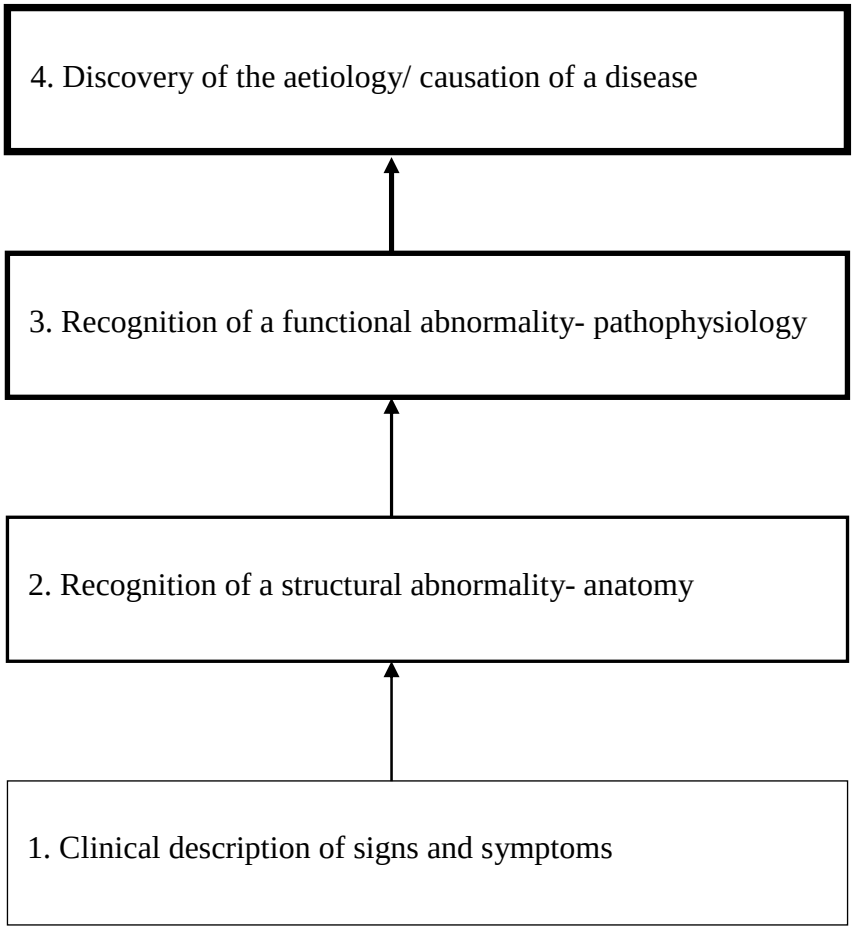
Classification is the "activity of ordering or arrangement of objects into groups or sets on the basis of their relationships", and nosology is the application of classification in medicine (Parshall & Priest 1993). Taxonomy- is the theoretical study of classification, which is described as an attempt to move from the question of, "how we classify?" to "how should we classify?" (Frances *et al.* 1994).

Most branches of science have established systems of classification. In medicine, the first attempts at classification are traced back to the ancient Greeks, and the philosophical schools of Plato and Aristotle (Parshall & Priest 1993). Central to classification in medicine (nosology) is the process of diagnosis.

Medical diagnosis is described as "organising unorganised illness" (Balint 1964). There are multiple stages involved and one end-point of the process is assigning an individual's symptoms and signs to a named categorical diagnosis (Elstein & Schwartz 2002). Therefore, at one level, the process of diagnosis is a form of classification. Throughout this thesis the term categorical diagnostic classification systems will be used to refer to the current classification systems used in medicine, and more particularly in the study of mental disorders, and psychiatry.

Based on a historical view of the development of classification, a model of the classification of health and disease applicable to all branches of medicine was proposed, illustrated in figure 1.1 (Scadding 1988). In Scadding's model (Scadding 1988), the development of a classification system begins with the clinical description of symptoms and signs, gradually integrating the more robust/ scientific characteristics- disorder of structure, disorder of function, and aetiological description. This model illustrates that, as knowledge of health and disease move forward, classification systems become increasingly sophisticated.

Figure 1.1. Scadding's hierarchical model of the characteristics of classification systems for disease.



1.1.1 Approaches to developing systems of classification

The classification of intellectual disabilities is used to illustrate two different approaches to classification.

Intellectual disabilities is the internationally accepted term used to describe the needs of individuals with significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills- originating before age

18 (American Association on Intellectual and Developmental Disabilities 2010). Such needs necessitate additional support from an individual's family, community and/ or services.

1.1.1.1 A "top-down" consensus approach to classification

Historical conceptualisations of intellectual disabilities used socially derived definitions to classify individuals as belonging to a distinct category. Eminent theorists, and social commentators of the day presented their opinions, influenced by broader social systems and ideas (Berrios 1999). This is an example of a "*top down*" approach to classification which results in categorical definitions. The 13th century legal system provided one of the earliest proposals to separate intellectual disabilities (termed idiocy) from mental disorders (lunacy). Such categories were defined on the basis of unifying characteristics; for example, individuals with intellectual disabilities were seen as having a permanent disability, present from birth; whilst mental disorders were believed to be acquired after birth, with some possibility of change over time (Digby 1996). Further sub-categorisation emerged in the 18th and 19th century- using the terms such as feeble-minded, idiocy and imbecility - based largely on an individual's ability to carry out work (Berrios & Porter 1998).

1.1.1.2 A "bottom-up" statistical approach

An alternative to categorisation in classification is the study and description of individual human traits, or dimensions, which is considered to provide a more detailed representation of the complex pattern of similarities and differences between individuals (Sternberg & Kaufman 1998).

In the late 19th and early 20th century, researchers with an interest in understanding the construct of intelligence began the development of "*bottom- up*" empirical methods used in the study of traits and dimensions (Brody 2000). These statistical methods, such as factor analysis, have subsequently provided evidence comparing dimensional models with categorical diagnostic classification systems for mental disorders (Krueger 1999; Brown & Barlow 2005).

One of the earliest individuals interested in examining dimensions underlying intelligence was Charles Spearman. As part of his work, Spearman developed factor analytic methods to examine whether a single underlying intelligence factor could explain correlations between separate dimensions of intellectual functioning- such as sensory perception, memory, attention etc. Spearman's work, alongside that of Jensen, Eysenck and others contributed to a theory of general intelligence- the *g factor*, with an alternative theory of multiple intelligences proposed by Thurstone, Gardner and Sternberg (Deary 2001). This early work on general intelligence made a clear contribution to ideas around the normal distribution of intelligence, and intelligent quotient (IQ) testing - both of which are integral to current definitions of intellectual disabilities.

1.1.2 Intellectual disabilities in current classification systems

Both the "top-down" and "bottom-up" approaches have had an influence on the criteria for intellectual disabilities in contemporary classification systems. These criteria comprise three parts:

- a measure of intellectual functioning- usually IQ
- a measure of adaptive functioning
- a time/ duration criterion.

These parts from the definition used in the Diagnostic Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR; (American Psychiatric Association 2000) categorical diagnostic classification system (which uses the term mental retardation) are presented in table 1.1.

Table 1.1 Diagnostic criteria for intellectual disabilities from DSM-IV-TR

	DSM-IV-TR
Intellectual functioning	Significantly sub-average intellectual functioning: An IQ of approximately 70 or below on an individually administered IQ test.
Adaptive behaviour	Concurrent deficits or impairments in present adaptive functioning (i.e., the person's effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care and home living, social skills, use of community resources, self-direction, functional academic skills, work, leisure, health issues, safety
Age of onset	The age of onset is before 18 years old

The other commonly used categorical diagnostic classification system in medicine is the International Statistical Classification of Diseases, Tenth Edition (ICD-10; (World Health Organisation 1993). The description of the ICD-10 term mental retardation below is provided,

> "*A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition.*"

This is followed by the use of IQ as the basis to further categorise individuals with mild (approximate IQ range 50-69), moderate (approximate IQ range 35-49), severe (approximate IQ range 20-34) and profound (IQ under 20) intellectual disabilities.

The inclusion of IQ measurements within the criteria for intellectual disabilities shows that a categorical diagnosis can make use of the "top-down" consensus and "bottom-up" statistical processes.

1.2 Classification systems for mental disorders

Psychopathology is defined as the study of abnormal experience, cognition and behaviour (Sims 2003). It is, both, a core skill in psychiatry and the basis for the classification of mental disorders (Wallace 1994). A categorical model of psychopathology is used in current categorical diagnostic classification systems.

The two main, generic classification systems for mental disorders, ICD and DSM, have acted as the basis for the development of categorical diagnostic classification systems for the classification of mental disorders experienced by adults with intellectual disabilities- the *ICD-10 Guide to Mental Retardation* (ICD-10-MR; World Health Organisation 1996); the *Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities* (DC-LD: Royal College of Psychiatrists 2001) and the *Diagnostic Manual-Intellectual Disability: a textbook of diagnosis of mental disorders in persons with intellectual disability* (DM-ID: Fletcher *et al.* 2007). Therefore, examining ICD and DSM is necessary before a more detailed description of these categorical diagnostic classification systems specific to intellectual disabilities.

1.2.1 The requirements for a good classification system of mental disorders.

Any classification system for mental disorders will be used for multiple purposes, simultaneously (Johnstone 1998):

- communication with service users, carers and professionals
- clinical decision making
- strategic development of services
- research
- teaching and training
- legal purposes
- service commissioning and reimbursement.

Although each of these purposes has different requirements, there is a degree of consensus about the core characteristics which a classification system should have; utility- defined in terms of comprehensiveness and ease of use- reliability and validity (Kendler 1990; Kendell & Jablensky 2003).

Reliability refers to the consistency, or repeatability, with which a decision, or statement, is made. Although there are many types of reliability, the key one in the diagnosis and classification of mental disorders is inter-rater reliability (Helzer *et al.* 1977). Inter-rater reliability refers to the level of agreement in the diagnoses independently reached by two, or more, clinicians or researchers.

As well as reliability, the validity of categorical diagnostic classification systems has also been examined. Validity is defined as the, "…best available approximation to the truth or falsity of a given inference, proposition or conclusion…" (Cook & Campbell 1979). There are many types of validity, the use of which are determined by the context. The three types of validity relevant to diagnosis in mental disorders are each given below with a short description:

- face validity- the criteria and diagnostic category seem to represent the experiences of individuals with mental disorders, and clinicians
- discriminant validity- the criteria used to define a specific diagnostic categories adequately distinguish it from neighbouring, related categories
- predictive validity- a diagnostic category makes it possible to predict outcome or prognosis.

1.2.2 A history of the classification of mental disorders

During the classical Greek era, a system of classification based on psychopathology described five categories of mental disorder; phrenitis (delirium), mania, melancholia, hysteria and epilepsy. Galen adopted the first aetiologically based model for the classification of mental disorders comprising the vesanias, which were caused by poisons, the lunacies caused by phases of the moon, and the hereditary insanities (Everitt & Landau 1998). As medical knowledge developed, Galen's early shift towards

the higher levels of classification on Scadding's hierarchical model (figure 1; Scadding 1988) was not sustained.

In the 19th, and early 20th, centuries the process of developing a classification system for mental disorders was dominated by the "*famous professor principle*" (Kendler 1990). Similar to the "*top-down*" approach to the definition of intellectual disabilities, described in section 1.1.1.1, European professors of psychiatry put forth their own ideas on classification. Amongst the many eminent names that contributed to thinking on classification, Kraepelin is most often cited as significantly influencing the development of ideas on classification (Moller 2008). Postulating that all psychotic disorders converge in "*natural disease entities*" he produced his basic idea that psychotic disorders can be dichotomized into "*dementia praecox*" and "*manic depressive insanity*" (Kraepelin 1921). This idea of distinct categories of mental disorders informed the development of current categorical diagnostic classification systems- ICD and DSM.

1.2.3 International Classification of Disease (ICD)

In 1853, two medical statisticians presented a list of causes of death which became known as *Bertillon's Classification of the Cause of Death*. Subsequent revisions lead to the International List of Causes of Death. This was used by the World Health Organisation (WHO) as the basis for the publication of the *International Classification of Diseases, Injuries and Causes of Death* (ICD-6) in 1948. Published in revised form approximately every 10 years, the most recent edition was published as ICD-10 in 1993.

ICD-10 aims to provide comprehensive coverage of all causes of morbidity across all the major body systems across. Organised into separate chapters for diseases with shared aetiology, chapter V is for the classification of *Mental and behavioural disorders*. Although ICD-10 is viewed as the main classification system in use internationally, the majority of the developments in the classification of mental disorders have been taken forward by the American Psychiatric Association, in subsequent editions of the DSM. Since these innovations in DSM have generally been

incorporated into the ICD *Mental and behavioural disorders* chapter, a fuller description of DSM is given here, and reference made to ICD where appropriate.

1.2.4 Diagnostic and Statistical Manual of Mental Disorders (DSM)

In 1952, the American Psychiatric Association published DSM-I. Both DSM-I, and also DSM-II published in 1968, were designed primarily for the specific purpose of counting the number of cases of individuals with specific diagnoses (Kraemer 2007). To meet this requirement, the early versions of DSM clearly had a focus on ensuring adequate face validity i.e. the descriptions of clinical syndromes matched the views of experts (Kendler 1990).

An influential paper by Robins and Guze (1970), extended the focus on face validity to a more research based approach to validity- suggesting five criteria for diagnostic validity, added to by Kendell (1989) to comprise:

- identification and description of a syndrome- face validity
- demonstration of boundaries between syndromes- discriminant validity
- follow up studies and course of illness- predictive validity
- outcome of therapeutic trials- predictive validity
- family studies- pathophysiology and aetiology
- association with a biological or psychological abnormality- pathophysiology and aetiology.

This shift to a research-based development process created a clear break point in the revision of classification systems. Studies had shown that DSM-III had poor inter-rater reliability (Kreitman *et al.* 1961; Sandifer *et al.* 1968). The International Pilot Study of Schizophrenia examined diagnosis in nine countries (Carpenter. *et al.* 1973) and found that schizophrenia was diagnosed significantly more frequently at the centre in the United States of America (U.S.A.) and the Union of Soviet Socialist republics (U.S.S.R.), than in other countries. As a consequence of these findings attempts were made to improve the reliability of categorical diagnoses through the introduction of operationalised criteria in classification systems.

Via the specific description of operationalised criteria, including items of psychopathology, DSM-III provided a classification system that could be more readily observed and replicated across settings, and between observers. This was shown to improve upon the poor reliability DSM-II (Kreitman *et al.* 1961; Sandifer *et al.* 1968) in the DSM-III field trials (Spitzer *et al.* 1979), and subsequent studies (Mellsop *et al.* 1991). The operationally defined criteria were further refined in DSM-IV, and ICD-10 and have been shown to have good reliability (Klin *et al.* 2000; Brown *et al.* 2001). As a consequence, it has been suggested that the major improvements in reliability have been achieved (Kendell 2002).

DSM-IV was published in 1994, with a text revision, DSM-IV-TR, following in 2000. For these, there was considerable time and resource spent in examining any evidence that could inform the diagnostic criteria in DSM-IV. Prior to publication, extensive field trials were carried out with the draft criteria, again largely focusing on the inter-rater reliability and face validity of the classification system. DSM-IV-TR has been used as the basis for the development of DM-ID.

There has been a recent focus on a more evidence-based approach to developing classification systems for mental disorders. However, overall the "top-down" consensus approach has had the biggest influence.

1.3 Mental disorders and intellectual disabilities

As described in section 1.1.1, mental disorders and intellectual disabilities have been conceptualised as separate categories for several centuries. Interest in the study of mental disorders experienced by individuals with intellectual disabilities has developed gradually since early case reports in the 19th century (Clouston 1883). This gathered pace in the mid 20th century, with the recognition that individuals with intellectual disabilities experience higher rates of mental disorders than individuals who do not have intellectual disabilities.

In 1936, a study of the 2134 individuals in the Severalls Mental Hospital categorised the mental disorders of the inpatient sample as schizophrenia, organic insanities, manic

depressive insanity, epileptic psychosis, and cases without definite psychotic symptoms (explained as neurosis, psychoneurosis, emotional instability, and mental defect uncomplicated by mental disorder). These categories were in keeping with the use of terminology to describe mental disorders at that time. The level of abilities of participants was also assessed, and intellectual disabilities classified using the historical terms dull, feebleminded, imbecile and idiot (Duncan *et al.* 1936). Within the 40.8% of the sample assessed as having intellectual disabilities (defined as having an equivalent mental age of less than 10), there were high rates of schizophrenia, manic depressive insanity and epileptic psychosis. The authors concluded that there may be a shared aetiological factor between manic-depression and intellectual disabilities (Duncan 1936). Subsequent studies confirmed the increased rates of mental ill health in adults with intellectual disabilities- using a similar inpatient sample in a large institution and the available categorical diagnostic system of the time (Penrose 1938; Pollock 1945; Heaton-Ward 1977; Reid 1972; Corbett 1979; Wright 1982). Even in the earliest of these studies the limitations, of the available classification systems for mental disorders, based on categorical models of psychopathology, when used with persons with intellectual disabilities were recognised (Duncan *et al.* 1936).

1.3.1 The classification of mental disorders experienced by individuals with intellectual disabilities

The use of generic classification systems, such as ICD and DSM, for the diagnosis of mental disorders in persons with intellectual disabilities is recognised to be problematic (Reid 1983; Sovner 1986; Sturmey 1993; Clarke *et al.* 1994; Einfeld & Aman 1995; Einfeld & Tonge 1999; Cooper *et al.* 2003). Since they were designed for the diagnosis of mental disorders in the general population, they:

- are reliant on verbal communication
- require an understanding of abstract and complex concepts beyond the cognitive abilities of many individuals with intellectual disabilities
- do not include problem behaviours and other psychopathology relevant to intellectual disabilities.

Therefore, ICD and DSM are less reliable and valid for the assessment and diagnosis of mental disorders in individuals with intellectual disabilities (Cooper *et al.* 2003). Various authors have debated whether to amend existing systems of classification, particularly for use with individuals with mild intellectual disabilities (Sovner & Hurley 1983; Reid 1983; Sovner 1986; Bruininks 1991; Sturmey 1993; Clarke *et al.* 1994; Einfeld & Tonge 1999; Clarke & Gomez 1999; Cooper & Bailey 2001) or to publish classification systems specific to intellectual disabilities. Ultimately, a combined approach has been adopted, with the publication of three classification systems, based upon ICD and DSM, designed for specific use in the diagnosis of mental disorders, experienced by individuals with intellectual disabilities- ICD-10-MR (World Health Organisation 1996); DC-LD (Royal College of Psychiatrists, 2001) and the DM-ID (Fletcher *et al.* 2007). The publication of these specific systems may act as an important stimulus to take forward developments in research and clinical practice; aiming to improve the outcomes and quality of life of individuals with intellectual disabilities experiencing mental disorders.

1.3.1.1 ICD-10 Guide to Mental Retardation (ICD-10-MR)

The World Health Organisation published the *ICD-10 Guide to Mental Retardation* in 1996 (World Health Organisation 1996). Although it has never been adopted as part of routine clinical practice, or used extensively in research, it represented the first attempt to tackle the challenges inherent in the classification of mental disorders experienced by persons with intellectual disabilities.

Similar to ICD-10 and DSM-IV-TR, ICD-10-MR proposed a multi-axial classification system, with five axes:

- axis I -severity of intellectual disabilities and problem behaviours
- axis II-associated medical conditions not causative of intellectual disabilities
- axis III-associated psychiatric disorders
- axis IV-global assessment of psychosocial disability
- axis V-abnormal psychosocial conditions.

With regards to the classification of mental disorders using axis III, ICD-10-MR did not change any of the psychopathology, duration or impairment criteria compared to the generic ICD-10. Rather, the guide makes comment where there are specific issues relevant to a particular diagnosis in individuals with intellectual disabilities. For example, a comment is made on the association of Down syndrome with Alzheimer's disease, and the need to rule out hypothyroidism as a differential diagnosis for depressive symptoms in persons with Down syndrome. Given that ICD-10-MR did not really address any of the issues relevant to assessing and diagnosing mental disorders in individuals with intellectual disabilities, it is not surprising that it has never been taken up and used by professionals working in clinical practice, or research. One study that trialed its use in the diagnosis of mental disorders experienced by young people with intellectual disabilities highlighted some of the inconsistencies and discrepancies (Einfeld & Tonge 1999). It was concluded that there was a need to establish working groups to further develop a reliable and valid classification system.

1.3.1.2 Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities (DC-LD)

An expert working group, of specialists in intellectual disabilities psychiatry, developed the DC-LD on behalf of the Royal College of Psychiatrists (Royal College of Psychiatrists 2001). Using ICD-10 and DSM-IV as a basis, the working group set out with the aim of developing a classification system that would be reliable and valid for use in research and clinical settings (Cooper *et al.* 2003). Similar to the development of DSM-IV, the working group used a consensus process, informed by comprehensive literature searches and a field trial of the draft criteria. This lead to the publication of DC-LD, in 2001.

Although DC-LD has a multiaxial system of classification, it is quite distinct from that in ICD-10-MR:

- axis I-severity of learning disabilities
- axis II-cause of intellectual disabilities
- axis III-psychiatric disorders

– DC-LD level A: developmental disorders

- DC-LD level B: psychiatric illness
- DC-LD level C: personality disorders
- DC-LD level D: problem behaviours
- DC-LD level E: other disorders.

The introduction to DC-LD emphasises the importance of using a hierarchical approach to classification. When an item of psychopathology is identified, it is recommended that the person making the diagnosis moves systematically down the axes, and five levels in axis III- considering, at each stage, the appropriate axis, or level, to consider the item of psychopathology as part of classification. It is relevant to note that an item of psychopathology can be attributed, and used as part of classification, in several axes, or levels, in the hierarchical system. However, the introduction to DC-LD emphasises the need to give careful consideration before counting psychopathology twice within the hierarchical model of classification.

The format and content of DC-LD addresses many of the previously expressed concerns over the use of ICD-10 and DSM-IV, when diagnosing mental disorders experienced by persons with intellectual disabilities. Furthermore, DC-LD specifically addresses some of the criticisms of ICD-MR made by Einfeld and Tonge (Einfeld & Tonge 1999). For example, whereas ICD-10-MR included problem behaviours in the same axis as severity of intellectual disabilities (Einfeld & Tonge 1999), DC-LD conceptualises problem behaviours as a separate level within psychiatric disorders in axis III.

In contrast to ICD-10-MR, DC-LD has altered some of the ICD-10 criteria for certain categorical diagnoses of mental disorders. For example, a DC-LD diagnosis of depressive episode can be made if one key depressive symptom, from a choice of two-either depressed mood or loss of interest or pleasure in activities-is identified; whereas in ICD-10, two key depressive symptoms, from a choice of three -depressed mood, loss of interest or pleasure in activities, and loss of energy-are required. Overall, only minor modifications to ICD-10 criteria were made on the basis that there was evidence to

support the changes, and it is stated that further research is needed to examine the reliability and validity of the modifications that have been made (Royal College of Psychiatrists 2001).

Some initial work examining the utility of DC-LD has been published. A retrospective case note study, carried out in an institution in Ireland, looked at the utility of DC-LD to classify mental disorders in 113 adults with intellectual disabilities. The majority of participants (87.6%) had severe or profound intellectual disabilities. This study reported improved utility of DC-LD to diagnose problem behaviours and eating disorders, compared to ICD-10 and DSM IV. However, a significant number of "residual category" or "not otherwise specified" diagnoses were recorded, as DC-LD or ICD-10 criteria were not fully met.

Cooper *et al* (2007a) applied DC-LD, ICD-10 and DSM-IV-TR diagnostic criteria to a large sample of adults with intellectual disabilities, who had been assessed using a comprehensive, standardised process. The prevalence of mental disorders using DC-LD criteria was more than double the prevalence when ICD-10 and DSM-IV-TR criteria were used. Furthermore, DC- LD diagnoses showed a greater level of agreement with the gold standard consensus clinicians' diagnoses, than ICD-10 and DSM-IV-TR. This provides evidence for the utility and face validity of DC-LD.

Finally, Hove and Havik (2008) used the operationalised DC-LD criteria to develop 10 psychopathology and eight problem behaviour checklists. Informants working with adults with intellectual disabilities, comprising paid carers and health care staff, completed the checklists for 583 individuals. The checklists were found to have acceptable internal, and inter-rater reliability, and specificity-although sensitivity was found to be poor.

Further research examining the reliability, validity and utility of DC-LD is required. However, these initial studies suggest that it is an important initial step in tackling some of the problems associated with the use of ICD and DSM categorical diagnostic

classification systems for mental disorders experienced by individuals with intellectual disabilities.

1.3.1.3 Diagnostic Manual-Intellectual Disability (DM-ID)

DM-ID can be used to make diagnoses in children and adults with intellectual disabilities. Similar to DC-LD, an expert consensus process was used to produce the DM-ID. For each section in DSM-IV-TR, a detailed literature review was carried out to examine the evidence on the diagnosis of particular categories of disorders, and this was used to inform the adaptation of DSM-IV-TR criteria.

In a general DM-ID chapter on assessment and diagnosis (Hurley *et al.* 2007), it is suggested that all five axes of DSM-IV-TR can be used with individuals with intellectual disabilities:

- axis I- mental disorders, other than personality disorders and intellectual disabilities
- axis II- for coding level of intellectual disabilities and personality disorders
- axis III- medical disorders relevant to any medical disorders, or the cause of intellectual disabilities
- axis IV- allows coding of relevant psychosocial and environmental stressors
- axis V- the Global Assessment of Functioning (GAF), is a rating scale to allow clinicians to rate an individual's overall level of functioning.

DM-ID states that axes I-V should be used as part of a multi-axial diagnosis for adults with intellectual disabilities. The majority of DM-ID reviews the use of criteria for axis I and axis II diagnostic categories for persons with intellectual disabilities. It is suggested that axis III should be used as it stands in DSM-IV-TR, and modified versions of axes IV and V can be used.

There are potential problems in using axis V, the GAF, to rate the overall functioning of individuals with intellectual disabilities (Hurley 2001; Shedlack *et al.* 2005). One issue arises because clinicians are asked to rate overall functioning based on the impairments due to mental disorders, which in DSM-IV-TR would include intellectual disabilities. This could lead to persons with severe intellectual disabilities, but with no mental

disorders such as depression or schizophrenia, being rated with very low scores, despite leading happy, fulfilling lives. Since the impact on functioning of impairments due to physical disabilities is excluded from the axis V rating, it has been suggested that intellectual disabilities be viewed similarly (Hurley 2001). As individuals would not be starting with artificially low scores this would make it more likely that changes in functioning due to mental disorders could be reliably rated.

Examining DM-ID, there are very few adaptations to the DSM-IV-TR criteria for individual diagnostic categories. More commonly, qualifying statements are made about individual criteria, often separately for individuals with mild/ moderate and severe/ profound intellectual disabilities. Thus, DM-ID is largely identical to DSM-IV-TR with suggestions to clinicians on how best to apply criteria.

A field trial was carried out to examine the clinical usefulness of the DM-ID (Fletcher *et al.* 2009). Sixty three clinicians in 11 countries were asked to make use of the DM-ID with individuals on their existing clinical caseloads and to provide a DSM-IV-TR and DM-ID diagnoses for each case. The clinicians were also asked to complete a short questionnaire, with six specific items rating the usefulness of the DM-ID. Although no data on the reliability or validity of the DM-ID was presented, overall, DM-ID was rated as clinically useful in reaching a diagnosis in 51.7% of the 845 cases, and *easy* or *very easy* to use in 67.9% of cases. Importantly, clinicians rated it as useful in diagnosing clinical disorders across the full range of abilities and the authors tentatively suggest DM-ID may have advantages over DSM-IV-TR experienced by individuals with intellectual disabilities (Fletcher *et al.* 2009).

To date, only one study examining the reliability, validity or utility of DM-ID has been published. A retrospective case note review of clinic attendees with intellectual disabilities concluded that many individuals with depression would not meet the adapted DM-ID criteria for depressive disorder (Hurley 2008). This was attributed to the communication skills of people with intellectual disabilities making self-report of symptoms difficult, and the limitations around informant report of symptoms.

1.3.2 Summary of the classification of mental disorders in intellectual disabilities

The general requirements for a good classification system of mental disorders have been described. Specific categorical diagnostic classification systems for mental disorders experienced by persons with intellectual disabilities have been published. However, few published studies have examined whether DC-LD and DM-ID meet the requirements for a good classification system. Since the generic ICD-10 and DSM-IV categorical diagnostic classification systems were used to develop DC-LD and DM-ID, the next section reviews the evidence on generic ICD and DSM classification systems.

1.4 The advantages and disadvantages of categorical diagnostic classification systems

1.4.1 Advantages of categorical diagnostic classification systems

ICD and DSM are able to fulfill many of the purposes, and characteristics of an adequate system described in section 1.2.1. They have lead to enhanced communication with service users and amongst professionals, improved reliability, and have been widely utilized in research and teaching (Kendell & Jablensky 2003). Categorical diagnoses act as a short hand description of an individual's experiences, symptoms and presentation to clinical services. The improved reliability of communication between professionals, associated with existing categorical classification systems is reported as the most valued feature of DSM and ICD (Mellsop *et al.* 2007; Bell *et al.* 2008).

With respect to communication with service users, using a diagnostic term that is familiar to an individual can have a positive impact. Although, more often categorical diagnoses are linked to the stigmatization of individuals with mental disorders, research has also described the positive effects that some individuals experience when they are told of a recognizable diagnosis (Dinos *et al.* 2004; Holm-Denoma *et al.* 2008). Moreover, at a population level the use of categorical diagnoses provide a shared language essential for anti-stigma (Crisp *et al.* 2005; Mehta *et al.* 2009) and public mental health campaigns (Jorm *et al.* 1999).

The improved reliability of the diagnostic process through the use of categorical diagnostic classification systems was discussed previously whilst describing the

changes in DSM. This has encouraged the development of semi-structured diagnostic interviews. Beginning with the development of the Diagnostic Interview Schedule (Robins *et al.* 1981), which produced diagnoses based on DSM-III, the major diagnostic interview schedules identify disorders described in the ICD and DSM diagnostic classification systems:

- Schedules for Clinical Assessment in Neuropsychiatry (SCAN; (Wing *et al.* 1990)- ICD-10 and DSM-IV
- Structured Clinical Interview for DSM IV (SCID; First *et al.* 1994)- DSM-IV
- Composite International Diagnostic Interview (CIDI; (Kessler & Ustun 2004)
- Clinical Interview Schedule- Revised (CIS-R; (Lewis *et al.* 1992).

This link between classification systems and diagnostic interviews is useful for certain types of research, such as epidemiological studies.

ICD-10 and DSM have also been used as the framework to design outcome measures used in clinical and research settings. The clearest example of this is the Patient Health Questionnaire (PHQ-9), widely used as an outcome measure for depression. The PHQ-9 comprises the nine DSM-IV criteria for depression, self- scored on a scale of 0 (not at all) to 3 (nearly every day), and has been shown to be reliable and valid (Lowe *et al.* 2004).

This relationship between ICD, DSM, diagnostic interviews and outcome measures has encouraged the consistent use of methods in clinical practice and research, internationally.

1.4.2 Disadvantages of categorical diagnostic classification systems

1.4.2.1 Evidence on the validity of categorical diagnostic classification systems

The discriminant validity of a categorical diagnosis depends upon being able to clearly demonstrate a boundary between the category in question, and alternative categories. For example, Kraepelin's dichotomous boundary between schizophrenia and bipolar disorder is widely utilised in clinical practice and research. In "carving nature at the joints" (Pickles & Angold 2003), categorical diagnostic classification systems seek to

delineate categories from one another, and also to establish a discontinuity between normality and pathology, defined as a category, or syndrome.

One approach to examining the validity of a categorical system of diagnosis is to consider the distribution of psychopathology. If diagnostic categories are valid, we might expect to identify a natural breakpoint, or "point of rarity"(Sneath 1957), between neighbouring categories, or find that psychopathology has a bimodal distribution (Murphy 1964; Everitt 1981; Meehl 1995). A commonly cited example of a bimodal distribution is the frequency peak at the tail of the normally distributed IQ distribution curve. This is believed to represent individuals with intellectual disabilities associated with genetic, and other biological, syndromes or causes.

In the case of psychopathology, researchers have sought to examine points of rarity, or a bimodal distribution, to discriminate between:

- normality and caseness
- neighbouring, categorically defined diagnoses.

To examine if there is a categorical breakpoint between normality and caseness, a study examined non-psychotic psychopathology, in a nationally representative sample of 9556 UK adults from the National Household Psychiatric Morbidity study (Melzer *et al.* 2002). The CIS-R (Lewis *et al.* 1992) was used to collect the data on psychopathology and analysis carried out to identify the best fitting theoretical distribution curve. The best fit for the distribution was a single exponential curve with no points of rarity or frequency peaks to distinguish between normality from caseness. No evidence to support a bimodal distribution of psychopathology was found (Melzer *et al.* 2002). Although the study had a large sample size and used a structured method to identify psychopathology, the exclusion of individuals with psychopathology suggestive of psychosis could have impacted on the findings. In particular, the finding that psychopathology has a continuous distribution cannot be generalized to diagnostic categories of schizophrenia, schizoaffective and bipolar disorders.

Large studies, of non-clinical populations, have been used to explore the distribution of specific types of psychopathology in order to identify whether a bimodal distribution can identify a cut-off point for a diagnostic category. Studies focused on psychotic symptoms (Allardyce *et al.* 2007b), depressive symptoms (Flett *et al.* 1997; Solomon *et al.* 2001) and anxiety symptoms (Anderson *et al.* 1993) all seem to conclude that there is a continuous distribution of these types of psychopathology in the population. Similar findings have been reported for the distribution of psychopathology in representative samples of children and adolescents (Levy *et al.* 1997; van den Oord *et al.* 2003). Although more readily accepted for anxiety and depressive symptoms, which have long been conceptualised as variations on normal human emotional experience, the suggestion that psychotic psychopathology exists on a continuum that extends into normal experience is perhaps more surprising. However, multiple studies support this continuous distribution of positive psychotic symptoms in non-clinical populations (Allardyce *et al.* 2007b), with rates between 4% (Eaton *et al.* 1991) and 17.5% (van Os *et al.* 2000).

Further evidence in support of a continuous distribution of psychopathology emerges from studies examining sub-threshold clinical syndromes, in non-clinical samples. In the case of affective disorders, high rates of sub-threshold depressive (Angst *et al.* 1997; Wagner *et al.* 2000; Cuijpers *et al.* 2004; Chuan *et al.* 2008) and hypomanic symptoms (Angst *et al.* 2003; Kessler *et al.* 2006; Merikangas *et al.* 2007) are described. These studies used established structured methods to assess psychopathology but have not all used representative, population-based samples (Wagner *et al.* 2000) and not all the studies found that these sub-threshold syndrome were associated with impairment (Angst & Merikangas 1997). Despite these limitations in some studies, the concept of depressive (Angst & Merikangas 1997) and bipolar spectrum disorders (Judd & Akiskal 2003) have emerged, with similar arguments being made for schizophrenia (Siever & Davis 2004), and obsessional (Bienvenu *et al.* 2000) spectrums.

A second method used to examine the discriminant validity of categorical models of psychopathology is to study categories with a postulated overlap, or some shared

features. With regard to such neighbouring categorical diagnoses, most studies have focused on psychopathology in the psychoses. Krapelin's original dichotomisation continues to influence work attempting to delineate psychosis associated with schizophrenia and affective disorders; although it is interesting to note that Kraepelin recognized the problems discriminating between the two when he wrote, '. . . it is becoming increasingly clear that we cannot distinguish satisfactorily between these two illnesses . . .' (Taylor 1992). Early studies, examining psychopathology, failed to identify points of rarity, or a bimodal distribution, that could distinguish between schizophrenia and the affective psychoses (Kendell & Gourlay 1970; Kendell & Brockington 1980). Nor has more recent work found that psychopathology discriminates between the categories of psychoses described in ICD and DSM.

Two studies used factor analysis to examine the psychopathology experienced by adults meeting the criteria for schizophrenia, schizoaffective disorder and affective psychoses- using DSM-III-R in a study with 314 participants (Peralta *et al.* 1997) and ICD-10 with 387 participants (Murray *et al.* 2005). Factors extracted, that included positive, negative and disorganization psychopathology, were scored highly in participants with and without schizophrenia, and depressive and mania/ hypomania factors scored highly in individuals diagnosed with schizophrenia. Although these findings require further validation, particularly using categorical diagnostic classification systems using operationalised criteria, such as DSM-IV-TR, they suggest an overlap between diagnostic categories. This area of work has moved beyond just psychopathology with detailed reviews reaching the conclusion that the overlapping psychopathology, risk factors and outcomes of schizophrenia and psychotic bipolar disorder argue against the existence of separate diagnostic categories (Maier *et al.* 2006).

A further challenge to the categorical classification of psychopathology has come from the evidence that individuals with mental disorders have very high levels of comorbidity. The suggestion is that the high levels of comorbidity in epidemiological studies are due to the poor discriminant validity of diagnostic categories, such that the boundaries between categories are not valid, and so individuals end up meeting criteria

for more than one diagnosis. This issue has raised concerns that current categories are not representative of distinct clinical entitities (Mineka *et al.* 1998).

The extent of comorbidity experienced by persons with mental disorders first became clear during the Epidemiological Catchment Area (ECA) study (Bourdon *et al.* 1992). Of the 28.1% of participants with one diagnosis, over 60% had two or more diagnoses. Similarly, the National Comorbidity Survey (Kessler *et al.* 1994) reported that of 29.5% of participants with one diagnosis in the prior 12 month period, 56% had two or more diagnoses. In the follow up National Comorbidity Survey- replication study (Kessler *et al.* 2005) of 26.2% of participants meeting criteria for at least one diagnosis over the prior 12 month period, 45% met criteria for two or more diagnoses. Such consistently high rates of comorbidity raised concerns about the validity of the categories defined within the classification systems, which in these studies was DSM.

There are cases where an individual meeting criteria for more than one diagnosis represents the presence of distinct, yet comorbid, psychopathology. However, the more common finding is that the multiple diagnoses are similar enough to one another to suggest a shared pathophysiology, or aetiology. For example, one study reported high rates of comorbid depressive and anxiety diagnoses (Brown *et al.* 2001). The Anxiety Disorder Interview Schedule for DSM-IV: Lifetime Version (ADIS-IV-L; (Di Nardo *et al.* 1993) was used to assess psychopathology in 1, 127 individuals attending two specialist centres for the management of anxiety disorders in the U.S.A. Fifty seven per-cent of participants had current co-morbid mood and anxiety disorders, and the rate of lifetime comorbidity was 81% (Brown *et al.* 2001). Given that the recruiting sites were specialist treatment centres for anxiety disorders it could be that the sample is biased towards inclusion of individuals with severe, treatment resistant disorders. This may have influenced the high rates of comorbidity.

The predictive validity of a diagnostic classification system is considered by some to be the single most important requirement (Kendell 1989; Kendell & Jablensky 2003). However, less research has focused on this aspect of the validity of categorical diagnostic classification systems, than discriminant validity. Early studies reported that

the criteria for a categorical diagnosis of schizophrenia were not associated to an individual's prognosis (Hawk *et al.* 1975; Brockington *et al.* 1978). This raised concerns that categorical diagnostic classification systems had poor predictive validity. However, more recent studies have suggested that the inclusion of operationalised criteria within the categorical diagnosis of schizophrenia has improved predictive validity (Mason *et al.* 1997). However, other studies have found that ICD-10 and DSM-IV categorical diagnostic classification systems may lack predictive validity when used to classify a broader range of mental disorders (Jager *et al.* 2004). Overall, the evidence base on the predictive validity of categorical diagnostic classification systems in at an early stage. There is a recognized need to study this further (Kendell & Jablensky 2003; Vieta & Phillips 2007).

1.4.2.2 The use of categorical models of psychopathology in research

The evidence suggesting that categorical diagnostic classification systems may lack discriminant and predictive validity raises concerns about their utility in research.

It is recognised that the use of a categorical variable to describe what is actually a continuous variable, will affect the power and precision of research (Cohen 1983; MacCallum *et al.* 2002; Altman & Royston 2006). The evidence described above suggests that psychopathology appears to have a continuous distribution in the population. Although it is a common practice, the two general criticisms of dichotomizing a continuous variable are that it is leads to a loss of data - affecting the power of studies - and distorts the understanding of the relationship between variables. A calculation of the extent of the loss of power, estimated that three times the sample size is needed for equivalent power, compared to use of a continuous variable (Neale *et al.* 1994).

These issues are highly pertinent to psychopathology research, for example as described affecting the results in a randomised controlled trial of CBT for eating disorders (Kraemer 2007). An initial analysis using a categorical outcome measure found no evidence for the efficacy of the intervention. Reanalysis using a dimensional outcome measure suggested that the effects of the intervention are statistically

significant, and potentially clinically relevant. It was argued that the loss of power associated with the use of categorical outcome measures, creates a need for unnecessarily large sample sizes and then misinterpretation of clinically relevant findings.

As has already been stated, the DSM-I and DSM-II categorical systems of classification were originally devised for use in epidemiological research (Kraemer 2007). Whilst existing systems appear to meet criteria for use in this type of work, a case is emerging around the limitations of the use of categorical diagnostic classification systems in biological research in the field of mental disorders, such as genetics, and neuroscience (van Praag 1997; Verhoeven & Tuinier 2001). Whilst the methods in research in genetics and neuroscience have developed considerably, further developments are held back by the diagnostic categories in use.

Studies have shown an overlap in the genetics of separate diagnostic categories. The genetic overlap between bipolar disorder and schizophrenia (Craddock *et al.* 2006; Maier 2008) and between anxiety and mood disorders (Kendler *et al.* 2008) adds weight to the argument above. This apparent lack of validity of the diagnostic categories hinders genetic aetiological research. In light of this, and other problems that have emerged in the interface between genetics and diagnoses, researchers have begun to examine associations between genetics and more detailed phenotypes, to allow a degree of separation from the limitations imposed by diagnostic categories.

Research in psychosis has begun to identify endophenotypes that it is hoped will be of greater relevance to genetic studies than categorical diagnoses (Craddock *et al.* 2006; Cardno *et al.* 2008). Endophenotypes are identifiable, quantitative clinical features, or functional impairments. These tend to be continuous, or dimensional, in nature and are often measurable using objective, laboratory tests-for example, neuropsychological batteries of assessment (Gottesman & Gould 2003; Braff *et al.* 2007). Examples of endophenotypes studied include, measures of verbal memory, and neurophysiological measures such as the P50 event related suppression. Of course, this approach still involves challenges to successfully identify the relevant components of the adult

phenotype to study. However, initial findings linking endophenotypes to genetic factors in schizophrenia (Greenwood *et al.* 2007) and depression (Nash *et al.* 2004) are of interest.

As well as considering the impact on genetic research, it is also relevant to consider the use of categorical diagnostic classification systems of psychopathology in neuro-scientific research. Similar to genetic research, scientists working in neuro-imaging, and related fields, have begun to identify neuro-endophenotypes (Glahn *et al.* 2007) and link these to models of psychopathology distinct from diagnostic categories (Pan *et al.* 2009). Furthermore, the opportunity to combine work on neuro- imaging, genetics and endophenotypes offers promise to the understanding of the development of the normally developing human brain (Lenroot & Giedd 2008), as well as the pathophysiology of mental disorders (Potkin *et al.* 2009).

Although the relationship between ICD, DSM, diagnostic interviews and outcome measures is a potential advantage, this is also a potential limitation to developing the evidence base. The clearest example of this has been described in relation to the inclusion of the clinical significance criterion in DSM-IV (Spitzer & Wakefield 1999). Some authors have argued that this additional criterion improves the validity of the classification system because individuals diagnosed with a disorder have higher levels of suicidality, disability and service utilization (Narrow *et al.* 2002). However, this would seem to be a tautology, since the disorder is defined in terms of "clinically significant distress or impairment in social, occupational, or other important areas of functioning" (American Psychiatric Association 2000).

Similar problems arise in relation to outcome measures developed from ICD and DSM. There is evidence to support the use of the PHQ-9 as an outcome measure (Kroenke *et al.* 2001). However, given that the nine DSM-IV criteria for depressive disorder were the basis for it's original development, the findings are again potentially subject to a tautology (Lowe *et al.* 2004), similar to the one described for the significance criterion.

In summary, although the improved reliability of categorical diagnostic classification systems was an important step forward, the concerns over validity raises questions about the need for alternative, or complementary approaches. The lack of evidence to support the validity of categories suggests this may be impacting upon research to elucidate the aetiology of mental disorders (Hyman 2002), and preventing any move towards the higher levels of Scadding's hierarchical model of diagnosis (figure 1.1). Although the publication of DSM-III in 1980 has had a positive effect on classification, the groups working on DSM-V recognize that very little progress has been made on developing an understanding of the aetiology and pathophysiology of mental disorders (First 2009).

1.4.3 Summary of the advantages and disadvantages of categorical diagnostic classification systems

Existing categorical diagnostic classification systems are based on a categorical model of psychopathology. These systems fulfill many of the requirements for a good classification system in 1.2.1 and are valued, and widely used in clinical practice. However, research has highlighted limitations surrounding the validity of these systems, which may be a particular issue for research. Given these limitations there is a need to further consider categorical and other models of psychopathology.

1.5 Dimensional models of psychopathology

The main alternative to classification systems of mental disorders that are based on categorical models of psychopathology are based on dimensional models of psychopathology. Before reviewing the intellectual disabilities literature on dimensional models of psychopathology, an overview is provided of relevant findings from studies that did not include adults with intellectual disabilities.

1.5.1 Research on dimensions of psychopathology

In contrast to the "*top-down*" development of existing categorical diagnostic classification systems, via the consensus of experts process, dimensional models of psychopathology have been derived from studies that used statistical methods to examine the underlying structure of psychopathology.

Much of this work has developed from the factor analytic methods used by Spearman in the study of intelligence. Early studies used factor analysis to study psychopathology in an attempt to identify broad dimensions of psychopathology, and examine the tendency of symptoms to cluster together (Wittenborn 1951; Lorr 1957). A review of the early work using exploratory factor analysis, identified 12 dimensions of psychopathology from observer psychopathology ratings of inpatients, listed below with the key characteristic symptoms cited in the review (Bolton 1973):

- Paranoid Delusions (feels systematically persecuted; believes others influence him; believes people talk about him)
- Thinking Disorganization (irrelevant speech; disoriented; emotional disharmony)
- Anxiety-Depression (doubts he can be helped; feelings of impending doom; unrealistic self-blame)
- Excitement- Hostility (initiates physical assaults; destructive; obscene)
- Excitement-Depression (shouts, sings, and talks loudly; irritable; temper tantrums)
- Withdrawal-Retardation (speech is slowed or deliberate; shut-in personality; lacks motivation)
- Perceptual Distortions (visual hallucinations; auditory hallucinations; tactile hallucinations)
- Phobic-Compulsive Reaction (behavior disrupted by phobias; compulsive acts occur daily; obsessional thinking)
- Paranoid (grandiose convictions; dramatically attention-demanding; voices praise or extol him)
- Motor Disturbances (manneristic movements; giggling; assumes bizarre postures)
- Deterioration (incontinent because of own negligence; foreign objects in mouth; unaware of the feelings of others)
- Conversion Hysteria (no organic basis for complaints; organic pathology with emotional basis; use made of physical disease symptoms).

From these early broad dimensions, research on adult psychopathology has examined dimensions related to specific domains of psychopathology, such as psychosis. As discussed in section 1.4.2.1, studies included individuals meeting criteria for

schizophrenia, schizo-affective disorder and affective psychoses on the basis of categorical diagnostic classification systems (Peralta *et al.* 1997; Murray *et al.* 2005). Since categorical models are used to define potential participants, the dimensions identified are not generalisable beyond individuals with these specific mental disorders.

The studies examining dimensions of psychopathology with relevance to a broader range of individuals has used common forms of psychopathology in large, population-based, non-clinical samples (Krueger 1999; Vollebergh *et al.* 2001; Slade & Watson 2006; Slade 2007). These studies have tended to focus on affective, neurotic, interpersonal and substance misuse psychopathology. This is because the non-clinical nature of the samples used in these studies, means that psychotic psychopathology does not occur at a high enough frequency for inclusion in the factor analyses. Once again these studies examined dimensions of psychopathology using categorical models of psychopathology as an integral part of the research methodology. In each of the four studies, the psychopathology experienced by participants was classified based on criteria within ICD-10 (Slade & Watson 2006; Slade 2007), DSM-III-R (Krueger 1999; Vollebergh *et al.* 2001) and DSM-IV (Slade & Watson 2006) categorical diagnostic classification systems. Multivariate statistical methods were then used to examine how the categorical diagnoses correlate. The findings seem relatively consistent across studies, with dimensions of psychopathology mapping onto two higher order dimensions- labeled internalizing and externalizing (Slade & Watson 2006; Slade 2007). This consistent description of two higher order, internalizing and externalizing, dimensions of psychopathology is proposed as a way of conceptualising the high levels of comorbidity (i.e. the poor discriminant validity described in section 1.4.2.1) of categorical diagnostic classification systems (Krueger & Markon 2006; Slade 2007). However, given that the categorical diagnostic classification systems were used to diagnose participants' mental disorders it does not appear that these studies are identifying the underlying dimensional structure of psychopathology.

Internalising and externalizing dimensions of psychopathology were originally described from studies involving children and adolescents as participants. In contrast to adult studies, the methods used did not use categorical models of psychopathology.

These studies used factor analysis, and other multivariate methods, to examine the structure underlying psychopathology assessed with a instruments that included individual items of psychopathology. For example, the Child and Adolescent Psychopathology Scale (CAPS; Lahey *et al.* 2004) includes all non-psychosis DSM-IV and ICD-10 items of psychopathology relevant to mental disorders experienced by children and adolescents. Principal components analysis was used to examine 1, 382 informant ratings of psychopathology experienced by a representative sample of 4-17 year olds in Georgia, U.S.A. Six stable dimensions of psychopathology were identified labeled as hyperactivity-impulsivity, depression, inattention, conduct disorder, separation anxiety/ fears and social anxiety (Lahey *et al.* 2004). The significant correlations between the six dimensions agreed with earlier conceptions of two higher–order, internalizing (depression, separation anxiety/ fears and social anxiety) and externalising (hyperactivity-impulsivity, inattention, conduct disorder) dimensions of psychopathology (Achenbach 1966; Achenbach & Edelbrock 1978; Cantwell 1996). These studies included children and adolescents who did not have intellectual disabilities. Therefore, the findings may not be generalisable to psychopathology experienced by individuals with intellectual disabilities. However, the results highlight the value of using factor analysis to identify dimensions underlying items of psychopathology, rather than the methods in adult studies that used categorical models of psychopathology (Krueger 1999; Vollebergh *et al.* 2001; Slade & Watson 2006; Slade 2007). An important aspect of the conceptualization of internalizing and externalizing dimensions of psychopathology is these have consistently been shown to apply in studies that have included participants from early childhood (Achenbach *et al.* 1987; van den Oord *et al.* 1995) through adolescence (Leung & Wong 1998; Seiffge-Krenke & Kollmar 1998). This is potentially of interest to the field of intellectual disabilities where there is a need to study psychopathology in individuals with widely varying developmental levels.

1.5.2 Comparing dimensional and categorical models of psychopathology

As well as research to identify the structure of dimensional models of psychopathology, studies have begun to examine the potential relevance of the models. Since they are less well established than categorical diagnostic classification systems, less research has

looked specifically at the advantages and disadvantages of dimensional models of psychopathology. Rather, there has been a focus on examining whether dimensional models are of value in relation to questions over the validity of classification systems using a categorical model of psychopathology. As discussed above, the research on adult psychopathology has focused on a narrower range of psychopathology, than studies including children and adolescents as participants. However, these serve to illustrate potential uses of dimensional models of psychopathology.

1.5.2.1 Models of psychopathology and the severity of mental disorders

Two cross-sectional studies examining the association of a multi-dimensional model of psychopathology and the severity of mental disorders were identified.

A study of 706 participants recruited to a randomized controlled trial of case management in individuals with psychosis, compared the associations of dimensional and categorical models of psychopathology with measures of the severity of mental disorders (van Os *et al.* 1999). To identify the dimensional model, principal component analysis (PCA) was used to identify dimensions of psychopathology from the Operational Criteria Checklist for Psychotic Illness (OCCPI; McGuffin *et al.* 1991). The categorical diagnoses from ICD-10 and DSM-III-R were generated using the Operational Criteria for Psychotic Illness (OPCRIT; McGuffin *et al.* 1991). Clinical measures, including measures of the severity of mental disorders were used in the analysis: quality of life (Lancashire Quality of Life Profile, Oliver *et al.* 1997), satisfaction with services, movement disorders (Abmormal Involuntary Movement Scale, AIMS; Guy *et al.* 1986), social disability (Disability Assessment Schedule, DAS; Jablensky *et al.* 1980), unmet and met needs (Camberwell Assessment of Need, CAN; Phelan *et al.* 1995), living independently, occupational status, suicidality, misuse of drugs and alcohol; neuropsychological functioning [National Adult reading Test, NART; (Nelson 1982); Trail Making Test b, TRAILS B; (Reitan 1958)], course of illness WHO Life Chart (World Health Organisation 1992), service use in the previous two years (days in hospital, psychotherapy use), and psychotropic medication use in the previous two years (antidepressants, anitpsychotics & lithium). The measures of severity were used as the dependant variables in regression analyses including the

measures of psychopathology as the independent variables, and adjusting for gender, age, occupational status, and ethnicity. Four dimensions were identified and labeled depressive, manic, negative and positive psychopathology. The multi-dimensional model of psychopathology was more strongly associated with 15 of 18 measures of severity; categorical diagnosis was more strongly associated with employment status, use of antipsychotics and use of lithium. When both models were included in an analysis, the dimensional and categorical models were both associated with social disability, employment status, suicidality and use of antidepressants and lithium; the dimensional model was significantly associated with 12 of the remaining 13 measures of severity and neither model was associated with antipsychotic use. Therefore, it was concluded that the multi-dimensional model of psychopathology was more strongly associated with measures of severity than the categorical model (van Os *et al.* 1999a).

The second study looked only at depressive psychopathology (Prisciandaro & Roberts 2009), collected using the Composite International Diagnostic Interview (CIDI; Robins *et al.* 1988) from 8098 participants in the National Comorbidity Study (NCS; Kessler *et al.* 1994). Since the psychopathology data was binary, weighted least squares estimation was used in the exploratory factor analysis. The categorical diagnoses from the DSM-III-R were generated using the NCS diagnostic algorithm (Kessler *et al.* 1994). The variables representing the severity of mental disorders were:

- Interference with activities- interference with life and activities; work impairment & social impairment
- Treatment seeking- contact with mental health professionals; psychiatric hospitalization and use of psychotropic medications.

These measures of severity were used as the dependant variables in regression analyses with the measures of psychopathology as independent variables, unadjusted for socio-clinical variables. Two dimensions were identified and labelled cognitive-affective and somatic. The dimensional model of depressive psychopathology, and categorical diagnoses were both significantly associated with both measures of severity. However, when the analyses including both dimensional measures and categorical diagnoses were carried out, categorical diagnoses were not independently associated with the measures

of severity. The authors concluded that the dimensional model of depression was more strongly associated with the measures of severity (Prisciandaro & Roberts 2009).

Therefore, from these two studies it appears that dimensional models are more strongly associated than categorical models of psychopathology to measures of the severity of mental disorders.

1.5.2.2 Models of psychopathology and the longitudinal outcome of mental disorders

Three studies comparing the associations of dimensional and categorical models of psychopathology with measures of the outcome of mental disorders were identified.

A cohort of 337 admissions, with at least one psychotic symptom, to two London hospitals were assessed using the Present State Examination (PSE; (Wing *et al.* 1974) and the data used to complete the Operational Criteria Checklist for Psychotic Illness (OCCPI; McGuffin *et al.* 1991). ICD-10 and DSM-III-R categorical diagnoses were generated with the OPCRIT computer program (McGuffin *et al.* 1991). PCA was used to identify dimensions of psychopathology from the baseline OCCPI and factor scores calculated. Follow-up interviews after four years were carried out with 166 (49%) of participants and nine outcome measures completed- the DAS (Jablensky *et al.* 1980), Lager negative symptom scale (Lager *et al.* 1985; van Os *et al.* 1996), usual negative symptoms, usual symptom severity, course of illness, time in hospital, time living independently, unemployment and employment status at follow-up. The nine outcome measures were used as the dependent variables in regression anlyses, adjusted for gender, catchment area and duration of illness. Seven factors were identified from the PCA and labeled inappropriate-catatonia, delusions-hallucinations, mania, insidious-blunting, depressions, lack of insight and paranoid delusions. The multi-dimensional model was found to be significantly associated with all nine measures of outcome. The categorical diagnoses were only associated with the score on the DAS (Jablensky *et al.* 1980) and employment status at follow up. When the dimensional model and categorical diagnoses were both included in a regression analyses, the dimensional model was a consistently better predictor of outcome and course of illness. One aspect

of the study that may have impacted on the results is a sampling bias towards including individuals with more severe disorders. The initial sample included inpatients and the loss to follow-up of 51% of the initial participants may have biased the sample further. Individuals with more severe disorders are more likely to remain in contact with services, and are therefore more readily identified at the time of follow up. As well as affecting the generalisability of the findings, inclusion of more severe disorders may have impacted differently on the multi-dimensional and categorical models of psychopathology (van Os *et al.* 1996).

In a study of a sub-sample of the 694 participants in the Maudsley Family Study, psychopathology on the OPCRIT from 191 individuals with psychotic or mood disorders was used in PCA to identify a multi-dimensional model of psychopathology (Dikeos *et al.* 2006). OPCRIT categorical diagnoses from DSM-IV were included in the analyses. The associations of the dimensional and categorical models were compared to measures of longitudinal outcome - employment, social adjustment, personality disorder, potential stressor triggering episode, age of onset, impairment during episodes, quality of remisson between episodes, deterioration from pre-morbid functioning, response to anti-psychotics and overall course of illness. Five dimensions of psychopathology were identified- described as mania, reality distortion, depression, disorganization and negative symptomatology- and regression factor scores calculated for each dimensions. In regression analyses, adjusted for gender, age, occupational status, and ethnicity, the categorical diagnoses were associated with pre-morbid social adjustment, mode of onset, no remission between episodes, no response to anti-psychotics and bad overall course of illness. The multi-dimensional model of psychopathology was associated with these same parameters and stressors. When both models were included in the analyses, the dimensional and categorical models were both retained as independently associated with the measures of outcome.

The final study identified, used a different methodology, examining the correlations between change in dimensional measures of of psychopathology and outcome. Psychopathology data was used from 708 participants recruited to a randomized controlled trial of case management in individuals with psychosis and followed up for

two years (van Os *et al.* 1999b). PCA was used to identify dimensions of psychopathology from the OCCPI data (McGuffin *et al.* 1991). Categorical diagnoses were also generated OPCRIT (McGuffin *et al.* 1991). Using twenty measures of outcome, change over time in the multi-dimensional model of psychopathology was found to be strongly associated with the measures of outcome, than categorical diagnoses.

The findings comparing the associations of dimensional and categorical models of psychosis are inconsistent; one study reporting that the dimensional models of psychopathology were more strongly associated with measures of longitudinal outcome of mental disorders (van Os *et al.* 1996; van Os *et al.* 1999b) and one concluded that they were similar and complementary (Dikeos *et al.* 2006).

1.5.3 Summary of research on dimensional models of psychopathology

There is evidence that dimensional models are a useful alternative to categorical models of psychopathology incorporated in current categorical diagnostic classification systems. The evidence suggests that:

- identified dimensions of psychopathology may be correlated to form higher order dimensions of psychopathology
- dimensional models appear more strongly associated than categorical models of psychopathology with the severity of mental disorders
- since the findings on predictive validity to date are inconsistent, further work is required to examine the associations of dimensional and categorical models of psychopathology with longitudinal outcome.

1.6 Dimensional models of psychopathology and intellectual disabilities

This section examines previous studies that have used multivariate statistical methods to identify dimensional models of psychopathology experienced by adults with intellectual disabilities. As discussed above, general research has compared the associations of dimensional and categorical models with the severity and outcome of

mental disorders. Thus, research is reviewed that could inform studies to examine the utility of dimensional models of psychopathology in adults with intellectual disabilities.

1.6.1 Studies using exploratory factor analysis to identify dimensional models of psychopathology in intellectual disabilities

There is less published evidence on dimensional models of psychopathology in adults with intellectual disabilities. Work to date has mainly been by research groups examining the psychometric properties of rating scales, or interview schedules, for the identification and measurement of psychopathology in individuals with intellectual disabilities.

Table 1.2 outlines the results from studies that have used empirical methods to examine dimensions of psychopathology in adults with intellectual disabilities. Over and above the small number of studies in table 1.2, there are some limitations in the evidence which makes interpretation of the results from these studies difficult.

Several factors relating to the samples used in the studies cited in table 1.2 are relevant. General guidelines on the sample size required for factor analysis is that a ratio of cases to variables should be at least 5:1 (Costello & Osborne 2005), with a total sample size of 300 (Tabachnik & Fidell 2001). The only studies meeting these criteria are one of the five using the Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Balboni *et al.* 2000), the three studies using the Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD checklist; Moss *et al.* 1998; Sturmey *et al.* 2005; Hatton & Taylor 2008) and the studies using the Diagnostic Assessment of the Severely Handicapped, version II (DASH-II; Sturmey *et al.* 2004) and the Brief Symptom Inventory (BSI; Kellett *et al.* 2004). Although these guidelines are not absolute, they have been demonstrated to affect the power and reliability of the results of factor analyses (Costello & Osborne 2005).

Table 1.2. Studies of the dimensions of psychopathology in adults with intellectual disabilities

Authors	Sample	Measure of psychopathology	Methods	Number of factors retained (% variance)	Dimension names (eigenvalue, % variance, number of items)
Matson *et al.* 1984	N= 110 clinic sample, borderline= 8.1%, mild= 47.3%, moderate= 40.9%, severe= 3.7%; Mean age= 45.9 (18-71, SD N/A[1])	PIMRA- 56 psychopathology items derived from DSM-III criteria for schizophrenia, affective, psychosexual, adjustment, anxiety, somatoform and personality disorders. Self-report and informant versions available.	PCA[2], varimax rotation, factor extraction eigenvalue> 1.5, item loading ≥ 0.35. Only factors with at least five items are reported.	Self- report version 2 (N/A) Informant version 3 (N/A)	**Self-report:** Anxiety (N/A, N/A, 8 items), Social adjustment (N/A, N/A, 5 items); **Informant:** Affective (N/A, N/A, 14 items), Somatoform (N/A, N/A, 5 items), Psychosis (N/A, N/A, 5 items)
Linaker 1991	N= 169 inpatients; mild= 3.6%, moderate= 20.1%, severe= 50.9%, profound= 15.2%, unknown= 9.7%. Mean age= 40.4 (16-65, SD N/A)	PIMRA- informant version	PCA, varimax rotation, factor extraction eigenvalue> 1.5, item loading ≥ 0.35.	9 (49.3%)	Somatoform (5.06, 10.3%, 8), gender identity (3.68, 7.5%, 3), hostility (3.11 6.3%, 4), psychosis (2.66, 5.4%, 5), self-consciousness (2.29, 4.7%, 4), adjustment problem (2.25, 4.6%, 4), anxiety (1.88, 3.8%, 3), autistic traits (1.69, 3.4%' 3), avoidant/ anxious (1.53 3.1%, 3)
Balboni *et al.* 2000	N=652 mixed sample- community (411) institution (241); mild= 34%,	PIMRA- informant version	PCA, varimax rotation, factor extraction eigenvalue> 1.5, item loading ≥	7 (34.5%)	Anxiety (6.03, 10.8%, 11), Adjustment problem (3.28, 5.9%, 7), Somatoform (2.74, 4.9%, 9), Schizophrenic isolation (2.01, 3.6%, 5), Schizophrenic

	moderate= 39%, severe/profound= 27%. Mean age= 33.6 (17-74, SD N/A)		0.35		bizarreness (1.96, 3.5%, 5), Soundness (1.75, 3.1%, 6), gender identity (1.50, 2.7%, 5)
Gustafsson & Sonnander 2005	N= 101, mixed sample- community (30), institution (71); mild= 25.7%, moderate= 32.9%, severe/profound= 41.4%. Mean age= 50.2 (24-94, SD= 14.3)	PIMRA- informant version	PCA, varimax rotation, factor extraction eigenvalue> 1.5, ≥ 3 items/ factor with loading ≥ 0.4	5 (51%)	Somatoform (4.29, 16.5%, 5), Psychosis (3.17, 12.2%, 7), Psychosexual (2.37, 9.1%, 4), Adjustment problem (1.85, 7.1%, 5), Anxiety (1.56, 6.0%, 5)
Watson *et al.* 1988	N= 160 mixed sample living in community (95) & institutuional (65) settings; borderline= 19.4%, mild= 47.5%, moderate= 33.1%. Mean age= 29.4 (18-67, SD= 11.4)	PIMRA	Self & informant version; PCA, varimax rotation, factor extraction eigenvalue> 1.5, item loading ≥ 0.35	4 (N/A)	**Self- report**: Anxiety ; Social adjustment; Identity/ reality concern; Unlabelled **Informant**: Affective concerns; Social adjustment; Somatoform; Unlabelled (Problem behaviours)
Moss *et al.* 1998	N= 201 community sample; Mean age= 44 (18-83, SD N/A)	PAS-ADD checklist- 29 item screening instrument, completed by	PCA, quartimax rotation, item loading ≥ 0.5	8 (N/A)	Depression (N/A, N/A, 6), Restlessness (N/A, N/A, 4), Phobic anxiety (N/A, N/A, 5), Psychosis (N/A, N/A, 3), Hypomania (N/A, N/A, 3),

		informant to identify possible mental ill-health			Autistic spectrum (N/A, N/A, 3), Depression (N/A, N/A, 2), Non-specific (N/A, N/A, 2)
Sturmey *et al.* 2005	N=226 clinic attendees; mild= 68%, moderate= 20%, severe/profound= 12%. Mean age= 34 (Range N/A, SD= 13.5)	PAS-ADD checklist	PCA, quartimax rotation, factor extraction eigenvalue ≥ 1, item loading ≥ 0.5	9 initially but only 3 factors interpretable (34.6%)	Mood (5.33, 19.7%, 8); Sleep (2.20, 8.1%, 3); Psychosis (1.83, 6.3%, 3)
Hatton & Taylor 2008	N= 1, 115 administrative sample (98% response rate); Mean age= 44.0 (17-92, SD= 15.19)	PAS-ADD checklist	PCA, varimax rotation, factor extraction eigenvalue> 1.0, rotated factors account > 5% variance, sufficient factors included to account > 60% variance	7 (61.25%)	Depression 1 (4.19, 15.50%, 7); Sleep problems (2.46, 9.10, 3); Organic problem (2.35, 8.70%, 4); Panic (2.11, 7.80%, 3); Psychosis (2.09, 7.72%, 4); Hypomania (1.72, 6.37%, 3); Depression 2 (1.64, 6.06%, 2)
Hove & Havik 2008	N= 593 administrative sample (66% response rate); mild= 23%, moderate= 44%, severe= 19%, profound= 14%. Mean age= 42 (18-97, SD= 14.5)	P-AID[3]- 18 checklists of psychpathology and problem behaviours, derived from DC-LD - 260 items rated by informant, scores psychpathology and problem behaviours	PCA of checklist sum scores, varimax rotation, factor extraction eigenvalue ≥ 1, item loading ≥ 0.3	4 (54.9%)	Problem behaviour I -includes OCD (4.56, 17.5%, 7), Anxiety (2.21, 14.5%, 5), Severe psychopathology- depression, dementia, mania, psychosis (1.91, 14.5%, 4), Wandering/ sexual problem behaviours (1.21, 8.2%, 2)
Sturmey *et*	Three samples:	RSMB[4]- 38 item	PCA, varimax	Sample 1= 1 factor	Sample 1: General factor (6.55,

al. 1996	Sample 1 n= 180 community sample, Sample 2 n= 102 college sample, Sample 3 n= 71 institutional sample. Age and ability level N/A	screening instrument for identification of emotional and behaviour problems	rotation, factor extraction eigenvalue> 1.0, item loading ≥ 0.3	(25.2%); Sample 2 & 3= 3 factors (Sample 2 44.2%; Sample 3 41.5%)	25.2%, 26); Sample 2: Extrapersonal maladaptive behaviour (6.24, 24%, 9), Psychosis (2.94, 11.3%, 8), Intrapersonal maladaptive behaviour (2.31, 8.9%, 6); Sample 3: Extrapersonal maladaptive behaviour (5.62, 21.6%, 11), Psychosis (2.91, 11.2%, 10), Intrapersonal maladaptive behaviour (2.26, 8.7%, 8)
Sturmey *et al.* 2003	N= 163 clinic sample; borderline= 3%, mild= 22%, moderate= 28%, severe= 38%, profound= 9%. Mean age= 54 (30-84, SD= 10.7)	MOSES[5]- 40 items of psychopathology & behaviour, interviewer rated based on informant report and observation	PCA, varimax rotation, factor extraction eigenvalue> 1.0, item loading ≥ 0.3	3 (42.2%)	Self- care (8.0, 20.6%, 6), Irritability/ depression (5.6, 14.6%, 11), Withdrawal (2.7, 7.0%, 8)
Sturmey *et al.* 2004	N= 451 institutional sample; severe= 11%, profound= 89%. Mean age= 48 years (Range N/A, SD=15)	DASH-II- 84 items of psychopathology and behaviour	PCA, varimax rotation, factor extraction eigenvalue> 1.5, item loading ≥ 0.35	5 (26%)	Emotional lability/ antisocial (9.1, 11.1%, 9), Langauge disorder (3.9, 4.8%, 4), Dementia/ anxiety (2.9, 3.6%, 7), Sleep disorder (2.8, 3.4%, 3), Psychosis (2.5, 3.1%, 3)
Tsiouris *et al.* 2003	N=92; mild= 24%, moderate= 30.4%, severe= 26%, profound= 10.9%,	CBCPID[6]- 30 items, psychopathology and problem behaviour over past two weeks	PCA, varimax rotation, factor extraction eigenvalue> 1.0, item loading ≥ 0.3	1 (9.4%)	Depression (6, 9.4%, 5)

	unknown= 8.7%. Mean age= 42.6 (Range N/A, SD= 17.4)				
Kellett *et al.* 2004	N=335, sample of clinic attendees with mild intellectual disabilities. Mean age= 33.0 (16-64, SD= 10.65)	BSI- 53 item self-report inventory of psychopathology, rated on five point Likert scale	PCA, varimax rotation, factor extraction eigenvalue> 1.0, item loading ≥ 0.35	8 (50.26%)	Depression (16.19, 30.56%, 13), Anxiety (2.32, 4.39%, 11), Somatisation (1.91, 3.61%, 10), Cognitive impairment (1.73, 3.27%, 8), Suicidal ideation (1.62, 3.06%, 6), Paranoia (1.44, 2.72%, 5), Hostility (1.39, 2.63%, 7), Anger (1.37, 2.59%, 4)

[1] N/A not available from the details provided in the paper

[2] PCA Principal components analysis

[3] P-AID Psychopathology Checklists for Adults with Intellectual Disability

[4] RSMB Reiss Screen For Maladaptive Behaviours

[5] MOSES Multi-dimensional Observational Scale for Elderly Subjects

[6] CBCPID Clinical Behaviour Checklist for People with Intellectual Disabilities

There appear to be some common dimensions identified across studies. Table 1.3 lists those dimensions identified in at least two studies that used different instruments. Additional details of the instruments, dimensional labels and the relevant items of psychopathology extracted in the dimension are also provided.

Table 1.3 Dimensions of psychopathology identified across studies in adults with intellectual disabilities

General description of common factor	Instrument	Dimension name- eigenvalue, % variance, number of items (Authors)
Anxiety	PIMRA-self report	Anxiety- N/A, N/A, 8 (Matson *et al.* 1984)
		Anxiety- N/A (Watson *et al.* 1998)
	PIMRA- informant	Anxiety- 1.88, 3.8%, 3 (Linaker 1991)
		Affective concerns- N/A (Watson et al. 1998)
		Anxiety- 6.03, 10.8%, 11 (Balboni *et al.* 2000)
		Anxiety- 1.56, 6.0%, 5 (Gustafsson & Sonnander 2005)
	P-AID	Anxiety- 2.21, 14.5%, 5 (Hove & Havik 2008)
	DASH-II	Dementia/ anxiety- 2.9, 3.6%, 7 (Sturmey *et al.* 2004)
	BSI	Anxiety- 2.32, 4.39%, 11 (Kellet *et al.* 2004)
Depression	PIMRA- informant	Affective- N/A, N/A, 14 (Matson *et al.* 1984)
	PAS-ADD checklist	Depression 1- N/A, N/A, 6; Depression 2- N/A, N/A/ 2 (Moss *et al.* 1998)
	PAS-ADD checklist	Mood- 5.33, 19.7%, 8 (Sturmey *et al.* 2005)
	PAS-ADD checklist	Depression 1- 4.19, 15.50%, 7; Depression 2- 1.64, 6.06%, 2 (Hatton & Taylor 2008)
	MOSES	Irritability/ depression- 5.6, 14.6%, 11 (Sturmey *et al.* 2003)
	CBCPID	Depression- 6, 9.4%, 5 (Tsiouris *et al.* 2003)
	BSI	Depression- 16.19, 30.56%, 13 (Kellet *et al.* 2004)

Mania/ hypomania	PAS-ADD checklist	Hypomania- N/A, N/A, 3 (Moss *et al.* 1998)
	PAS-ADD checklist	Hypomania- 1.72, 6.37%, 3 (Hatton & Taylor 2008)
Psychosis	PIMRA- informant	Psychosis- N/A, N/A, 5 (Matson *et al.* 1984)
		Psychosis- 2.09, 7.72%, 4 (Linaker 1991)
		Schizophrenic isolation- 2.01, 3.6%, 5 (Balboni *et al.* 2000)
		Schizophrenic bizarreness- 1.96, 3.5%, 5 (Balboni *et al.* 2000)
		Psychosis- 3.17, 12.2%, 7 (Gustafsson & Sonnander 2005)
	PAS-ADD checklist	Psychosis- N/A, N/A, 3 (Moss *et al.* 1998)
	PAS-ADD checklist	Psychosis- 1.83, 6.3%, 3 (Sturmey *et al.* 2005)
	PAS-ADD checklist	Psychosis- 2.09, 7.72%, 4 (Hatton & Taylor 2008)
	RSMB	Psychosis- 2.94, 11.3%, 8 (Sturmey *et al.* 1996)
	DASH-II	Psychosis- 2.5, 3.1%, 3 (Sturmey *et al.* 2004)
Problem behaviours	P-AID	Problem behaviour I (includes OCD)- 4.56, 17.5%, 7 Problem behaviour II- 1.21, 8.2%, 2 (Hove & Havik 2008)
	RSMB	Extrapersonal maladaptive behaviour - 6.24, 24%, 9 Intrapersonal maladaptive behaviour- 2.31, 8.9%, 6 (Sturmey *et al.* 1996)
	DASH-II	Emotional lability/ antisocial- 9.1, 11.1%, 9 (Sturmey *et al.* 2004)
	PIMRA- informant	Unlabelled (problem behaviours)- N/A (Watson *et al.* 1998)
Sleep problems	DASH-II	Sleep- 2.20, 8.1%, 3 (Sturmey *et al.* 2005)
	PAS-ADD checklist	Sleep problems- 2.46, 9.10, 3 (Hatton & Taylor 2008)
		Sleep disorder- 2.8, 3.4%, 3 (Sturmey *et al.* 2004)
Somatoform	PIMRA- informant	Somatoform- N/A, N/A, 5 (Matson *et al.* 1984)
		Somatoform difficulty-N/A (Watson *et al.* 1988)

		Somatoform- 5.06, 10.3%, 8 (Linaker 1991)
		Somatoform- 2.74, 4.9%, 9 (Balboni *et al.* 2000)
		Somatoform- 4.29, 16.5%, 5 (Gustafsson & Sonnander 2005)
	BSI	Somatisation- 1.91, 3.61%, 10 (Kellet *et al.* 2004)
Autism	PIMRA- informant	Autistic traits- 1.69, 3.4%, 3 (Linaker 1991)
	PAS-ADD checklist	Autistic spectrum - N/A, N/A, 3 (Moss *et al.* 1998)
Phobic anxiety/ avoidance	PIMRA- informant	Avoidant/ anxious- 1.53 3.1%, 3 (Linaker 1991)
	PAS-ADD checklist	Phobic anxiety- N/A, N/A, 5 (Moss *et al.*1998)
		Panic- 2.11, 7.80%, 3 (Hatton & Taylor 2008)

From table 1.3, it appears that the dimensions of anxiety, depression, psychosis and problem behaviours are extracted more consistently across studies, using a greater range of assessment instruments of psychopathology. This suggests that these dimensions may have greater validity, compared to the sleep problems, somatoform, autism and phobic anxiety/avoidance dimensions- each of which are only reported across two instruments. However, part of this effect may be explained by the format and content of the specific instruments used in the different studies. For example, the PIMRA only has one question on sleep problems and therefore it is unlikely that a sleep problems dimension would ever be identified using the PIMRA.

A further point of interest is the variation across studies that use the same instrument. Throughout table 1.3, it is evident that even where an instrument identifies a similar dimension across studies, the individual items that load onto the dimension can vary considerably. For example, the anxiety dimension of psychopathology is consistently identified across the studies that use the PIMRA. However, despite some degree of overlap, the individual items that loaded onto the dimension can vary between studies. Examining the three studies that have examined the dimensional structure of the PAS-

ADD checklist, there appears to be greater consistency in the items that load on to the relevant dimensions.

The significant variation between samples is relevant. The inclusion of only inpatients (Linaker 1991), or participants with mild intellectual disabilities (Kellett *et al.* 2004) most clearly affects the generalisability of results. The samples in other studies vary considerably in sampling strategy, the distribution of level of intellectual disabilities and age. This variation in samples will interact with the wide variation in content, and approach of the instruments used to assess psychopathology across the studies in table 1.2. For example, the use of a self report instrument with participants who have mild intellectual disabilities (Kellet *et al.* 2004) is likely to produce very different results to a study using a sample of adults with severe or profound intellectual disabilities, in which paid carers provide proxy reports of psychopathology (Sturmey *et al.* 2004). Assessing psychopathology across a range of developmental samples is a challenge in any study. Potentially, at least, this is a reason for further research to examine dimensional models of psychopathology in persons with intellectual disabilities.

With regard to the assessments of psychopathology, it is also worth noting that the only instruments assessing psychopathology for which there is more than one relevant published study are the PIMRA and PAS-ADD checklist. The PIMRA and the PAS-ADD checklist are screening instruments, and the PAS-ADD checklist includes a restricted range of psychopathology (29 items of psychopathology). Therefore, no comprehensive assessment of psychopathology has more than one exploratory factor analysis reported in the literature.

A final point of note is that all the studies in table 1.2 use PCA as the method of factor analysis. However, PCA was designed for use with continuous variables and the variables in all the psychopathology instruments of assessment in table 1.2 are categorical- either binary or ordinal. The use of PCA in factor analyses of categorical variables has been shown to identify unstable and unreliable models (Linting *et al.* 2007). Therefore, specific methods of factor analysis using categorical variables have been developed (Wood *et al.* 2002; Meulman & Heiser 2004). Since these methods

were not used in the studies in table 1.2, the models are likely to have limited reliability and stability.

Overall, relatively few studies have used factor analysis to examine the dimensions of psychopathology in adults with intellectual disabilities and there are methodological limitations and variation across studies.

1.7 The associations of psychopathology with socio-clinical variables

The studies in section 1.5.2 that compared the associations of dimensional and categorical models of psychopathology with the severity and outcome of mental disorders controlled for a small number of potential confounders, such as gender, age, occupational status and ethnicity (van Os *et al.* 1999a; van Os *et al.* 1999b). Therefore, the evidence on the association of socio-clinical variables with psychopathology in adults with intellectual disabilities was reviewed.

Population based studies of adults with intellectual studies are less likely to report findings significantly affected by sampling bias. Therefore, table 1.4 summarises the findings from studies that used population based samples to examine the independent associations of socio-clinical variables with psychopathology. The majority of studies in table 1.4 identified used categorical diagnostic classification systems, although two studies used continuous measures, not derived empirically using multivariate statistics (Taylor *et al.* 2004; Hove & Havik 2010).

Several socio-clinical variables were associated with psychopathology across studies in table 1.4- gender, age, living circumstances, level of intellectual disabilities, epilepsy and Down syndrome. These are examined separately in more detail below, followed by a discussion of the other socio-clinical variables shown to be less consistently associated with psychopathology.

Table 1.4: Population based studies examining the associations of psychopathology and socio-clinical variables

Authors	Sample (percentage of identified population)	Measure of psychopathology	Socio-clinical variables included in analysis	Socio-clinical variables significantly associated with psychopathology
Cooper & Bailey (2001)	A random sample of 207 adults from the Leicestershire Learning Disabilities Register. 109 men and 98 women. Mild ID[1]14.2%, moderate 22.2%. severe 40.3% and 23.3% profound.	Psychiatric disorder diagnosed with the Diagnostic Criteria for Research- ICD-10.	Level of intellectual disabilities-	Lower ability level associated with a greater risk of having a diagnosed psychiatric disorder.
Taylor *et al.* (2004)	1115 (98%) adults. 664 men, 491 women. Mean age= 43.97 (SD±15.19 years, range 17-92).	PAS-ADD checklist subscales: • affective/ neurotic • psychosis • organic	age; gender, residence type	Female gender- affective/ neurotic Younger age- affective/ neurotic Living in hospital- psychosis
Cooper *et al.* 2007a; Cooper *et al.* 2007b; Cooper *et al.* 2007c; Jones *et al.* 2008	1023 adults (562 men, 461 women; mean age= 43.9 ±12.6 years: mild ID 38.9%, moderate 24.2%, severe 18.9%, profound ID18.0%	[2] Mental ill health (excluding specific phobias and autism spectrum disorders) [3] Psychotic disorder [4] Current DC-LD depressive episode [5] DC-LD problem behaviours	age; gender; marital status; level of ability; presence of visual impairment; presence of hearing impairment; presence of epilepsy; presence of severe physical disabilities (quadriplegia); presence of mobility impairment; presence of communication impairment; presence of incontinence of urine; presence of incontinence of bowels; type of living or support arrangement; whether previously a longstay hospital resident, area-based measure of deprivation for the area in which the	[2] Female gender, lower ability level, number of life events, number of GP appointments, severe physical disability/ quadriplegia, not having mobility problems, urinary incontinence, smoker, living with a paid carer (rather than living with a family carer) [3] Visual impairment, ex long-stay hospital resident, smoker, not having epilepsy [4] Female gender, number of life events, number of GP appointments, not having a

			person lived; whether the person had any type of daytime occupation; number of consultations with the general practitioner or family physician within the preceding 12-month period; number of hospital admissions in the preceding 12-month period; number of life events in the preceding 12-month period; whether the person smoked	hearing impairment, smoker [5] Male gender, lower ability level, living in a congregate care setting, or with paid carer support (rather than living with a family carer), having attention deficit hyperactivity disorder (ADHD), urinary incontinence, visual impairment, not having Down syndrome, not having severe physical disability/ quadriplegia.
Bailey 2007	Random sample of 121 adults with moderate- profound ID. Men 62.0% and women 38.0%. (Mean age = 38.5 years, SD= 1.30, range 20-77).	Diagnosed with a mental disorder using DC-LD criteria	Age; gender; developmental age in months; life event in last year; number of professionals, apart from GP involved in care; number of antipsychotic medications, number of physical illnesses; HoNOS[6] score; HoNOS-LD[7] score.	Higher HoNOS score and lower developmental age were associated with diagnosis of mental disorder.
Hassiotis *et al.* 2008	105 adults with borderline ID from the British National Survey of Psychiatry Morbidity (69 men, 46 women) of specialist intellectual disability mental health services.	Common mental disorders (agoraphobia, any phobia, depressive episode)[8]	age; gender; social class; marital status; ethnicity; education level; debts; income support	1.Younger age 2. Female gender 3. Asian ethnicity 4. Social class 5. Debts 6. Receiving income support

Hove & Havik (2010)	593 (65.8%) adults. 315 men, 278 women; mean age 41.8 (SD = 14.53, range 18–97). mild ID 21.6%, moderate 41.0%, severe 18.0% and profound ID 13.0%	P-AID checklists for: • dementia • psychosis • depression • mania • anxiety disorders • problem behaviours • overall mental ill-health[9]	age; gender; autism, genetic syndrome; neurological conditions; level of intellectual disabilities	1. Older age- dementia 2. Younger age- problem behaviour 3. Autism- psychosis, anxiety, OCD[10], problem behaviour, overall mental ill-health 4. Genetic syndrome- dementia 5. No neurological condition- anxiety 6. Social care- dementia, psychosis, depression, mania, anxiety disorders, problem behaviours, overall mental ill-health 7. More severe ID- anxiety, OCD, problem behaviours, overall mental ill-health

[1] ID Intellectual disabilities

[2] Cooper *et al.* 2007a

[3] Cooper *et al.* 2007b

[4] Cooper *et al.* 2007c

[5] Jones *et al.* 2008

[6] HoNOS Health of the Nation Outcome Scale (Wing *et al.* 1998)

[7] HoNOS-LD Health of the Nation Outcome Scale- Learning Disabilities (Roy *et al.* 2002)

[8] Diagnosed with ICD-10

[9] Total score from sum of individual checklists

[10] OCD Obsessional Compulsive Disorder

1.7.1 Psychopathology and gender

Female gender was found to be associated with an increased risk of having a diagnosed mental disorder (Cooper *et al.* 2007a), affective/ neurotic psychopathology (Taylor *et al.* 2004; Cooper *et al.* 2007c; Hassiotis *et al.* 2008) and problem behaviours (Jones *et al.* 2008). Thus it appears that similar to findings from studies involving adults who do not have intellectual disabilities (Kessler *et al.* 1993; Bijl *et al.* 2002; Kessler *et al.* 2005), women with intellectual disabilities experience higher rates of affective/ neurotic psychopathology.

Relevant to this thesis, an argument has been made that the use of categorical diagnostic classification systems may contribute to bias in the studies that find significant gender differences. It is suggested that the criteria within certain categorical diagnoses may preferentially represent the presentation of psychopathology for either women or men (Hartung & Widiger 1998). Indeed, whereas higher prevalence rates of depressive disorders are consistently found in studies using categorical models of depressive psychopathology, this was not the case in a study comparing dimensional and categorical models of psychopathology (Hildebrandt *et al.* 2003).

1.7.2 Psychopathology and age

The relationship between age and psychopathology is of particular relevance to fields of study that make use of developmental models of psychopathology, such as intellectual disabilities and the study of mental disorders experienced by children and adolescents.

The overall risk of having any diagnosed mental disorder was not independently associated with age in the population based epidemiological studies in table 1.4 (Bailey 2007; Cooper *et al.* 2007a). This contrasts from studies of adults who do not have intellectual disabilities where the overall rates of mental disorders decrease with increasing age (Kessler *et al.* 1993; Bijl *et al.* 2002).

For more specific psychopathology, younger age in table 1.4 was associated with affective/ neurotic psychopathology (Taylor *et al.* 2004; Hassiotis *et al.* 2008) and problem behaviours (Hove & Havik 2010). Older age was found to be associated with organic disorders (specifically dementia) in one study (Hove & Havik 2010) but not another (Taylor *et al.* 2004).

1.7.3 Psychopathology and living circumstances

It appears from the studies outlined in table 1.4 that living in circumstances with some degree of paid support is independently associated with psychopathology. Comparison between the studies is made difficult by the different samples, measures of psychopathology and descriptors of living circumstances used. However, living in hospital was found to be associated with psychosis (Taylor *et al.* 2004); compared to individuals living with family carers, living in a congregate setting such as nursing home was associated with problem behaviours (Jones *et al.* 2008) and individuals living with paid carer support were more likely to be diagnosed with any mental disorder (Cooper *et al.* 2007a) and problem behaviours (Jones *et al.* 2008).

It is difficult to be clear about the direction of the association between psychopathology and living circumstances. On the one hand, perhaps individuals experiencing psychopathology are more likely to move to circumstances in which they receive some degree of paid support as part of a management plan. Alternatively, there could be factors associated with living with paid support that increase an individual's risk of psychopathology, or act as precipitants for mental disorders. Either way, the findings from the studies to date highlight the relevance of studying further these associations.

1.7.4 Psychopathology and level of intellectual disabilities

As well as highlighting the need to examine the relationship between age and psychopathology, the use of developmental models of psychopathology in the field of intellectual disabilities also places a focus on the need to understand how psychopathology relates to an individual's level of intellectual disabilities.

In table 1.4, lower ability level was associated with increased risk of having any mental disorder (Cooper & Bailey 2001;Cooper *et al.* 2007a; Bailey 2007; Hove & Havik 2010), and problem behaviours (Jones *et al.* 2008, Hove & Havik 2010).

There are concerns that existing categorical diagnostic classification systems may be less reliable and valid when used to understand psychopathology in individuals with severe and profound intellectual disabilities. As described in section 1.5.1, a potential strength of dimensional models of psychopathology is their applicability across the range of developmental levels across childhood and adolescence (Achenbach, Edelbrock & Howell 1987; van der Oord, Koot *et al.* 1995; Leung & Wong 1998; Krenke & Kollmar 1999). The functional range of abilities of adults with mild-profound intellectual disabilities can be conceptualised as similar to the developmental levels across childhood and adolescence (World Health Organisation 1994). Therefore, it is noteworthy in table 1.4 that few studies have examined the relationship between dimensional models of psychopathology and level of intellectual disabilities. Two studies use specific psychopathology checklists of symptoms (Taylor *et al.* 2004; Hove & Havik 2010) but only the study using the P-AID checklists examines the association between psychopathology and level of intellectual disabilities (Hove & Havik 2010). Given the potential advantages to, and the limited number of studies, using dimensional models of psychopathology across the full range of abilities there is a clear need for further work in this area.

1.7.5 Psychopathology and epilepsy

Epilepsy is the clinical variable most often examined against psychopathology in epidemiological studies. In table 1.4 it was not having epilepsy that was independently associated with a higher risk of psychosis (Cooper *et al.* 2007b) and anxiety (Hove & Havik 2010).

No studies explicitly using dimensional models of psychopathology to examine the association with epilepsy were identified. However, a different approach was adopted in a population based study, which used data from the Leicestershire Learning Disability Register to examine the relationship between epilepsy and individual

psychological symptoms and problem behaviours (McGrother *et al.* 2006). Adjusting for age, sex and level of understanding (based on three categories describing an individual's understanding of verbal communication), epilepsy was significantly associated with having one or more psychological symptoms, experiencing mood swings, or lethargy. Reporting any type of problem behaviour, or the specific behaviours- attention seeking, night-time disturbance, and uncooperative behaviours- were also significantly associated with epilepsy. Given the inconsistent findings from studies using categorical models of psychopathology, this study suggests the potential value of using alternative models of psychopathology to examine the relationships with clinical variables, such as epilepsy.

1.7.6 Psychopathology and Down syndrome

Individuals with Down syndrome were found to have lower rates of problem behaviours (Jones *et al.* 2008), and higher levels of organic psychopathology (Hove & Havik 2010) in the studies summarised in table 1.4.

There were no significant associations between overall risk of mental disorders and Down syndrome in table 1.4. However, two other population based studies, have suggested that adults with Down syndrome experience lower rates of mental disorders than adults with intellectual disabilities who do not have Down syndrome (Mantry *et al.* 2007; Morgan *et al.* 2008). This confirms the findings from several previous studies that, similarly, used categorical models of psychopathology (Myers & Pueschel 1991; Collacott *et al.* 1992; Haveman *et al.* 1994).

Apart from the Norwegian study above (Hove & Havik 2010), relatively few studies have examined psychopathology in adults with Down syndrome and intellectual disabilities using dimensional or continuous models of psychopathology. On the basis of the association of Down syndrome and dementia, several studies have examined qualitative differences in the organic psychopathology in adults with Down syndrome relative to comparison groups (Cooper & Prasher 1998; Ball *et al.* 2006; Deb *et al.* 2007). However, no other studies were identified that used other dimensions of psychopathology, in adults with Down syndrome.

1.7.7 Psychopathology and other socio-clinical variables

Sections 1.7.1- 1.7.6 above considered those variables identified as significantly associated with psychopathology across more than one of the population based studies in table 1.4. However, there are other socio-clinical variables identified as potentially relevant by a significant association in a single study.

1.7.7.1 Psychopathology and autism

Autism was found to be associated with higher scores on checklists for psychosis, OCD, anxiety, problem behaviours and overall mental ill-health (Hove & Havik 2010). However, another study did not find an independent association between autism and problem behaviours (Jones *et al.* 2008). The two studies that reported contrasting findings on problem behaviours used different methods to identify a diagnosis of autism. One study used carer report of a known diagnosis of autism (Hove & Havik 2010), whilst the diagnosis was made as part of a comprehensive psychiatric assessment, using a structured checklist of ICD-10 criteria in the second study.

One other study using continuous models of psychopathology was identified reporting psychopathology in adults with autism and intellectual disabilities (Hill & Furniss 2006). They studied 82 individuals with autism and intellectual disabilities, and examined psychopathology using the DASH-II (Matson *et al.* 1991). Compared to participants with intellectual disabilities who di not have autism, individuals with autism were found to have higher mean scores on the DASH-II subscales representing organic, anxiety, mania, PDD/ autism and stereotypy dimensions of psychopathology (Hill & Furniss 2006). This study is included because it used a continuous measure of psychopathology, which is closer to a dimensional model than the categorical diagnoses used in the majority of studies in table 1.4. However, since this study used a clinic sample, the likely sampling bias makes the findings less reliable than reported in the population based studies.

Looking further at studies using a categorical model of psychopathology, an analysis was done using the Glasgow data (Cooper *et al.* 2007a) using a matched control

design to examine the prevalence and incidence of mental disorders in adults with autism and intellectual disabilities (Melville *et al.* 2008). No difference in the prevalence, or incidence of any mental disorder, or problem behaviours was found between the participants with autism and intellectual disabilities, compared to the participants with intellectual disabilities who do not have autism. Overall then, there remains some ambiguity about the exact association between autism and psychopathology. However, from the findings described above it appears that continuous models of psychopathology are of potential relevance.

1.7.7.2 Psychopathology and sensory impairments, incontinence and mobility

Fewer studies have examined the relationships between psychopathology and sensory impairments, mobility problems and incontinence in adults with intellectual disabilities.

From the Greater Glasgow population based epidemiological studies using categorical models of psychopathology in table 1.4, there is evidence for an independent association between urinary incontinence and the risk of any mental disorder (Cooper *et al.* 2007a) and problem behaviours (Jones *et al.* 2008). An association between urinary incontinence and mental disorders has also been described in adults who do not have intellectual disabilities (cited in Mantry *et al.* 2008).

From the Glasgow studies, the associations with mobility problems, visual impairment, and hearing impairment are more complex. There is an association between having a visual impairment and psychosis (Cooper *et al.* 2007b) and problem behaviours (Jones *et al.* 2008). However, the association is reversed for mobility problems and hearing impairment. There is an independent association between not having mobility problems and being diagnosed with any mental disorder (Cooper *et al.* 2007a), and not having a hearing impairment and affective disorders (Cooper *et al.* 2007c).

There is a higher prevalence of sensory impairments in adults with intellectual disabilities. Some evidence suggests that there is an association between

psychopathology and hearing (van Gent *et al.* 2007) and visual impairments (Lupsakko *et al.* 2002) in individuals who do not have intellectual disabilities. However, no studies were identified showing a significant association between categorical models of psychopathology and sensory impairments in adults with intellectual disabilities (Carvill 2001).

Overall, there is limited evidence for a relationship between psychopathology and sensory impairments, continence and mobility problems in adults with intellectual disabilities. Since dimensional models of psychopathology may have greater power when examining correlations between variables (Cohen 1983; MacCallum *et al.* 2002), it may be particularly useful to explore the relationships between variables for which there is less evidence of an association with psychopathology. Therefore, the relationships between psychopathology and visual impairment, hearing impairment, mobility problems, urinary and bowel incontinence will be examined in this thesis.

1.7.8 Summary of findings on socio-clinical variables associated with psychopathology in intellectual disabilities

The evidence suggests that socio-clinical variables likely to be associated with psychopathology are gender, age, living circumstances, level of intellectual disabilities, a diagnosis of autism, Down syndrome, epilepsy, visual impairment, hearing impairment, mobility problems, urinary incontinence and bowel incontinence. These are potential confounders in the relationship between psychopathology and the severity and outcome of mental disorders.

1.8 Psychopathology and measures of the severity of mental disorders

General research suggests that, compared to categorical models of psychopathology, dimensional models may be more strongly associated with measures of severity. This section, examines the evidence for the relationship between psychopathology and the severity of mental disorders experience by adults with intellectual disabilities.

A single instrument was used to measure the severity and outcome of mental disorders for example in the studies comparing dimensional and categorical models of

psychopathology from the UK700 study (van Os *et al.* 1999a; van Os *et al.* 1999b). The term severity of mental disorders is used to describe a cross-sectional measure. Longitudinal outcome is the term used to describe results from a follow-up study, where a measure is completed on at least two occasions. Studies examining the longitudinal outcome in intellectual disabilities are examined in section 1.9.

No intellectual disabilities studies comparing the associations between dimensional and categorical models of psychopathology with severity of mental disorders were identified. Indeed, few studies have sought to understand how psychopathology relates to the severity of mental disorders experienced by adults with intellectual disabilities. To take account of the limited evidence–base, it is necessary to consider the results from a broader range of studies than would be necessary in other fields of research, for example, the studies which are not primarily designed to answer questions relating to psychopathology and severity, or have samples including persons with intellectual disabilities and other cognitive impairments (Endermann & Zimmermann 2009). Nonetheless, these studies offer some insight into our current understanding of the relationship between psychopathology and the severity of mental disorders.

Quality of life was the measure of severity of mental disorders used in the studies summarised in table 1.5. These three studies used continuous measures of psychopathology, derived from the use of structured instruments for the assessment of psychopathology.

Table 1.5: Cross sectional studies reporting the associations between psychopathology and measures of severity for individuals with intellectual disabilities

Authors	Sample	Measures of severity	Variables included in analysis	Significant correlates of outcome	Comments
Lunsky & Benson 2001	84 adults with mild intellectual disabilities living in the community. 41 men, 43 women; mean age=38 years (range 20-65).	Quality of Life Questionnaire[1] (QoLQ)	1. Depressive psychopathology- Birleson Depressive Short Scale[2] (BDS-S) 2. Social support self-report for mentally retarded adults[3] (SSSR) 3. Residential loneliness questionnaire[4] (RLQ) 4. Social strain- Inventory of Negative Social Interactions[5] (INSI)	1. SSSR (r=.23, p<.05) 2. RLQ (r=-.28, p<.05) 3. BDS-S (r=-.55, p<.001)	Only bivariate correlation results for the depressive psychopathology variable are reported in the paper
Beadle-Brown *et al.* 2009	86 adults with intellectual disabilities followed up over 25 years (Original Camberwell cohort- 166 children with intellectual disabilities living in a defined geographical area	Quality of Life-Lifestyle Satisfaction Scale[6] (LSS)	1. Skills & behaviour Schedule of Handicaps Behaviours and Scales[7] (HBS) 2. Adaptive functioning- Adaptive Behaviour Skills- part 2 (ABS)[8] 3. Performance IQ 4. Type of residential placement	1. ABS (t=2.347, p<.05) 2. IQ below 50 (t=-3.295, p<.001) 3. Presence of problem behaviour (t=-2.206, p<.05)	Proxy respondents completed the LSS for 72 (84%) of the sample. Small study of inter-rater reliability showed that proxy responses had good level of agreement with responses from participants with mild intellectual

	in London. Mean age=34 years (SD=4.3; range 27-41)		5. Social impairment 6. Presence of challenging behaviour (Y/N) 7. IQ below 50		disabilities.
Endermann & Zimmermann (2009)	36 individuals (90% of total population) admitted, in 2005, to specialist epilepsy unit for individuals with cognitive impairments. 22 men, 14 women; mean age= 25.6 years (S.D. = 6.0; median = 24.0; range = 18–40)	Health Related Quality of Life (HRQoL)- Quality of Life in Epilepsy Inventory -31 (QOLIE-31)[9]	1. Age at onset of epilepsy 2. Number of different seizure types 3. Duration of epilepsy 4. Number of AEDs 5. Neuroticism- NEO-FFI 6. Anxiety- HADS[10] 7. Depression- HADS	Lower HRQoL: 1. Younger age at onset of epilepsy (β=-.27, $p<.05$) 2. Higher neuroticism- NEO-FFI [11](β=-.72, $p<.001$)	Neuroticism, anxiety and depression were all significantly correlated ($p<.001$) with HRQoL in the bivariate analyses, so only neuroticism was used in the multivariate analysis. The assumption is made that the results would have been the same if anxiety or depression had been used.

[1] Schalock & Keith 1993
[2] Birleson 1981
[3] Lunsky & Benson 1997
[4] Chadsey-Rusch *et al.* 1992
[5] Lakey *et al.* 1994
[6] Harner & Heal 1993
[7] Wing & Gould 1978
[8] Nihira *et al.* 1993
[9] Cramer *et al.* 1998
[10] HADS: Hospital Anxiety and Depression Scale (Zigmond & Snaith 1983)
[11] NEO-FFI: Neo- Five Factor Inventory (Costa Jr & McCrae 1989)

The only finding reported across more than one study is the significant correlation between depressive psychopathology and lower quality of life in adults with mild intellectual disabilities (Lunsky & Benson 2001; Endermann & Zimmermann 2009). One study found that a measure representing the anxiety dimension of psychopathology (Endermann & Zimmermann 2009), and another that the presence of problem behaviour (Beadle-Brown *et al.* 2009), are correlated with measures of severity.

These studies are limited in the scope of the evidence they provide on the relationship between psychopathology and measures of severity. Firstly, each of the three studies only uses one measure of severity, which is a quality of life measure in all three studies. This is an issue because it is generally recognised that there are advantages to the use of multiple measures of severity and outcome (Slade 2002). The second limitation is related to the limited range of psychopathology included in the analyses. None of the studies have used a broad measure of psychopathology, and two studies have only included a measure of a single form of psychopathology (Lunsky & Benson 2001: Beadle-Brown *et al.* 2009). As a consequence there are unanswered questions about the relationship between different types of psychopathology and severity-specifically with reference to problem behaviours and other psychopathology. Finally, the findings are limited by aspects of the samples used. Only the study by Beadle-Brown *et al.* (2009) used participants with a range of abilities. The other two studies were limited to participants with mild intellectual disabilities (Lunsky & Benson 2001; Endermann & Zimmermann 2009) and Endermann & Zimmermann (2009) only included individuals with complex epilepsy. Given these limitations, combined with the small number of studies, caution is needed regarding the generalisability of the findings.

In terms of other variables found to be associated with severity, the main finding of interest is that a lower level of adaptive functioning and lower IQ was correlated with increased severity (Beadle-Brown *et al.* 2009). This could not be examined in the two other studies which were limited to participants with mild intellectual disabilities (Lunsky & Benson 2001; Endermann & Zimmermann 2009).

There is a far larger body of evidence examining the cross-sectional correlations between variables that correlate with quality of life than is shown in table 1.5 (Schalock 2004). However, these are the only studies identified that included some measure of psychopathology in the analysis. This is surprising as research that involves adults with mental disorders who do not have intellectual disabilities has closely studied the relationship between psychopathology and quality of life (Ruggeri *et al.* 2002; Eack & Newhill 2007) as well as other measures of severity (Malla *et al.* 2002; Drukker *et al.* 2008). Such work has offered insights into the extent to which psychopathology contributes to the severity of a disorder, or need for care.

1.8.1 Summary of findings on the association of psychopathology and the severity of mental disorders in intellectual disabilities

Overall, there is limited evidence on the relationship of psychopathology and the severity of mental disorders experienced by adults with intellectual disabilities. No studies comparing the associations between dimensional and categorical models of psychopathology with severity of mental disorders were identified. However, using continuous measures, depressive, anxiety and problem behaviour psychopathology were associated with greater severity. Increased severity of intellectual disabilities may be associated with the severity of mental disorders.

1.9 Psychopathology and the longitudinal outcome of mental disorders

The final area where dimensional models of psychopathology have been found to be of interest is in studying the relationships between psychopathology and longitudinal outcome.

No studies of the associations between dimensional models of psychopathology and longitudinal outcome in adults with intellectual disabilities and mental disorders were identified. Therefore, to describe the evidence base that psychopathology is related to outcome of mental disorders experienced by adults with intellectual disabilities, the findings from two types of longitudinal studies are discussed:

- studies of adults with intellectual disabilities and mental disorders using specific clinical services

- examining childhood psychopathology, and other socio-clinical variables, as predictors of adult outcomes.

1.9.1 Longitudinal studies examining psychopathology in users of specific clinical services

The studies identified, which consider the association between psychopathology and outcome, are limited to studies of users of inpatient services for adults with intellectual disabilities and mental disorders. The three studies are summarised in table 1.6.

Table 1.6: Studies reporting psychopathology as a predictor of outcome for individuals with intellectual disabilities

Authors	Sample	Measures of outcome (duration of follow-up)	Predictors of outcome included in analysis	Significant predictors of outcome (t, p)	Comments
van Minnen *et al.* 1997	50 individuals mild intellectual disabilities, randomised to inpatient (20 men, 5 women; mean age=31.4±12.6 years) or outreach (18 men, 7 women; mean age=31.0±10.8 years) treatment.	Combined score from the PIMRA and RSMB (28 weeks)	1. Psychopathology- combined PIMRA & RSMB score 2. Aggressive behaviour- SAB[1] 3. Social competence- SCS[2] 4. Previous hospitalizations at baseline	1. Aggressive behaviour- SAB (-3.14, .003) 2. Social competence- SCS (2.03, .049) 3. Previous hospitalizations at baseline (1.99, .052)	The analysis examining predictors of outcome included participants in both treatment groups Final model explained 46% of the variance in the outcome.
Xenitidis *et al.* 2004	71 individuals admitted to inpatient services over 35 month period (36 men, 35 women. Mean age=34.55 years (SD ±13.11); Mild ID= 58, Moderate= 10, Severe= 3	1. Total number of symptoms on the PAS-ADD[3] 2. Disability- total DAS[4] score 3. Behavioural impairment- DAS-behavioural score 4. Overall functioning- GAF 5. Severity of Mental Health Problem- total TAG[5] score (12 months)	1. Gender 2. Age 3. Psychopathology- total PAS-ADD symptoms 4. Autism 5. Epilepsy 6. Length of inpatient stay 7. Diagnosis of psychosis 8. Legal status	None	Outcome measure was calculated as mean of baseline and follow-up score. Each of the 5 outcome measures used as dependant variable in multivariate analyses to examine predictors of outcome

Spiller *et al.* 2007	Random sample of 115 users (69 men, 46 women) of specialist intellectual disability mental health services. Mild ID = 72, moderate= 29, severe= 14.	Service consumption	1. ICD-10 categorical diagnosis 2. Psychosis symptom score 3. Affective/ neurotic symptom score 4. Organic symptom score 5. Gender 6. Age 7. Ethnicity 8. Level of ID 9. Residence type 10. Contact with behaviour support team	Heavy service use associated with: 1. Diagnosis of schizophrenia spectrum disorder (F20-27) 2. Higher baseline affective/ neurotic symptom score	Categorical diagnoses made by two consultant psychiatrists based on data from a standardised assessment.. Affective/ neurotic, organic and psychotic psychopathology scores were calculated from the PAS-ADD checklist completed by an informant.

[1]SAB Scale for Aggressive Behaviour for People with Mental Retardation (Kraijer & Kema 1981)

[2] SCS Social Competence Sclae for People with Mental Retardation (Kraijer & Kema 1981)

[3] PAS-ADD Psychiatric Assessment Schedule for Adults with Developmental Disability (Moss *et al.* 1997)

[4] DAS Disability Assessment Scale (Holmes *et al.* 1982)

[5] TAG Threshold Assessment Grid (Slade *et al.* 2000)

Although there are different findings across the three studies, the results are of interest to examining the relationship between psychopathology and longitudinal outcome. Therefore, it is worth examining the methodology and results of the studies in more detail (Van Minnen *et al.* 1997; Xenitidis *et al.* 2004, Spiller *et al.* 2007). To summarise the results:

- two studies found that general measures of psychopathology were not predictive of outcome (Van Minnen *et al.* 1997; Xenitidis *et al.* 2004)
- higher scores on a continuous measure of neurotic/ affective psychopathology and a categorical diagnosis of a schizophrenia spectrum disorder predicted increased service use, but not continuous measures of psychosis and organic psychopathology (Spiller *et al.* 2007)
- only one study included problem behaviour at baseline as an independent variable, and found it predicted poorer outcome (Van Minnen *et al.* 1997)

The only consistent finding across studies was that an overall measure of psychopathology- measured with the PIMRA and RSMB in one study (Van Minnen *et al.* 1997) and the PAS-ADD in another (Xenitidis *et al.* 2004)- was not associated with longitudinal outcome. Since the measures of psychopathology used in these studies were incorporated into the measures of outcome at follow up, it is surprising that neither study found a significant association. One possible explanation relates to the process used to complete the measures of psychopathology and the reliability of the measures. Both studies collected data prospectively, but it is not clear whether the same raters completed the measures at baseline and follow-up. The inter-rater reliability of the psychopathology items on the Dutch version of the PIMRA (van Minnen *et al.* 1994) and RSMB (van Minnen *et al.* 1995), and the PAS-ADD (Moss *et al.* 1998) have all been shown to be low. Such low reliability could affect the findings of prospective follow-up studies, and may explain the absence of a correlation between psychopathology at baseline and follow-up.

In keeping with the finding in the cross-sectional study by Endermann & Zimmermann (2009) discussed in section 1.8, a continuous measure of neurotic/ affective psychopathology was found to be significantly associated with outcome in users of specialist intellectual disabilities mental health services (Spiller *et al.* 2007). It

is noteworthy that the psychosis and organic dimensions of psychopathology did not predict outcome (Spiller *et al.* 2007). Since only 7 (6.2%) of the participants had a diagnosis of dementia, the reason that the organic dimension of psychopathology did not predict outcome may be due to the small number of participants with psychopathology on this dimension. However, as 28 (24.3%) of participants were diagnosed with a schizophrenia spectrum disorder (ICD-10 categories F20-27) this is unlikely to be the case for the psychosis dimension of psychopathology. and furthermore, the categorical measure of psychosis did predict outcome. A more likely explanation is that the psychosis dimension on the PAS-ADD checklist comprises only three items (suspicious/ paranoid; strange experiences; strange beliefs) whereas the neurotic/ affective dimension has 19 individual items of psychopathology (Moss *et al.* 1998). The lack of coverage of psychosis psychopathology has been previously recognised (Cooper *et al.* 2007a) and makes it likely that even individuals with active psychosis may not score on this psychopathology dimension of the PAS-ADD checklist. A specific measure of problem behaviours was also associated with outcome (van Minnen *et al.* 1997). However, these findings are as likely to be affected by issues related to inter-rater reliability described previously.

A final point of interest from table 1.6 is the differing result for the two studies that examine level of ability as a predictor of outcome (Van Minnen *et al.* 1997; Spiller *et al.* 2007). Although not identical to level of intellectual disabilities, a measure of social competence was found to be a significant predictor of outcome in the study by van Minnen *et al.* (1997); whilst level of intellectual disabilities did not predict outcome in the study by Spiller *et al.* (2007). Although it did not include any measure of psychopathology in the analysis, one other study has examined the specific question of whether individuals with more severe intellectual disabilities have poorer outcomes from the use of a specialist inpatient service (Lunsky *et al.* 2010). This study found that the GAF score at follow up was significantly correlated with the binary measure of the level of intellectual disability (mild, moderate/severe). Participants with mild intellectual disabilities experienced a significant improvement in the GAF score, but participants with moderate/ severe intellectual disabilities did not. However, the authors conclude that the between groups differences in the change in the GAF is attributable to a lack of sensitivity of the GAF when used to measure outcome in

individuals with more severe intellectual disabilities. From the description of the methods used to score the GAF, it appears that the effect of a person's intellectual disabilities on functioning was used in scoring the GAF. A potential solution to this problem, as described in section 3.4.3.3, is the use of the modified scoring system (Hurley 2001).

The suggestion that lower ability levels are associated with increased severity of mental disorders has been described in the study by Beadle-Brown *et al.* (2009) in section 1.8, and van Minnen *et al.* (1997) and Lunsky *et al.* (2010) in this section. However, since Lunsky *et al.* (2010) discount their finding that more severe intellectual disabilities is predictive of poorer outcome on methodological grounds, and Spiller *et al.* (2007) did not find that level of intellectual disabilities predicts outcome, the exact relationship between level of intellectual disabilities and outcome requires further study.

1.9.2 Longitudinal studies examining childhood psychopathology and outcomes in adulthood

The results presented in this thesis relate to psychopathology and outcomes in adulthood. Therefore, studies that follow-up children with intellectual disabilities do not provide directly comparable findings. In particular, the measures used to assess psychopathology in childhood and the length of follow up affect the generalisability of the results to the work of this thesis. Furthermore, since three of the studies in table 1.7 below use psychopathology as the adult measure of outcome these studies could be considered as studies of the stability of psychopathology. Despite these limitations, given the small number of relevant studies on psychopathology and outcome it is worth considering the evidence from longitudinal studies from childhood to adulthood.

Overall, it appears from the results of the studies in table 1.7, that socio-economic disadvantage in childhood (McCarthy 2008) and level of ability (Maughan *et al.* 1999; McCarthy 2008; Beadle-Brown *et al.* 2009) are potentially more important childhood predictors of adult outcome than psychopathology.

Table 1.7: Longitudinal studies reporting childhood psychopathology, and other variables, as predictors of adult outcomes

Authors	Sample	Measures of outcome	Childhhood variables included in analysis	Significant predictors of outcome	Comments
Maughan *et al.* (1999)	122 adults with mild intellectual disabilities interviewed at age 33 years (51% of 275 in original birth cohort). 49 men, 51 women.	Adult Psychopathology-Malaise Inventory (Rodgers *et al.* 1999)	1. Childhood social disadvantage[1] 2. Childhood sensory and neurological impairment 3. General level of ability in childhood-reading comprehension and mathematics 4. Childhood behaviour problems-Bristol Social Adjustment Guides (BSAG:(Stott 1978)[2] 5. Contact with psychiatric services before age 16	Data used in analysis was gathered at age 11 and 16 years old. 1. Childhood social disadvantage (OR = 1.4, CI = 1.0-2.0, P = 0.07) 2. Childhood sensory and neurological problems (OR = 3.1, CI = 1.0-9.6, P = 0.05)	Additional data is provided for a comparison sample of 8554 individuals who do not have intellectual disabilities (71.1% of original birth cohort)
Beadle-Brown *et al.* (2009)	86 adults with intellectual disabilities followed up over 25 years (Original Camberwell cohort- 166 children with intellectual disabilities living	1. Quality of Life-Lifestyle Satisfaction Scale (LSS; Harner & Heal 1993)	Childhood ratings carried out at age 11 years. 1. Skills & behaviour-Schedule of Handicaps Behaviours and Scales (HBS; Wing & Gould 1978)[3] 2. Adaptive	Higher quality of life age 33 was only significantly associated with higher independent living skills in childhood (F = 5.847, P < 0.02)	Proxy respondents completed the LSS for 72 (84%) of the sample. Small study of inter-rater reliability showed that proxy responses had good level of agreement with responses from

	in a defined geographical area in London. Mean age=34 years (SD=4.3; range 27-41)		functioning- Adaptive Behaviour Skills- part 2 (ABS) 3. Cognitive ability- Leiter International Performance Scales (Leiter 1980) & the Reynell Language Development Scales (Reynell 1987) 4. Time spent in institutional care 5. Social impairment 6. Autistic on ICD-10		participants with mild intellectual disabilities.
McCarthy & Boyd 2001	52 individuals with Down syndrome- 28 men, 24 women; mean age= 26.63 years, SD = 3.45, range= 22- 33 years (Original childhood cohort of 193; mean age 10.65 years, SD = 3.49, range= 6-17 years).	Adult psychiatric disorder- assessed using the PAS-ADD (Moss *et al.* 1997)	1. Childhood level of functioning- Adaptive Behaviour Scale (ABS; Nihira *et al.* 1974) 2. Problem behaviours- Rutter A2 & B2 scales (Rutter 1970) 3. ICD-10 psychiatric disorder 4. Childhood externalising disorder 5. Social class- based on father's occupation 6. Quality of parental marriage 7. Parental ill-health	Parental social class ($p<.05$)	Social class was dichotomised into two group comprising classes I-III (professional/ managerial/ skilled) and IV-V (semi-skilled/ unskilled).

McCarthy (2008)	50 individuals with Down syndrome- 26 men, 24 women; mean age= 26.6 years, SD = 3.48, range= 22- 33 years (Original childhood cohort of 193; mean age 10.65 years, SD = 3.49, range= 6-17 years).	Adult problem behaviours- Additional Behavioural Inventory (ABI; (Turner & Sloper 1996)	1. Childhood level of functioning- Adaptive Behaviour Scale (ABS; Nihira *et al.* 1974) 2. Problem behaviours- Rutter A2 & B2 scales 3. ICD-10 psychiatric disorder 4. Childhood externalising disorder 5. Social class- based on father's occupation 6. Quality of parental marriage 7. Parental ill-health	1. ABS 2. ICD-10 psychiatric disorder 3. Social class	Social class was dichotomised into two group comprising classes I-II (professional/ managerial) and III-V (skilled/ semi-skilled/ unskilled).

† Eight-point social disadvantage index, including measures of childhood social class, family size, housing tenure and receptions into care.

‡ The BSAG was used to construct separate scales representing antisocial problems, emotional problems and restlessness

§ Used to derive separate scales for the analysis comprising basic self-care skills, educational skills, communication skills, independent living skills, social skills, abnormal behaviour and behaviour problems

Only the study examining problem behaviours in adults with Down syndrome found that childhood psychopathology was a significant predictor of outcome (McCarthy 2008). Children with Down syndrome who met the criteria for a categorical diagnosis of an ICD-10 psychiatric disorder were more likely to have a severe problem behaviour, aged 33 years old (McCarthy 2008), although this was not a significant predictor of having an ICD-10 psychiatric disorder in adulthood (McCarthy & Boyd 2001). Furthermore, problem behaviours in childhood did not predict adult outcome in the other three studies (Maughan *et al.* 1997; Beadle-Brown *et al.* 2009; McCarthy & Boyd 2001). These inconsistent findings across studies are in keeping with the results described in the longitudinal studies of service users in section 1.9.2.1 above.

Interestingly, Maughan *et al.* (1997) suggest that the lack of association between psychopathology in childhood and adulthood may be due to the poor sensitivity of the family and teacher-rated measures of childhood psychopathology. Since such ratings of psychopathology are used across all four of the studies in table 1.7, this could perhaps partly explain the finding that childhood psychopathology is not a significant predictor of outcome in adulthood. Further limitations of the studies described here are the use of single measures of outcome across all four studies, samples limited to individuals with mild intellectual disabilities (Maughan *et al.* 1997) or Down syndrome (McCarthy & Boyd 2001; McCarthy 2008) and the inclusion of measures of psychopathology that are limited in scope.

1.9.3 Summary of findings on the association of psychopathology and the longitudinal outcome of mental disorders in intellectual disabilities

Overall, there is limited evidence on the relationship of psychopathology and the outcome of mental disorders experienced by adults with intellectual disabilities. No studies examining dimensional models of psychopathology and outcome, or comparing the associations between dimensional and categorical models of psychopathology with the outcome of mental disorders were identified. However, using continuous measures, neurotic/ affective and problem behaviour psychopathology were associated with longitudinal outcome. Further research on the association of level of intellectual disabilities and outcome is required.

1.10 Conclusions from the review of the literature

The classification of mental disorders is dependent on the assessment of psychopathology and the use of categorical diagnostic classification systems, that are based on a categorical model of psychopathology. An important development was the publication of specific categorical diagnostic classification systems for the classification of mental disorders experienced by individuals with intellectual disabilities- DC-LD and DM-ID. These are based on the generic ICD and DSM categorical diagnostic classification systems. Few studies have examined the properties of DC-LD and DM-ID. However, research examining the characteristics of ICD and DSM has highlighted important strengths and limitations of categorical diagnostic classification systems, particularly with regard to validity and their utility in some types of research. As a consequence, dimensional models of psychopathology have been proposed as an important corollary to categorical diagnostic classification systems.

The work done to examine the dimensions of psychopathology experienced by adults with intellectual disabilities is limited by small sample sizes, biased samples and the use of assessments that include a limited range of items of psychopathology. Furthermore, the methods of exploratory factor analysis used have methodological problems.

Socio-clinical variables are important to consider as potential confounders in examining the relationship between psychopathology and other aspects of mental disorders. No studies have examined the associations of dimensional models of psychopathology and socio-clinical variables. However, studies have identified socio-clinical variables that are associated with categorical models of psychopathology.

There has been general research published comparing the associations of dimensional and categorical models of psychopathology with the severity and outcome of mental disorders. No studies were identified examining the relevance of dimensional models of psychopathology to the severity and outcome of mental disorders experienced by adults with intellectual disabilities. Similarly, no studies comparing dimensional and categorical models of psychopathology in intellectual disabilities were identified. Therefore, relevant intellectual disabilities research using categorical models, or continuous measures, of psychopathology is needed.

Studies examining the relationship between psychopathology and the severity of mental disorders have tended to make use of measures of psychopathology which are limited in scope, eg. using either a broad, general measure of psychopathology or focussing on a single continuous measure of psychopathology, such as depressive psychopathology or problem behaviours. The samples included in the studies are biased towards individuals with mild intellectual disabilities. Finally, rather than making use of comprehensive assessments of severity, studies have largely used a single measure of severity- which to date have all been based on quality of life.

The longitudinal studies examining psychopathology and outcome are limited by the focus on users of inpatient services as participants. Since this is likely to comprise individuals with the most severe mental disorders it introduces potential sampling bias, and limits the generalisability of the findings. The measures of psychopathology used in the studies have largely focussed on problem behaviour psychopathology, or have only used overall measures of psychopathology. Only a single study, used more than one measure of outcome (Spiller *et al.* 2007), in contrast to the recommended use of multiple measures of outcome in mental disorder studies (Slade 2002). Finally, although one study includes several continuous measures of psychopathology (Xenitidis *et al.* 2004), these are not empirically derived from the PAS-ADD checklist, which is limited in scope and validity.

Chapter 2: Research aims and hypotheses

2.1 Research aims

Informed by the existing literature, five broad research aims were formulated:

1. To explore the dimensional structure of psychopathology experienced by adults with intellectual disabilities
2. To examine the associations of a dimensional model of psychopathology with socio-clinical variables
3. To examine the relationship of a dimensional model of psychopathology with the severity of mental disorders.
4. To understand the relationship between a dimensional model of psychopathology and the longitudinal outcome of mental disorders
5. To compare the associations of dimensional and categorical models of psychopathology with the severity and outcome of mental disorders, experienced by adults with intellectual disabilities.

2.2. Research hypotheses

To meet these aims 12 null hypotheses were formulated for examination:

Null hypothesis one:

There are no stable, identifiable dimensions of psychopathology experienced by adults with intellectual disabilities.

Null hypothesis two:

There are no significant correlations between the individual dimensions of psychopathology experienced by adults with intellectual disabilities.

Null hypothesis three:

There are no significant cross-sectional, bivariate relationships between dimensional measures of psychopathology and socio-clinical variables:

- gender
- age
- living circumstances
- level of intellectual disabilities
- diagnosis of autism

- Down syndrome
- epilepsy
- sensory impairments
- mobility problems
- incontinence.

Null hypothesis four:

There are no significant cross-sectional, multivariate relationships between dimensional measures of psychopathology and socio-clinical variables.

Null hypothesis five:

There are no significant bivariate relationships between dimensional measures of psychopathology and measures of the severity of mental disorders:

- Health of the Nation Outcome Scales- Learning Disabilities total score (HoNOS-LD)
- Global Assessment of Functioning (GAF)
- Clinical Global Impression (CGI)
- Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID) - unmet needs, and met needs.

Null hypothesis six:

There are no significant bivariate relationships between socio-clinical variables and measures of the severity of mental disorders.

Null hypothesis seven:

There are no significant multivariate associations between dimensional measures of psychopathology, socio-clinical variables and measures of the severity of mental disorders.

Null hypothesis eight:

There are no significant differences in the associations of dimensional and categorical models of psychopathology with measures of the severity of mental disorders.

Null hypothesis nine:

Dimensional measures of psychopathology are not significantly correlated to the longitudinal outcome of mental disorders.

Null hypothesis ten:

Socio-clinical measures are not significantly associated with the longitudinal outcome of mental disorders.

Null hypothesis eleven:

Dimensional measures of psychopathology and socio-clinical variables are not independently associated with the longitudinal outcome of mental disorders.

Null hypothesis twelve:

There are no significant differences in the associations of dimensional and categorical models of psychopathology with the longitudinal outcome of mental disorders.

Chapter 3: Methods

There are two study designs used to answer the research hypotheses:

1. A cross-sectional study examining the relationships between psychopathology, socio-clinical variables and measures of severity (research hypotheses one- eight)
2. A four-five year follow-up study to examine outcome baseline psychopathology and socio-clinical variables as predictors of longitudinal outcome (research hypotheses nine- twelve).

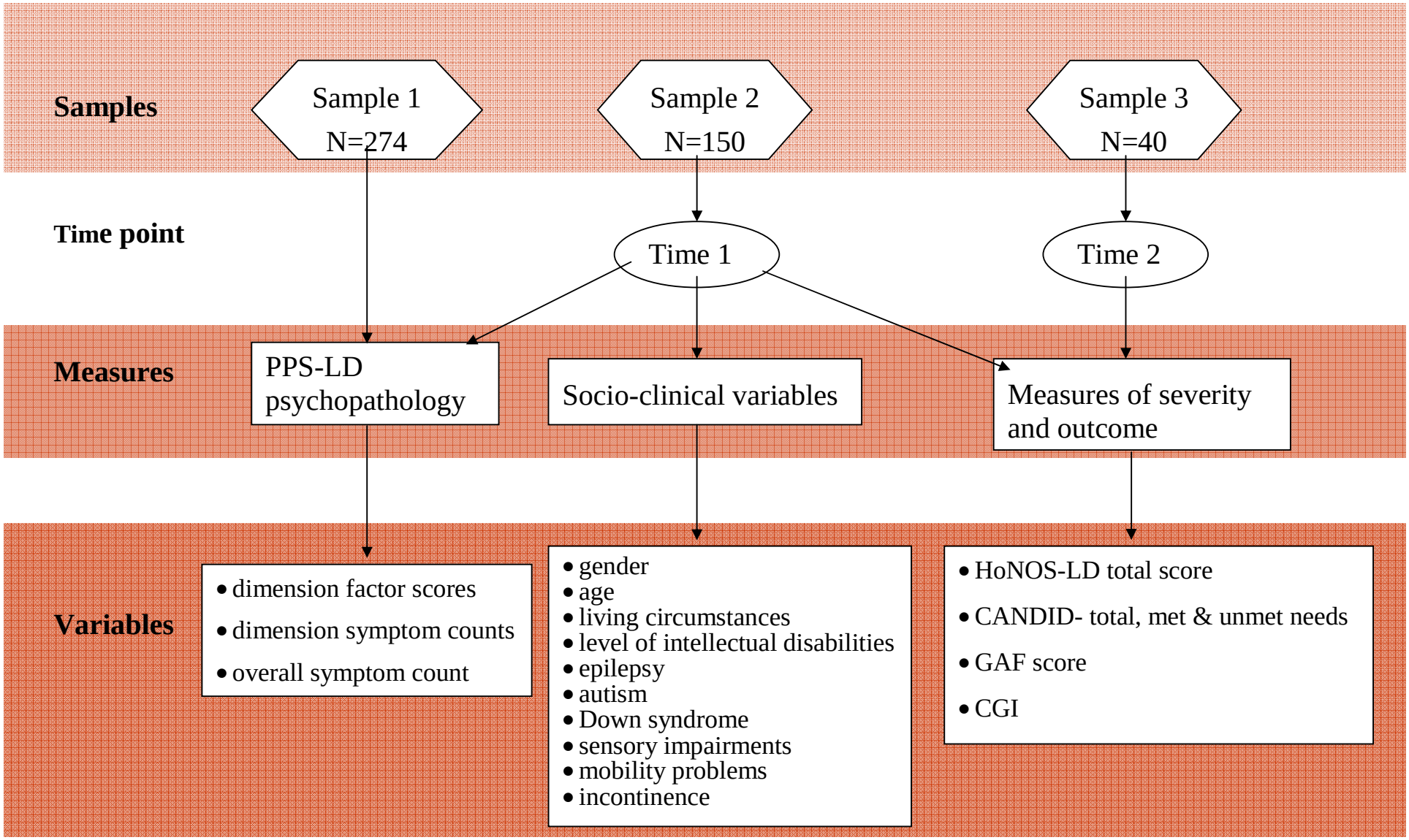
An illustration of the samples, measures and variables used to examine the research hypotheses is shown in figure 3.1.

Data collected from three samples of participants is used to answer the research questions addressed in this thesis. PPS-LD data from both samples was used for the exploratory factor analyses to identify dimensions of psychopathology. Data on socio-clinical variables and outcome measures was collected in studies involving individuals in samples 2 and 3 as participants.

Professor S-A. Cooper collected all the data from sample 1. The data was entered into a database by a member of administrative staff.Data from sample 2 was collected by intellectual disabilities psychiatrists working in the University Centre of Excellence in Developmental Disabilities (UCEDD). Professor S-A. Cooper, higher trainees in intellectual disabilities psychiatry and basic trainees in psychiatry were involved at different stages in collecting the data. Craig Melville worked in the UCEDD from August 2001-August 2002, and again from August 2003 onwards. During these time periods he was directly involved in data collection, and in the training and supervision of other psychiatrists collecting data. All sample 2 data used in the analyses in this thesis was taken from clinical case notes and entered into a database by Craig Melville.

All data for sample 3 was collected during face-to face interviews with participants and carers and entered into a database by Craig Melville.

Figure 3.1: Study design to illustrate samples, measures and variables to examine research hypotheses



3.1 Study participants

3.1.1 Sample 1- North Northamptonshire

Individuals in Sample 1 comprised all adults with intellectual disabilities living in North Northamptonshire, and referred to specialist intellectual disabilities psychiatric services during 1994-1999. The psychopathology data collected using the Psychopathology Present State-Learning Disabilities (PPS-LD) has not been reported previously.

3.1.2 Sample 2- Glasgow

Sample 2 comprises all individuals referred to the clinical service of the Glasgow University Centre for Excellence in Developmental Disabilities (UCEDD) between 2001 and 2004. Participants were referred to the UCEDD clinical service for a full assessment of their needs, on the basis that symptoms, or changes in behaviour, were recognised as suggestive of mental disorders, warranting further assessment by specialist intellectual disabilities services.

3.1.3 Sample 3

Sample 3 (n=40, 26.7%) is a sub-sample of sample 2. Participants in sample 2 (n=150) were all invited to meet with C.Melville and take part in a follow-up interview. The mean time between the baseline assessment and follow-up interview was 52.3 months (range= 46-69; SD=6.9).

3.1.4 Comparison of samples

A comparison of the socio-clinical variables in the three samples are shown in tables 3.1 and 3.2.

Table 3.1: Socio-clinical characteristics of samples 1 and 2

Variable		Sample 1 (n=274)		Sample 2 (n=150)		
		N	%	N	%	Statistic (p value)
Gender	Female	134	48.9	68	45.3	χ^2= 0.50 (.48)
	Male	140	51.1	82	54.7	
Level of intellectual disabilities	Mild	35	14.1	34	22.6	χ^2= 1.95 (.16)
	Moderate	54	21.7	32	21.3	
	Severe	73	29.3	33	22.0	
	Profound	87	34.9	51	34.0	
Epilepsy	No	174	63.7	105	70.0	χ^2= 2.64 (.10)
	Yes, seizures well controlled	51	18.7	29	19.3	
	Yes, seizures poorly controlled	48	17.6	16	10.7	
Vision †	Good	29	10.6	72	48.3	χ^2=.736 (.391)
	Good with glasses	153	55.8	50	33.7	
	Poor with glasses	62	22.6	9	6.0	
	Visual impairment	8	2.9	9	6.0	
	Severe visual impairment	18	6.6	9	6.0	
Hearing †	Good	230	90.6	131	87.9	χ^2= 2.942 (.086)
	Good with hearing aid	9	3.5	6	4.0	
	Poor with hearing aid	1	0.4	4	2.7	
	Hearing impairment	13	5.1	5	3.4	
	Severe hearing impairment	1	0.4	3	2.0	
Mobility †	Full mobility	187	73.0	112	75.2	χ^2= 0.297 (.586)
	Independent but poor	21	8.2	13	8.7	
	Uses a stick/ walking aid	5	2.0	2	1.3	
	Uses wheelchair outside	13	5.1	14	9.4	
	Always uses wheelchair	12	4.7	2	1.3	
	Unable to weight bear	18	7.0	6	4.0	
Urinary incontinence †	Fully continent	165	60.2	97	64.7	χ^2= 0.141 (.708)
	Occasional accidents	45	16.4	16	10.7	
	Incontinent only at night	12	4.4	8	5.3	
	Incontinent	52	19.0	29	19.3	
Bowel incontinence †	Fully continent	202	73.7	112	74.7	χ^2= 0.235 (.628)
	Occasional accidents	31	11.3	10	6.7	
	Incontinent only at night	2	.7	1	.7	
	Incontinent	39	14.2	27	18.0	

† At least one cell count was too small for analyses and therefore, for the purposes of the statistical analyses the variable was collapsed to the binary categories shown in table 3.5

Table 3.2: Socio-clinical characteristics of samples 2 and 3

Variable		Sample 2 (n=150)		Sample 3 (n=40)		
		N	%	N	%	Statistic (p value)
Gender	Female	68	45.3	22	45.0	χ^2= 1.932 (0.165)
	Male	82	54.7	18	55.0	
Level of intellectual disabilities	Mild	34	22.6	6	15.0	χ^2= 2.215 (0.529)
	Moderate	32	21.3	8	20.0	
	Severe	33	22.0	10	25.0	
	Profound	51	34.0	16	40.0	
Living circumstances	Lives independently	27	18.1	5	12.5	χ^2= 2.014 (0.365)
	Family carer support	35	23.5	8	20.0	
	Paid carer support	87	58.4	27	67.5	
Autism	Yes	24	16	6	15.0	χ^2= 0.248 (0.618)
	No	126	84	34	85.0	
Down syndrome	Yes	19	12.7	6	15.0	χ^2= 0.050 (0.824)
	No	131	87.3	34	85.0	
Epilepsy	No	105	70.0	28	70.0	χ^2= .010 (0.995)
	Yes, seizures well controlled	29	19.3	8	20.0	
	Yes, seizures poorly controlled	16	10.7	4	10.0	
Vision †	Good	72	48.3	21	52.5	χ^2=4.153 (.528)
	Good with glasses	50	33.7	14	35.0	
	Poor with glasses	9	6.0	1	2.5	
	Visual impairment	9	6.0	2	5.0	
	Severe visual impairment	9	6.0	2	5.0	
Hearing †	Good	131	87.9	33	82.5	χ^2= 5.543 (0.353)
	Good with hearing aid	6	4.0	2	5.0	
	Poor with hearing aid	4	2.7	3	7.5	
	Hearing impairment	5	3.4	1	2.5	
	Severe hearing impairment	3	2.0	1	2.5	
Mobility †	Full mobility	112	75.2	33	82.5	χ^2= 8.915 (0.178)
	Independent but poor	13	8.7	3	7.5	
	Uses a stick/ walking aid	2	1.3	0	0	
	Uses wheelchair outside	14	9.4	1	2.5	
	Always uses wheelchair	2	1.3	0	0	
	Unable to weight bear	6	4.0	3	7.5	
Urinary incontinence †	Fully continent	97	64.7	25	62.5	χ^2= 3.219 (0.359)
	Occasional accidents	16	10.7	3	7.5	
	Incontinent only at night	8	5.3	1	2.5	
	Incontinent	29	19.3	11	27.5	
Bowel incontinence †	Fully continent	112	74.7	29	72.5	χ^2= 7.852 (0.063)
	Occasional accidents	10	6.7	0	0	
	Incontinent only at night	1	.7	1	2.5	
	Incontinent	27	18.0	10	25.0	

† At least one cell count was too small for analyses and therefore, for the purposes of the statistical analyses the variable was collapsed to the binary categories shown in table 3.5

Data on the age of sample 1 participants at the time of data collection was available for 269 (98.2%) individuals, who had a mean age of 34.7 years (range= 16-76; SD= 13.0).The socio-clinical characteristics of the 150 individuals included in sample 2 are shown above in table 3.1. For sample 2, data on the age of the participants at the time of data collection was available for the whole sample, who had a mean age of 43.5 years (range= 17-74; SD= 13.0). The only between group difference for samples 1 and 2 was a significant difference in the mean age of samples 1 and 2 ($t = -6.7$, $p < 0.001$).

There was no significant difference ($t = -.20$; $p = .984$) in the mean age of sample 2 and sample 3 (43.53 years, SD= 11.94), or the socio-clinical variables in table 3.2, Therefore, sample 3 is representative of participants in sample 2.

3.2 Ethical approval

Participants in samples 2 and 3 lived in Scotland. The Adults with Incapacity (Scotland) Act, 2000 (Scottish Executive 2000) requires that research that involves adult participants who, potentially, do not have the capacity to make an informed decision on participating in research be considered for ethical approval by a designated Multi-centre Research Ethics Committee (MREC).

Participants had the full range of intellectual disabilities, therefore, some individuals would not have the capacity to make an informed decision on participating in research. Ethical approval was, therefore, obtained from Scotland Research Committee A (the MREC that deals with all applications for ethical approval of studies involving participants who do not have capacity) and site specific approval was obtained from the local research ethics committee (LREC) of NHS Greater Glasgow, Primary Care Trust.

3.3 Consent for participation in research

In Scotland, research involving adults who do not have the capacity to make an informed decision regarding their participation as covered by part five of the Code of Practice of the Adults with Incapacity (Scotland) Act, 2000 (Scottish Executive 2000). As stated in the Act,

"Research on adults incapable of consenting is authorised under the Act provided that:

it will further knowledge;

it is of benefit to the adult or others in a similar condition;

it entails little or no risk or discomfort;

the adult is not objecting;

consent has been obtained from a person with relevant powers; and

*the **research** has been approved by The Ethics Committee.***"**

Since the provisions of the act make it clear that assessment of capacity should be decision specific, and not an all or nothing statement on the capacity of an individual, researchers are required to assess the capacity of each potential participants. Based on the Adults with Incapacity (Scotland) Act, 2000 (Scottish Executive 2000), to assess capacity the researcher should assess whether an individual can:

- Understand in simple language what is involved in the research study, its purpose and nature and why it is being proposed
- Understand any principle benefits, risks and alternatives
- Understand in broad terms what will be the consequences of taking part in the research
- Retain the information long enough to use it and weigh it in the balance in order to arrive at a decision
- Express their decision, consistently, on whether to participate in research.

If an individual is assessed as having capacity to make an informed decision about participation in research, they are invited to choose whether they would like to participate- in which case they are invited to sign a consent form. In circumstances where an individual does not have capacity, the Adults with Incapacity (Scotland) Act, 2000 (Scottish Executive 2000) allows provision for consent to be given by the individual's nearest relative, or welfare guardian. The letters of invitation to potential participants, information sheets and consent forms are reproduced in appendix I and II.

3.4 Measures

All participants were assessed using a standardised methodology to assess the needs of individual's, based on a biopsychosocial-developmental model of health. The methods used include:

- Psychiatric examination- a detailed clinical history and mental state examination; with an emphasis on assessing change in a person's experiences, and level of functioning, within the context of the individual's development. To ensure the consistency, and comprehensiveness of the assessment, areas to be specifically enquired about, in all sub-sections of the history, are included in a written protocol used in every new assessment (further details are provided in table 3.3)
- A checklist of psychopathology – the Present Psychiatric State – Learning Disabilities (PPS-LD: Cooper 1997)
- A standardised measure of level of adaptive functioning – Vineland Adaptive Behaviour Scale – survey form (Sparrow *et al.* 1984).

The standardised psychiatric examination schedule is based on accepted practice for taking a clinical history and mental state examination, with specified items to be assessed in each subsection, as outlined in table 3.3 below. Additional information on an individual's development, health and functioning are sought from an informant, such as a family or paid carer. Relevant information on previous contact with health care services is summarised from case notes- often requested from statutory health care services, or institutions where individuals previously lived.

Information from the psychiatric examination, and any relevant details from an informant history and case note review, is used to make a categorical diagnosis using the DC-LD (Royal College of Psychiatrists 2001), ICD-10 (World Health Organisation 1994) and DSM-IV-TR (American Psychiatric Association 2000).

3.4.1 Measures of psychopathology

3.4.1.1 Psychiatric Present State- Learning Disabilities (PPS-LD)

The *Psychiatric Present State- Learning Disabilities* examination (PPS-LD) was developed specifically for the identification of psychopathology experienced by adults with intellectual disabilities (Cooper 1997). The development of the PPS-LD was based upon the *Schedules for Clinical Assessment in Neuropsychiatry* (SCAN: World Health Organisation 1992). In comparison to SCAN, the PPS-LD uses language appropriate to the developmental level of persons with intellectual disabilities and includes items of psychopathology that are absent from the SCAN which commonly present in adults with intellectual disabilities. The PPS-LD is designed to identify a broad range of psychopathology, including symptoms relevant to anxiety disorders, obsessive-compulsive disorders, affective disorders, cognitive impairment, and psychosis. In total there are 112 items on the instrument- 90 items on psychopathology, and 22 mental state items observed at the time of assessment.

Table 3.3: An outline of the standardised UCEDD psychiatric examination

Subsection of history and examination	Details
History of presenting complaints	Current psychopathology- form, duration and severity. Triggers and life events. Specifically assess whether any psychopathology suggestive of ADHD, ASD (reciprocal social interaction, social communication, repetitive & restricted repertoire of activities), and/ or problem behaviours are present. PPS-LD for the assessment of psychopathology
Past psychiatric history	Any episodes of mental disorders documented in case notes- symptomatology, diagnosis, treatment, and outcome. Dates of episodes of mental disorders.
Past medical history	Any physical disorders documented in case notes- symptomatology, diagnosis, treatment and outcome. Specifically assess whether epilepsy is present or not, and status of vision and hearing (and when last tested), mobility, hand use and continence. Relevant investigations and results. Make statement on risk of osteoporosis, GORD, nutrition/ weight status and mental disorders.
Drug history	Current medication- name, dose, administration and side effects. Include previous allergies or adverse events.
Personal and developmental history	Chronological account of all available history, noting the source. Any relevant developmental history. Cause of intellectual disabilities. Current Vineland Adaptive Behaviour Scales scoring
Current social circumstances	Describe current accommodation and level of support. Detail occupational/ leisure activities/ hobbies. Social network and contact with family and friends. Detail smoking, alcohol and drug intake. Professional supports e.g. detail current contact with intellectual disabilities health services. e.g. dietician, physiotherapist, community nurse etc.
Family history	Parents' and siblings' occupation, place of residence and health. Note any family history of psychiatric illness, epilepsy or learning disabilities.
Mental state examination	Appearance and behaviour; speech; mood and affect; thought form- rate, associations and possession; thought content- overvalued ideas, delusions; perceptions – psychotic phenomena, illusions; cognition – attention, concentration, memory, interest; insight. List positive and relevant negative findings from PPS-LD

Psychiatrists with specialist training and experience of working with adults with intellectual disabilities are trained to use the PPS-LD. The PPS-LD can be completed with the individual with intellectual disabilities alone, with both the individual and a relevant informant, or with an informant alone. Prompts and appropriate questions relevant to each item of psychopathology are provided, with follow-up, clarifying questions available, to be used flexibly, depending on a respondent's initial answer. All the items of psychopathology in the PPS-LD are rated by the psychiatrist.

Psychopathology is rated based on an individual's functioning in the previous four weeks. The scoring system varies between items, with most rated on a binary scale (0=no, 2= yes). Three items of psychopathology (worry/ apprehension, tearfulness and reduced self care) are scored on a three point scale (0=no, 1=a bit, 2=yes). Several questions on the PPS-LD rate several items of psychopathology together. For example, the question on sleep rates whether six forms of sleep disturbance are present (initial insomnia, mid-insomnia, early morning wakening, increased sleep during the day, reversed sleep pattern and reduced need for sleep). Other questions that rate multiple items of psychopathology are on diurnal mood variation (no DMV, worse in evening, worse in morning), and the mental state item on affect (euthymic, irritable affect, depressed affect, euphoric affect).

An item of psychopathology is scored positively, if it has been present in the past four weeks and associated with significant impairment. However, if on further questioning an interviewer determines that the item of psychopathology is long-standing, there is an option to rate the item as a trait characteristic (trait=7). Similarly, when an item of psychopathology is present, but is clearly a feature of an autism spectrum disorder a separate score can be recorded. For example, rituals as such as obsessional checking and repetitive behaviours could be rated positively (score = 2), or present as part of an autism spectrum disorder (score = 4).

The rating of certain items of psychopathology is more dependent than others on an individual's level of communication, or intellectual disabilities. The clearest example of this is where an individual does not have any verbal communication, which makes it impossible to rate items that require some degree of self-report e.g. hopelessness, intrusive obsessional thoughts and terms of psychosis. For the purposes of completing the PPS-LD, if an individual does not use verbal communication at a level where they speak

in sentences, such items are not rated. Similarly, if for any reason the interviewer is unsure whether an item of psychopathology is present or not, this is indicated on the interview schedule and the reason written in long hand. Common reasons for this can be to do with an individual's level of intellectual disabilities, or an informant being unable to give a clear description due to a lack of knowledge of a particular aspect of an individual's lifestyle e.g. sleep.

Data collected using the PPS-LD was used in this thesis for the exploratory factor analysis to identify underlying dimensions of psychopathology experienced by adults with intellectual disabilities during episodes of mental disorders.

3.4.1.2 DC-LD categorical diagnosis of mental disorder

As part of the standardised method of assessment, a decision is made as to whether the psychopathology an individual has experienced meets the criteria for any diagnoses from one, or more, categorical diagnostic classification systems. Since the publication of the DC-LD, a consensus process has been used to decide if an individual meets the criteria for diagnoses from DC-LD, ICD-10 and DSM-IV-TR. For the purposes of this thesis, the diagnoses from DC-LD are used, as the categorical model of psychopathology for comparison with the dimensional model of psychopathology. Details of DC-LD are in section 1.3.1.2. The DC-LD diagnoses for samples 2 and 3 are shown in table 3.4.

Table 3.4 DC-LD categorical diagnoses for samples 2 and 3.

DC-LD mental disorders	DC-LD diagnostic category	Diagnostic code	Sample 2		Sample 3	
			N	%	N	%
Dementia	Unspecified dementia	B1.1	3	2	1	2.5
	Dementia in Alzheimer's disease, unspecified	B1.2	1	0.67	0	0
	Vascular dementia, unspecified	B1.3	1	0.67	0	0
Non-affective psychotic disorders	Schizophrenic/ delusional episode	B3.1	5	3.33	2	5.0
	Schizoaffective episode	B3.2	1	0.67	1	2.5
	Other non-affective psychotic episode	B3.3	1	0.67	1	2.5
Affective disorders	Depressive episode	B4.1	45	30.67	9	22.5
	BPAD[1], current depressive episode	B4.1i	1	0.67	1	2.5
	BPAD, currently in remission	B4.1ii	1	0.67	1	2.5
	Recurrent depressive disorder, currently in episode	B4.1iii	6	4	2	5.0
	Depressive episode with psychotic symptoms	B4.1xa	1	0.67	1	2.5
	Manic episode	B4.2	1	0.67	0	0
	Bipolar affective disorder, current episode mixed	B4.3i	1	0.67	2	5.0
Neurotic & stress related disorders	Agoraphobia	B5.1	3	2	1	2.5
	Specific phobia	B5.3	3	2	0	0
	Panic disorder	B5.4	2	1.3	0	0
	Generalised anxiety disorder	B5.5	4	2.7	2	5.0
	Obsessional compulsive disorder	B5.8	2	1.2	1	2.5
	Adjustment disorder	B5.10	4	2.7	0	0
	Post-traumatic stress disorder	F43.1 †	1	0.67	0	0
Eating disorder	Pica	B6.9	1	0.67	0	0
Hyperkinetic disorders	Attention-deficit hyperactivity disorder	B7.1	5	3.33	1	2.5
Problem behaviours	Physically aggressive behaviour	D1.3	2	1.2	0	0
	Self-injurious behaviour	D1.5	1	0.67	0	0
Does not meet criteria for any categorical diagnosis	N/A	N/A	54	36.0	14	35.0

[1] Bipolar Affective Disorder † ICD-10 diagnostic code

3.4.2 Socio-clinical variables

The socio-clinical variables in the analyses were chosen on the basis of the literature review of the associations of psychopathology and socio-clinical variables in section 1.7:

- gender
- age in years, at time 1 (the time of referral to specialist services)
- living circumstances
- level of intellectual disabilities
- diagnosis of autism
- Down syndrome
- epilepsy
- visual impairment
- hearing impairment
- mobility problems
- urinary incontinence
- bowel incontinence

The variable describing an individual's living circumstances was based on the accommodation where the person lived. The different geographical settings that sample 1 and sample 2 lived in meant that the original categories used for data collection were not identical. Therefore, to allow comparison the categories were collapsed into three- lives independently with no support from paid carers; lives in own tenancy, or registered residential/ nursing home with support from paid carers; lives with parents or other family members.

The variables epilepsy, visual impairment, hearing impairment, mobility problems, urinary incontinence and bowel incontinence are coded as part of the PPS-LD. For the epilepsy variable, seizures are categorized as well controlled if they occur at a frequency of once per month, or less and poorly controlled at a frequency of more than once a month. Since several cell counts were too low for the purposes of statistical analyses, the original categories in the PPS-LD for visual impairment, hearing impairment, mobility problems, urinary incontinence and bowel incontinence were collapsed to binary categories. This is shown in table 3.5.

Table 3.5: Transformation of variables for purposes of analyses

Variable name	PPS-LD category	Collapsed binary category
Visual impairment	Good	Good
	Good with glasses	
	Poor with glasses	Visual impairment
	Poor	
	Severe visual impairment	
Hearing impairment	Good	Good
	Good with hearing aid	
	Poor with hearing aid	Hearing impairment
	Poor	
	Severe hearing impairment	
Mobility problems	Full mobility	Full mobility
	Independent but poor	Mobility problems
	Uses stick or frame	
	Uses a wheelchair only when outside	
	Uses a wheelchair all the time	
	Cannot weight bear/ immobile	
Urinary continence	Continent	Continent
	Occasional accidents	Incontinent
	Incontinent at night only	
	Incontinent	
Bowel continence	Continent	Continent
	Occasional accidents	Incontinent
	Incontinent at night only	
	Incontinent	

A diagnosis of autism which had previously made and recorded in the case notes was reviewed as part of the structured psychiatric assessment. In circumstances where an individual was believed to have autism by family or paid carers, or clinical services, but no formal record of the process and diagnosis was available a diagnostic assessment was carried out at the time of the original psychiatric assessment.

3.4.2.1 Level of intellectual disabilities- Vineland's Adaptive Behaviour Scales

The *Vineland's Adaptive Behaviour Scales* are widely used as a measure of intellectual functioning, and adaptive behaviour. The instrument is completed with a carer, or other informant, and assesses a person's level of abilities in three domains:

- Communication
- Daily Living Skills
- Social Functioning.

A standardised scoring system generates raw scores for each domain. Using tables derived from population normative data, age equivalent scores for each domain are calculated. These age equivalent scores are indicative of the level of intellectual disabilities as described in ICD-10:

- 0- 3 years equivalent to profound intellectual disabilities
- 3-6 years equivalent to severe intellectual disabilities
- 6-9 years equivalent to moderate intellectual disabilities
- 9-12 years equivalent to mild intellectual disabilities.

3.4.3 Measures of severity and outcome

It is suggested that severity and outcome measurement in mental disorders should involve the use a battery of measures, encompassing multiple domains (Jacobson *et al.* 1999; Slade 2002). Models of outcome measurement have been proposed for use in mental health for adults who do not have intellectual disabilities. For example, a systematic review of the use of outcome measures, categorised them into seven domains- well being, cognition/ emotion, behaviour, physical health, interpersonal, society, services (Slade 2002). Although studies involving participants with intellectual disabilities have used instruments relevant to these domains, outcome measures in general are less well established in the field of intellectual disabilities. Few studies have established the psychometric properties of instruments used to measure outcome, and in particular evidence is lacking on the sensitivity to change of measures used in mental ill health.

In order to examine the research null hypotheses, measures were chosen that could be applied across all level of abilities, and diagnoses of mental disorders.

3.4.3.1 Health of the Nation Outcome Scales- Learning Disabilities (HONOS-LD)

The *Health of the Nation Outcome Scales* (HoNOS) are a family of parallel instruments developed as a measure of outcome for use with individuals with mental disorders (Wing 1998). Conceived as a simple scale to provide a structured measurement of outcome, the HoNOS scales encompass key aspects of mental health and social functioning. Unlike most outcome measures, HoNOS is designed to be used with individuals with mental disorders, regardless of the diagnosis and the original version has been used to measure outcome in research and routine clinical practice. The original generic scale has been shown to be reliable, valid and sensitive to change (Pirkis *et al.* 2005) and served as the basis for the development of versions of the HoNOS for use with children and adolescents (HoNOSCA), older people (HoNOS65+) and groups of individuals with different needs, such as adults with intellectual disabilities.

The *Health of the Nation Outcome Scales for People with Learning Disabilities* (HoNOS-LD) was developed to take into account the specific needs of individuals with intellectual disabilities (Roy *et al.* 2002). HoNOS-LD has 22 items, which are rated on a five point scale (0= no problem, 1 = mild problem, 2 = moderate problem, 3 =severe problem, 4 = very severe problem). For each individual item, there is a specific descriptor for each rating on the five-point scale. The scores for each of the 22 items are added together to give a total (HoNOS-LD total, range = 0-44). In table 3.6 below, the names of the items included in HoNOS-LD are provided.

The original work to develop HoNOS-LD suggested it had adequate reliability, and validity and sensitivity to change to be used as a measure of outcome (Roy *et al.* 2002). Subsequently, there have been relatively few published studies that have reported on its use in research, or clinical settings. A recent study reported that it is a more reliable and valid measure of outcome in adults with mild/borderline intellectual disabilities than the generic HoNOS (Tenneij *et al.* 2009). Significant between group differences in the HoNOS-LD total score (Dowling *et al.* 2006) were described in a randomised controlled trial of a bereavement intervention, confirming that it has adequate sensitivity to change. Finally, in a follow-up study to look at the effectiveness of a specialist intellectual disabilities clinical service, HoNOS-LD was shown to have good discriminant validity- between inpatient and community service users- and was sensitive to change over time (Hall *et al.* 2006).

3.4.3.2 Camberwell Assessment of Need- Intellectual Disabilities (CANDID)

The measurement of the needs of individuals with mental disorders is well established, with several available instruments and a significant theoretical and research evidence base.

A commonly used instrument to measure needs is the Camberwell Assessment of Need (CAN), which has been shown to have good reliability and validity (Phelan *et al* 1995). Needs measured using the CAN have been shown to be associated with quality of life (Slade *et al.* 1999; Slade *et al.* 2004) and has been used to examine the utility of dimensions of psychopathology (van Os *et al.* 1999a). Similar to the HoNOS, the CAN has been used to develop a family of instruments for use across different clinical groups.

For the purpose of measuring need in adults with intellectual disabilities and mental disorders, the Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID; Xenitidis *et al.* 2000) was developed by modifying the CAN (Phelan *et al.* 1995). Like all versions of the CAN, there is a short (CANDID-S) and a research version of the CANDID (CANDID-R). The description below refers to the CANDID-R which was the version used in the study described in this thesis. The CANDID-R measures need across 25 domains (see table 3.6), in keeping with a biopsychosocial model of health. The timescale used to rate the CANIDID-R is the four weeks prior to the interview and participants are asked to rate whether a need is present, and if so whether it is currently met or unmet Only if a need is present are the other three sections of CANDID-R completed-section 2 rates how much help the person receives from friends or relatives with the need; section 3 rates how much help the person receives from local services; section 4 rates whether the person is receiving the right type of help, and their satisfaction with the amount of help they receive). For rating need in the 25 domains, there are four possible scores:

- no need (score=0)
- met need (score=1)
- unmet need (score=2)
- unknown (score=9).

The ratings for each domain are combined to give three summary variables- total number of unmet needs, total number of met needs, total number of needs (calculated by adding together the number of met and unmet needs). In conceptualising results from the CANDID-R as a measure of outcome it is worth noting that a lower number of unmet needs, and higher number of met needs are considered indicative of a better outcome.

It is standard practice to report all three summary variables, as will be done for descriptive statistics in the results in chapter 4. Since the total needs variable is a composite of the unmet and met needs variable, including it in statistical analyses would contravene best practice guidance on avoiding the use of data more than once in analyses. Therefore, the total needs variable was not included in bivariate and multivariate to answer the research hypotheses.

CANDID been shown to be a reliable and valid measure of met, and unmet health needs in adults with intellectual disabilities (Xenitidis *et al.* 2000). CANDID-S has been used in several studies since its publication and found to be a valid measure of need (Strydom *et al.* 2005; Hall *et al.* 2006), have discriminant validity (Hall *et al.* 2006) and be sensitive to change over time (Hall *et al.* 2006).

Table 3.6: Individual items rated on the HONOS-LD and CANDID

HoNOS-LD items	CANDID items
1. Behaviour problems- directed to others	1. Accommodation
2. Behaviour problems- directed to self	2. Food
3a. Behaviour destructive to property	3. Looking after the home
3b. Problems with personal behaviours	4. Self-care
3c. Stereotyped and ritualistic behaviours	5. Daytime activities
3d. Anxiety, phobias, obsessive compulsive behaviour	6. General physical health
3e. Other problem behaviours	7. Eyesight/ hearing
4. Attention and concentration	8. Mobility
5. Memory and orientation	9. Seizures
6. Communication (problems in understanding)	10. Major mental health problems
7. Communication (problems in expression)	11. Other mental health problems
8. Problems with hallucinations and delusions	12. Information
9. Problems with mood changes	13. Exploitation risk
10. Problems with sleeping	14. Safety to self
11. Problems with eating and drinking	15. Safety to others
12. Physical problems	16. Inappropriate behaviour
13. Seizures	17. Substance misuse
14. Activities of daily living at home	18. Communication
15. Activities of daily living outside the home	19. Social relationships
16. Level of self-care	20. Sexual expression
17. Problems with relationships	21. Caring for someone else
18. Occupation and activities	22. Basic education
	23. Transport
	24. Money budgeting
	25. Welfare benefits

3.4.3.3 Global Assessment of Functioning (GAF)

In keeping with recommendations to include a global measure of functioning in multi-dimensional batteries of outcome measures, the GAF (American Psychiatric Association 2000) was used. It was completed based on case note data for all participants from sample two, and completed a second time for individuals, from sample two, who participated in the follow-up, research interview.

GAF provides a single measure of social, occupational and psychological functioning in adults, on a continuous scale ranging from 1-100, with 100 representing the best possible functioning. The 100 point scale is divided into 10 subsections, each one covering 10 points on the scale e.g. 1-10, 11-20 etc. Each subsection has written symptom and behavioural descriptors.

The instructions for completing the GAF in DSM-IV TR were followed, rating the week prior to the interview date. Starting at the top subsection (100-91) the person scoring the GAF considers, " is **either** the individuals symptom severity OR level of functioning worse than indicated in the range description?". If so, the person scoring the GAF moves down the scale until the subsection with descriptors that best matches the individual's symptom severity OR level of functioning is reached, whichever is worse. The person then double checks that the correct subsection has been selected, the lower subsection has examined to ensure that the descriptors are too severe on both symptom severity and length of functioning. To determine the specific GAF rating within the 10- point range, the person scoring the GAF consider whether the individual is functioning at the higher or lower end of the 10 point range, and selects an appropriate score.

There is a little available data on the psychometric properties of the GAF from studies including adults with intellectual disabilities as participants. One study examined the inter-rater reliability of GAF scores rated by 19 health professionals, some of whom did not work with persons with intellectual disabilities. Participants rated case vignettes describing psychopathology experienced by adults with intellectual disabilities on the caseloads of psychiatrists. The participants received training to use the GAF as indicated in DSM-III-R (Oliver *et al.* 2003). Overall inter-rater reliability was fair (r= .49), and the authors concluded that the GAF was unreliable for use in intellectual disabilities, if used as described in DSM-III-R.

A second study used the GAF as one of several measures of the severity and outcome of mental disorders in adults with intellectual disabilities (Hall *et al.* 2006). Two groups of service users were included in the study- inpatients (n= 19) and outpatients (n= 18) receiving care from specialist, community intellectual disabilities services. Other measures used at baseline and follow-up at six months were the HoNOS-LD, CANDID-S and the Threshold Assessment Grid (TAG, Slade *et al.* 2000). The TAG is a method of assessing clinical risk developed for use with adults who do not have intellectual disabilities. All ratings were completed by unblinded intellectual disabilities psychiatrists, who rated the standard scoring method for the GAF. Although the two groups differed on the HoNOS-LD ($t= -2.068$, $p= .046$), CANDID-S unmet needs ($U=72.5$, $p= .040$) and TAG ($t=-4.038$, $p<.001$) at baseline, there was no between group difference in the GAF scores ($t=1.424$, $p=.163$). Whilst the GAF had poor discriminant validity between inpatient and community service users, it had similar sensitivity to change to the HoNOS-LD, CANDID-S and TAG- in both groups (Hall *et al.* 2006).

The issues with the inter-rater-reliability and discriminant validity of the GAF in these studies is likely to be due to the use of the standard method of scoring (Oliver *et al.* 2003; Hall *et al.* 2006). A problem arises when scoring the GAF for individuals with intellectual disabilities because the impact of a person's intellectual disabilities on level of functioning, could give an artificially low score (Hurley, 2001; Shedlack *et al.* 2005; Hurley *et al.* 2007). To take account of this, the GAF was rated in this thesis using an adapted methodology (Hurley, 2001). Similar to the recommended scoring system for persons with physical disabilities, the impact on functioning of impairments due to intellectual disabilities is excluded from the GAF rating. The rating is based solely on symptoms and level of functioning where there has been a clear change in functioning related to the onset of psychopathology, associated with an episode of a mental disorder.

3.4.3.4 Clinical Global Impression (CGI)

Given the limited evidence on the use of the GAF in studies with adults with intellectual disabilities as participants, the CGI was rated as a second global measure of functioning, at the same time as the GAF.

The CGI scales are designed to be completed by a clinician. Only the CGI scale that rates severity of illness was used for the study. The most severe level of illness over the past week was rated, on a seven point scale:

1. normal, not ill at all
2. borderline mentally ill
3. mildly ill
4. moderately ill
5. markedly ill
6. severely ill
7. among the most severely ill.

The CGI has been shown to be reliable in studies that include adults who do not have intellectual disabilities as participants (Dahlke *et al.* 1992; Zaider *et al.* 2003). However, although the CGI has been used in adults with mental disorders and intellectual disabilities (Van den Borre *et al.* 1993; McDougle *et al.* 1998) no studies have previously examined the psychometric properties of the CGI when used in intellectual disabilities research.

3.4.3.5 Calculating the scores for the measures of longitudinal outcome

Cross-sectional scores at time 1 for the five measures were used as the measure of the severity of mental disorders. For individuals in sample 2, who participated in the follow-up study, the longitudinal measures of outcome used in the analyses were based on the change in the measures of severity between time 1 and time 2. For each measure, this was calculated by subtracting the score on the measure of outcome at time 2 (follow up) from the score at time 1 (baseline).

The scoring format of the GAF differs from the other four measures. A higher score on the GAF represents a lower severity, whereas for the HoNOS-LD, CGI and CANDID-R a higher score represents a greater severity. Therefore, to facilitate comparison across the five measures the polarity of the GAF score representing longitudinal outcome was reversed.

Therefore, for all measures:

- a negative score represents a poorer outcome than a positive score i.e. the score on the measure at time 2 is greater than at time 1
- a higher positive score represents a better longitudinal outcome than a lower positive score
- a higher negative score represents a poorer longitudinal outcome than a lower negative score.

Table 3.7 provides details of the methods of assessment used to collect data from the three samples, organised in the domains of psychopathology, level of functioning and the severity of mental disorders.

Table 3.7: Methods of assessment used to collect data from samples 1, 2 and 3

	Domain and method of assessment		
Sample	**Psychopathology**	**Level of functioning**	**Severity**
Sample 1	Standardised psychiatric examination PPS-LD	Vineland's Adapative Behaviour Scales	N/A
Sample 2	Standardised psychiatric examination PPS-LD	Vineland's Adapative Behaviour Scales	HoNOS-LD GAF CGI CANDID-R
Sample 3	Standardised psychiatric examination PPS-LD	Vineland's Adapative Behaviour Scales	HoNOS-LD GAF CGI CANDID-R

3.5 Statistics and analysis of data

Quantitative data relevant to the work reported in this thesis was first entered into SPSS version 15.0. However, since the data from the PPS-LD for use in the EFA is binary appropriate methods of factor analysis were used, using TESTFACT 4 software (Woods *et al.* 2003).

A general description of statistical methods used to test multiple null research hypotheses is given followed by any methods specific to each null hypothesis.

3.5.1 Methods to assess whether variables are distributed normally

Parametric statistical tests are preferred in any analysis, since they are more reliable and powerful than non-parametric tests. A key assumption in the use of parametric tests is that the variables used in the analysis are normally distributed. Therefore, to decide on the use of parametric or non-parametric tests, the distribution of the continuous measures of psychopathology, age and measures of severity and outcome was explored using a histogram and normal distribution plot. Statistical tests of the skewness, kurtosis and difference of the distribution from normality were also calculated.

The histogram and normal distribution plot allowed a visual comparison of the distribution of the variable of interest against the normal distribution. In the histograms, a line representing the normal distribution is superimposed on the histogram. A variable with a normal distribution will be represented by a straight diagonal line in a normal probability plot. Superimposing a straight line on the normal probability plot allows visual inspection of how similar the distribution of a variable is to the normal distribution.

Skewness refers to the symmetry of the distribution. A normally distributed variable is symmetrically distributed around the mean and has a skewness score of zero. If a variable has a frequency distribution clustered around the lower values, and a longer tail moving towards the higher values then it has a positive skew, and the skewness score will be greater than zero. Alternatively, higher frequencies of the higher values and a longer tail towards the lower values is a negative skew and the skewness score is less than zero.

Kurtosis refers to the peakedness of a distribution. Whereas the normal distribution follows the shape of a bell, variables with high frequencies of values in the tails on either side of the mean, have a flat distribution and a negative kurtosis score- described as a platykurtic distribution. If there is a higher frequency of values clustering close to the mean the variable will have a pointed distribution and a positive kurtosis score- described as a leptokurtic distribution.

To obtain a standardised measure of skewness and kurtosis, the z-scores are calculated, by dividing the original scores by the standard error of the respective score. If the z-score is greater than 1.96 the skewness or kurtosis of the distribution differs from the normal distribution at a level of significance of $p < .05$, with the significance level increasing to $p < .01$ if the z-score is greater than 2.58 and $p < .001$ above z-scores of 3.58.

As well as the skewness and kurtosis z-scores, there are two tests available that examine whether the overall distribution differs significantly from normality- the Kolmogorov-Smirnov and Shapiro-Wilk test. Since the Shapiro-Wilk test is more reliable, particularly when used with samples greater than 30, only it was used in the analyses. The closer the Shapiro-Wilk test score is to 1, the closer the distribution is to a normal distribution, and p values represent the significance of any difference from normality.

Where the graphical and statistical methods suggest the distribution of a variable differs significantly from normality, data transformations were carried out in an attempt to move the distribution closer to normality. These transformations are of particular relevance when the distribution of a variable differs from the normal distribution due to skewness, rather than kurtosis. Three data transformations for positively skewed data are taking the square root ($\sqrt{X}$), the logarithm ($\log^{10} X$) and the inverse of the variable ($1/X$). Since these have an increasing hierarchical effect on positively skewed data they were used sequentially. The square root transformation was tried first and the graphical and statistical methods described above were then repeated to test whether the distribution was now closer to normality. If there was still a significant difference from normality, the logarithmic transformation and, if needed, the inverse transformations

were tested using similar methods. The least transformation which moves the distribution of the variable closer to normality was used.

There are problems with the use of square root, logarithmic and inverse transformations with variables with negative values, zeros or many scores between zero and one. This is an issue that is relevant to all the variables but particularly the dimension factor scores, which include negative values. To take account of this, prior to any transformation a constant was added to each individual variable to anchor them all at a minimum score of one. For the dimension symptom counts and overall measures of psychopathology, one was added to each variable score so that the minimum score of each variable is one. Since the dimension factor scores have negative values a different method of calculating the constant was needed. First the minimum value for the dimension factor score was identified. This minimum value was converted to a positive integer and the constant calculated by adding one. For example, for a dimension with a minimum score factor score of – 1.92, the constant is calculated as 1.92 + 1 and added to the original score for each case.

These methods were used to examine the distribution of measures of psychopathology, age and measures of severity and outcome, prior to their use in bivariate and multivariate analyses.

3.5.2 Methods to test null research hypothesis one

Null hypothesis one:
There are no stable, identifiable dimensions of psychopathology experienced by adults with intellectual disabilities.

Data on psychopathology from the PPS-LD was used to examine null hypothesis one, rather than data collected using the standardised psychiatric examination.

Psychopathology data collected using the PPS-LD has improved reliability compared to psychopathology data collected using the standardised psychiatric examination. The

reliability of the PPS-LD is maximised by the structured format, use of language and prompts appropriate to the level of functioning of adults with intellectual disabilities and the consistent description of criteria which are required to be met for the item of psychopathology to be rated positively.

Further contributions to the reliability of the use of the PPS-LD come from training on the use of the PPS-LD. All intellectual disabilities psychiatrists involved in data collection received training on the use of the PPS-LD, including shadowing a senior intellectual disabilities psychiatrist to observe the use of the PPS-LD, and completing the PPS-LD in parallel with the senior intellectual disabilities psychiatrist to check the inter-reliability reliability of the ratings of psychopathology.

3.5.2.1 Exploratory factor analysis to identify dimensions of psychopathology

To examine the dimensions of psychopathology experienced by adults with intellectual disabilities an exploratory factor analysis (EFA) was carried out on data gathered using the PPS-LD. Factor analysis is a commonly used statistical method that examines the correlations between variables, in order to identify variables that cluster together and define latent dimensions underlying a dataset. A model is created with a number of common factors, with variables clustering together and loading onto specific common factors and not others. Like any statistical analysis, the reliability of the factor analysis is dependant on the quality of the available data. Furthermore, there are some key decisions for the researcher to make, depending on the data and aims of the analysis. For the purposes of this EFA published "best practice" guidelines were followed (Costello & Osborne 2005) for:

- the sample size and case: variable ratio
- the statistical method used for factor extraction– common factor analysis
- method to decide on number of factors retained for rotation after factor extraction- scree test
- method of rotation- oblique
- minimum accepted item loading to a factor to ensure factor reliability= 0.32
- minimum number of items loading onto a factor to ensure factor stability= 3.

Expanded details of these aspects of the EFA are given in separate sections below.

3.5.2.2 Sample size required for exploratory factor analysis

General guidelines on the sample size required to generate a stable factor solution from EFA suggest that the ratio of cases to variables should be at least 5:1 (Costello & Osborne 2005), with a total sample size of 300 (Tabachnik & Fidell 2001). To achieve these two requirements, PPS-LD data from sample 1 (n=274) and sample 2 (n=150) was merged to give a sample size of 424. Since the EFA examines associations between variables, cases that only scored positively for one or less items of psychopathology (n= 84) were excluded leaving 340 cases for the EFA, with a case: variable of 8:1 (outlined in figure 3.2).

3.5.2.3 Items of psychopathology included in the EFA

All items on the PPS-LD were converted to a binary score (0=not present, 2=present). For the three items scored on a three point scale (worry/ apprehension, tearfulness, reduced self care), where an individual scored positively, regardless of the extent (1=a bit, 2=yes) the item was scored as present. Since this thesis is focussed on psychopathology experienced as part of an episode of mental disorders, where an item was rated as present as a trait/ characteristic (trait=7) this was converted to a score of not present.

For the two PPS-LD questions that rate multiple items of psychopathology (sleep problems and diurnal mood variation) separate variables were created:

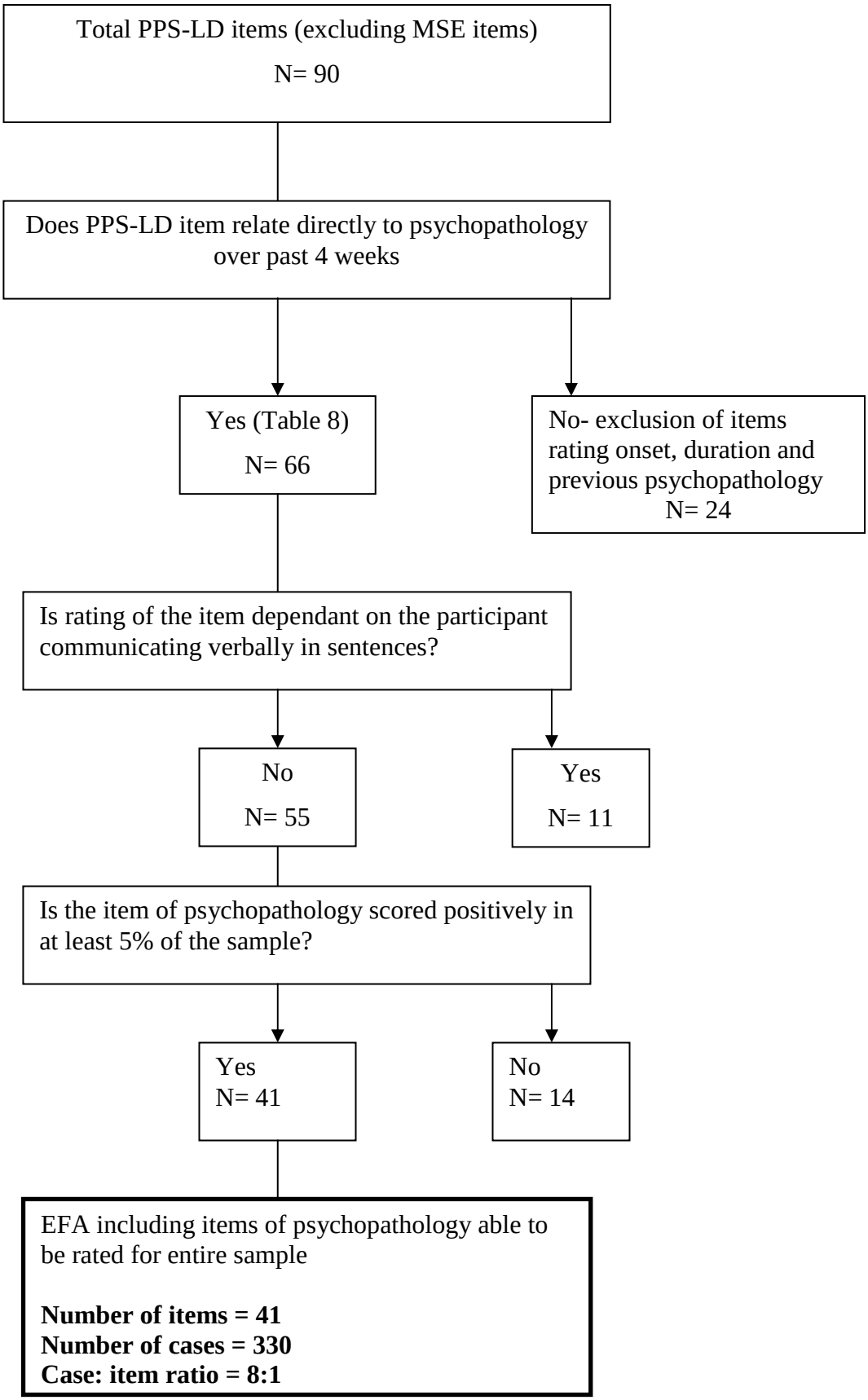
1. Original question- sleep problems
    - initial insomnia (0=not present, 2=present)
    - mid-insomnia (0=not present, 2=present)
    - early morning wakening (0=not present, 2=present)
    - increased sleep during the day (0=not present, 2=present)
    - reversed sleep pattern (0=not present, 2=present)
    - reduced need for sleep (0=not present, 2=present)
2. Original question- diurnal variation in mood
    - mood worse in evening (0=not present, 2=present)
    - mood worse in morning (0=not present, 2=present)

3.5.2.4 Selection of items of psychopathology for entry into the EFA

To maximise the stability of the solution extracted via the EFA careful consideration was given to which items from the PPS-LD to include in the EFA. Only items from the PPS-LD directly related to the presence of a specific item of psychopathology were considered for inclusion in the EFA. Figure 3.2 outlines the process used to decide which of the PPS-LD items were used for the EFA.

Since the mental state items and items of psychopathology are fundamentally different, it was decided to exclude the 22 items of the examination from the EFA. These mental state items are rated by the clinician rating the PPS-LD based on observation during the clinical interview. In contrast, the items of psychopathology are rated based upon the description by participants and carers of the person's mood, behaviour and functioning over the past four weeks. Exclusion of the mental state items left 90 items of psychopathology for possible inclusion in the EFA.

Figure 3.2: Flowchart of selection of PPS-LD items for inclusion in exploratory factor analysis



Twenty four items relating to the presence of physical health problems, previous episodes of mental disorders, onset of symptoms and previous response to treatment were excluded, leaving a total number of 66 PPS-LD items shown in table 3.5.

There are 11 items in the PPS-LD which are highly dependant on verbal communication, and recommended not to be rated unless an individual uses sentences to communicate. A significant number of individuals in sample 1 and sample 2 were unable to self-report on these items of psychopathology. Therefore, as indicated in table 3.7, these items were excluded from the exploratory factor analysis.

The reliability of a factor solution can be affected by the inclusion of items that score positively infrequently (low variance), or where two or more items are strongly correlated (correlation coefficient > 0.9 = high collinearity). To screen for this the frequency of occurrence of, and correlation between, individual items were examined.

There were 14 items of psychopathology from the PPS-LD which scored positively in less than 5% of cases, and were excluded from the EFA (see table 3.7). Since there were no items with correlations > 0.9, no items met the criteria for high collinearity. Therefore, a total of 41 items of psychopathology from the PPS-LD were retained for inclusion in the EFA, highlighted in bold in table 3.7.

Table 3.8: Items of psychopathology in the PPS-LD

	I. Worry, anxiety and phobias	**34**	Loss of financial skills *
1	**Worrying**	**35**	Word finding problems *
2	**Generalised anxiety**	**36**	**Change in personality**
3	**Agoraphobia**	**37**	**Loss of energy**
4	Social phobia *	**38**	**Increased energy levels**
5	**Animal phobia**		**V. Sleep, appetite, & concentration**
6	**Specific phobia**	**39**	**Initial insomnia**
7	**Increased need for reassurance**	**40**	**Mid-insomnia**
8	**Increased somatic complaints**	**41**	**Early morning wakening**
	II. Obsessional phenomena	**42**	**Increased daytime sleeping**
9	**Rituals**	**43**	Reversed sleep pattern *
10	**Excessive orderliness**	**44**	Reduced need for sleep *
11	Obsessional cleanliness *	**45**	**Loss of appetite**
12	Intrusive, distressing thoughts †	**46**	**Increased appetite**
	III. Changes in mood	**47**	**Weight loss**
13	**Low mood**	**48**	**Increased weight**
14	**Increased mood lability**	**49**	**Diurnal variation-worse in the morning**
15	**Irritable mood**	**50**	**Diurnal variation-worse in the evening**
16	**Social withdrawal**	**51**	**Less able to concentrate**
17	**Anhedonia**	**52**	Loss of interest in sex *
18	**Tearfulness**		**VI. Changes in behaviour**
19	Ideas of guilt †	**53**	**Increased verbal aggression**
20	Preoccupied with morbid thoughts †	**54**	Reduced verbal aggression *
21	Loss of self-esteem †	**55**	**Increased physical aggression**
22	Loss of hope for the future †	**56**	Reduced physical aggression *
23	Expansive mood *	**57**	**Self harm/ self-injurious behaviour**
	IV. Functioning, activities & energy	**58**	**Inappropriate sexual behaviour/ libido**
24	**Reduced quantity of speech**	**59**	Reckless, irresponsible behaviour *
25	**Increased quantity of speech**	**60**	Social disinhibition *
26	**Reduced self-care skills**		**VII. Psychosis**
27	**Reduced cognitive functioning**	**61**	Delusions †
28	**Forgetting names**	**62**	Auditory hallucinations †
29	**Gets lost in familiar places**	**63**	Visual hallucination †
30	**Reduced verbal comprehension**	**64**	Schneider's first rank symptoms †
31	**Memory problems**	**65**	Impossible, bizarre delusions †
32	Mixing up day and night *	**66**	Mood incongruous delusions †
33	Loss of literary skills*		

* Items rated positively in less than 5% of cases

† Items only rated if the individual communicates verbally in sentences.

3.5.2.5 Extraction of factors

The two commonest methods of factor analysis used are common factor analysis (CFA) and principal components analysis (PCA). There are concerns over the use of these methods with categorical data, and several alternative statistical methods have been developed to take account of this, such as *non-linear PCA*, used in CATPCA in SPSS (Meulman *et al.* 2004), and *item factor analysis*, used in TESTFACT (Woods *et al.* 2003). Item factor analysis and TESTFACT were used as these were more specifically developed for use with binary data, and have been used previously in EFA of psychopathology binary data (Allardyce *et al.* 2007a).

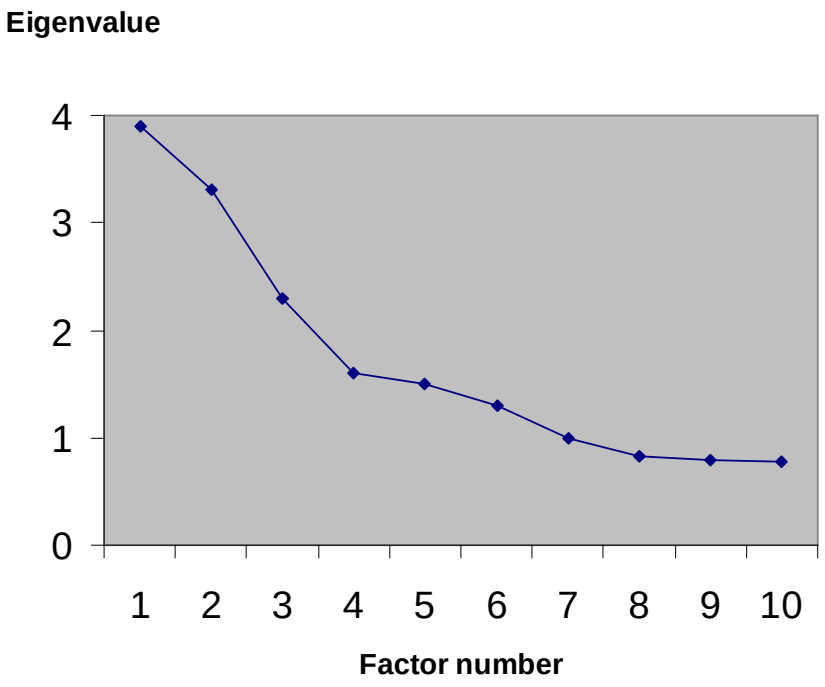
A key decision for a researcher is the number of factors to extract. The first factor extracted comprises the combination of items accounting for the greatest amount of variance. Subsequent factors extracted account for gradually reducing amounts of variance (Field 2005a). Rather than accepting the maximum number of factors extracted, the majority of which account for a too small an amount of variance to be relevant, and are unstable, the researcher has to decide how many factors to extract for the final factor solution. Although there are no absolute rules on which to base this decision, some general guidance is available on how best to manually select the number of factors to extract.

One method is to base the decision on the *eigenvalues* of extracted factors (reported for studies in table 1.2). The eigenvalue is the sum of the squared item loadings on a factor, and represents the total amount of variance accounted for by a factor. To calculate the proportion of the total variance accounted for by a factor the eigenvalue of the factor is divided by the number of the variables in the factor analysis. For example, if there are 20 variables in the dataset, an extracted factor with an eigenvalue of 1, accounts for 0.05, or 5%, of the total variance. Commonly, researchers take the decision to include all factors with an eigenvalues greater than one. However, recommended best-practice suggests that this is the least appropriate strategy (Costello & Osborne 2005). Research has suggested that there are some circumstances when extracting all factors with an eigenvalue greater than one is more likely to be accurate, such as when the number of variables is less than 30. However, as long as the sample size is more than 200 the recommended method is to use the scree test (Field 2005a).

The scree test is carried out by plotting each eigenvalues (y-axis) against the relevant factor (x-axis). Such a scree plot has a typical shape (see figure 3.3 for an example), characterised by a steep line, representing the eigenvalues of the initial factors extracted, followed by a long tail of factors accounting for a smaller proportion of the total variance, with much smaller eigenvalues. The initial number of factors to extract is one less than the factor at which the break point in the scree plot occurs.

In figure 3.3 below, the break point occurs at factor 4 and so the suggested starting point is the extraction of three factors. However, it is common practice to also carry out analyses extracting one more and one less factor than suggested by the scree plot. To decide on the final factor solution, interpretation of the three analyses is carried out to examine aspects relevant to factor stability- the number of items loading onto a factor, and the strength of the item loadings- and finally the practical relevance of the factor solutions. It can be seen from figure 3.3 that extracting factors with eigenvalues above one would suggest a six factor solution, and can, therefore, potentially produce a quite different factor solution.

Figure 3.3: The use of eigenvalues in a scree plot to determine the number of factors to extract



3.5.2.6 The significance of item loadings on factors

When a factor analysis is carried out, a loading for each item to the individual factors is calculated. The researcher decides which items are significant to the factor, usually by examining the size of the item loadings on the factor. A standard approach- again based on general guidance, rather than hard and fast rules- is to set a cut off for the minimum item loading accepted as significant.

An item loading is the correlation of the item and the factors, and so the squared item loading represents the amount of an item's total variance accounted for by the factor. The minimum item loading accepted as significant is usually taken as 0.32, since this translates to the factor accounting for 10% of the variance of the item (Field 2005a). A second approach links the statistical significance of an item loading to the sample size, with the recommendation that for a sample size of 200 a significant item loading is greater than 0.364, and for a sample size of 300 an item loading of 0.298 is significant. Since the sample size used in the EFA reported in chapter 3 is greater than 300, a minimum item loading of 0.32 will ensure greater stability of the factor solution.

A second issue relevant to factor stability is the number of items with loadings above the accepted cut-off for significance- in this case, 0.32. The consensus is that factors with less than three items with significant loadings are unstable (Costello & Osborne 2005). Hence, it was decided that only factors with three or more items, and with loadings greater than 0.32 would be retained in the final factor solution

3.5.2.7 Rotation of factors

Best practice suggests that rotation of initial factors should always be carried out to examine whether it produces a clear and more meaningful solution (Costello & Osborne 2005).

In exploratory factor analysis, the initial solution extracts factors based on the relative size of their contribution to the total variance. This tends to lead to the extraction of one general factor accounting for a large part of the variance, and several additional factors making smaller, and smaller, contributions to the overall variance (Field 2005a). As part of this initial solution items can load onto several different factors- known as cross-loading. By maximising the loading of individual items onto the factor they make the

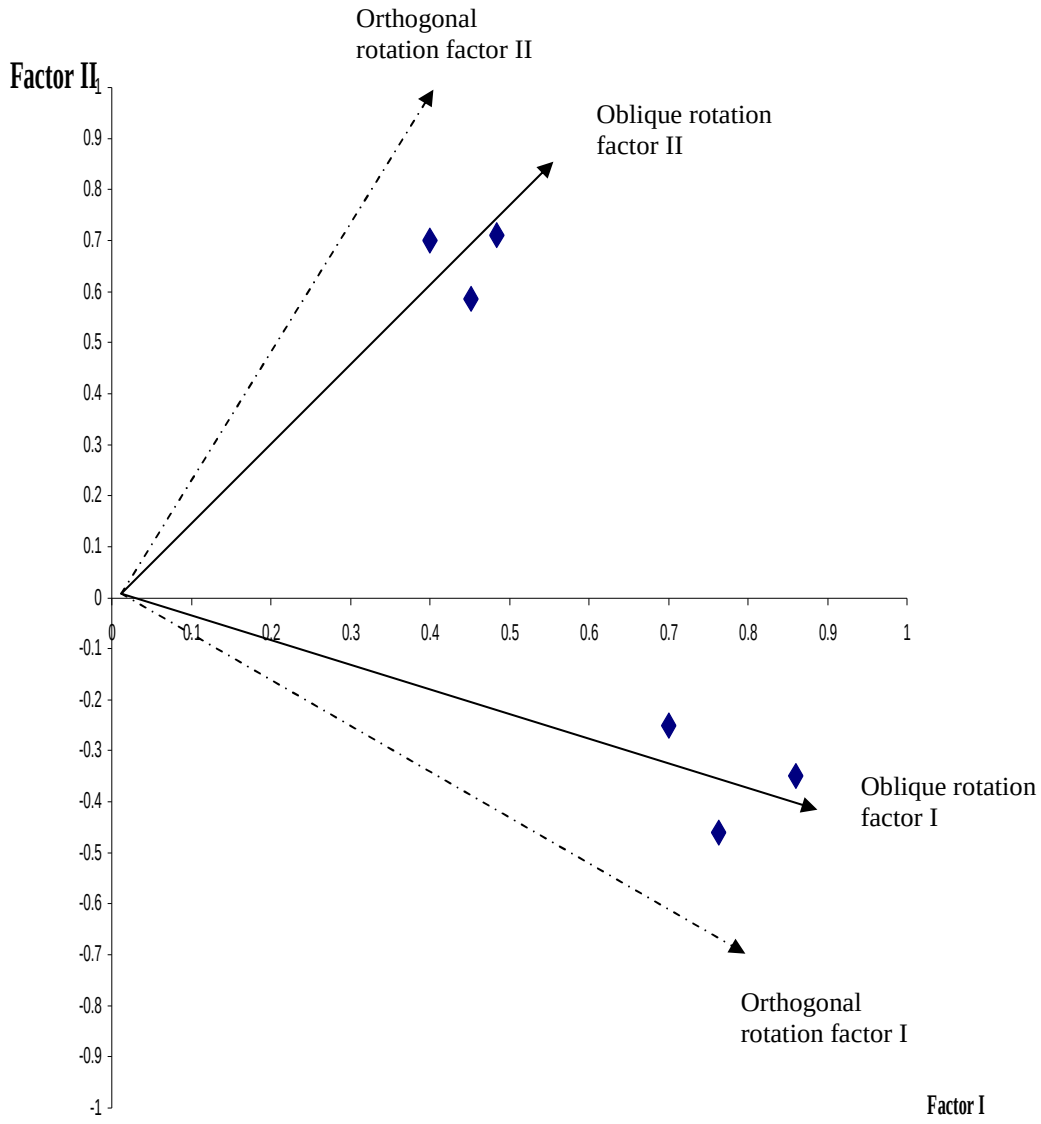
biggest contribution to, rotation of the factors minimises the cross-loading of items across multiple factors and therefore, derives a factor solution that is more straightforward, and potentially easier to interpret (Field 2005a).

A graphical representation of factor solutions helps to explain rotation of factors (Field 2005a). Figure 3.4 below has a graphical representation of a factor analysis. Six items included in the factor analysis are represented in the figure by the letters a-f. A two factor solution is shown with factor I represented on the x axis and factor II on the y axis (adapted from Field 2005a). The loadings for individual items to the two factors can be derived by drawing a perpendicular line to factor I (x-axis) and factor II (y-axis). It is clear that there are two clusters of items a-c and d-f. For the unrotated factors, the axes are represented by the x and y axes, the axes for the orthogonal rotated factors by broken lines and the axes for the oblique rotated factors by bold lines.

From the un-rotated solution, variables a-c have high loadings on factor I, and d-f have moderate loadings on both factors (cross-loading).

There are two methods of rotation- orthogonal and oblique. The assumption for orthogonal rotation is that the factors are uncorrelated, and therefore the axes are held at 90 degrees to one another. In an oblique rotation, the factors are allowed to correlate and so the axes are free floating (not always maintained at 90 degrees). The oblique rotation in figure 4 shows that when the axes are allowed to correlate, items can load together strongly to the most relevant factor. Following the oblique rotation the high loading of items a-c on factor I are maintained whilst maximising the loading of items d-f on factor II on which it has the greater loadings.

Figure 3.4: Graphical representation of orthogonal and oblique rotations of a two factor solution



Since oblique rotation is recommended as best practice (Costello & Osborne 2005), and previous research highlighted the potential relevance of correlations between dimensions of psychopathology in defining higher order internalising and externalising dimensions, an oblique rotation using the PROMAX methodology used in the EFA.

3.5.2.8 Examining the stability of the factor solution

To assess the stability of the factor solution the sample (n=330) was randomly split and the factor analysis repeated separately for the two random samples (Tabachnik & Fidell 2001). To maintain the minimum case: item ratio of 5:1 each sample needed a minimum of 205 cases.

SPSS was used to select a random sample of 205 cases from the 330 used in the EFA. The EFA extracting four factors was run for this first random sample. A second random sample of 205 cases was selected from the original 330 and the EFA run again. To compare the stability of the factor solution across the two halves, Pearson product moment correlations were done to compare the item loadings between the two factor solutions (Tabachnik & Fidell 2001).

3.5.2.9 Calculation of measures representing dimensions of psychopathology

The rotated factor solution was used to derive measures for each dimension of psychopathology, based on calculated factor scores. A factor score is a composite measure representing the degree to which an individual scores positively on the items with high loadings onto a dimension (Hair *et al.* 1998a). For example, if an exploratory factor analysis extracts a dimension labelled depression, an individual's factor score on the hypothetical depression dimension represents the extent to which they reported experiencing the items of psychopathology loading above the accepted cut-off on the dimension. Factor scores have been used in previous studies examining the relationship between dimensions of psychopathology, socio-clinical variables and outcome (Van Os *et al.* 1996; van Os et al 1999a; van Os et al 1999b; Dikeos *et al.* 2006; Prisciandaro & Roberts 2009). The regression method is used to calculate the dimension factor scores (Hair *et al.* 1998a).

It is recommended that more than one method be used to derive measures representing the dimensions extracted from an EFA (Grice 2001). The second measures used here were the dimension symptom counts. These have been used for comparison with the dimension factor scores in previous studies of psychopathology (Van Os *et al.* 1996; van Os *et al* 1999a). Whereas dimension factor scores are a composite measure of all the items used in the EFA, the dimension symptom count are based solely on items shown to load significantly to the individual factors (Hair *et al.* 1998a). Using the example of a

hypothetical depressive dimension of psychopathology, whereas the dimension factor score includes a score representing the items with significant loadings to the factor, and the other items of psychopathology, the dimension symptom count only counts the number of the items with significant loadings that an individual scores positively for. Therefore, dimension symptom counts are more in keeping with a summated scale model (Hair *et al.* 1998a) to represent the dimension of psychopathology, and are used here as the coarse measure of the dimensions of psychopathology. The use of these different measures to represent dimensions of psychopathology in the statistical analyses, will allow consideration of the potential advantages and disadvantages of each scoring method.

To further examine the utility of measures of the dimensions of psychopathology identified in the EFA, two overall measures of psychopathology relevant to the dimensions were also used in the analyses. The total dimension factor score and the total dimension symptom count for each participant were calculated by adding together the individual scores for the identified dimensions.

A third overall measure of psychopathology, unrelated to the dimensional model of psychopathology was derived from the PPS-LD. The EFA PPS-LD symptom count- 41 is calculated for each participant by counting the number of items of psychopathology rated positively, from the 41 PPS-LD items of psychopathology included in the EFA. The inclusion of the three overall measures of psychopathology allow consideration of whether the dimensional model of psychopathology can be used to derive an overall measure of greater relevance than the simple EFA PPS-LD symptom count- 41.

3.5.3 Methods to test null research hypothesis two

Null hypothesis two:
There are no significant correlations between the individual dimensions of psychopathology experienced by adults with intellectual disabilities.

3.5.3.1 Examining the correlations between individual dimensions of psychopathology

Research on dimensional models of psychopathology experienced by children, adolescents and adults, who do not have intellectual disabilities, has identified higher order internalising and externalising dimensions (see section 1.5.1: Achenbach & Edelbrock 1978; Cantwell 1996; Slade & Watson 2006; Slade 2007). To examine whether the higher order dimensions are relevant to psychopathology experienced by adults with intellectual disabilities, the Pearson correlation coefficients for individual dimensions identified in the EFA are examined.

3.5.4 Methods used to test null research hypotheses examining bivariate associations

Null hypothesis three:

There are no significant cross-sectional, bivariate relationships between dimensional measures of psychopathology and socio-clinical variables

Null hypothesis five:

There are no significant bivariate relationships between dimensional measures of psychopathology and measures of the severity of mental disorders:

Null hypothesis six:

There are no significant bivariate relationships between socio-clinical variables and measures of the severity of mental disorders.

Null hypothesis nine:

Dimensional measures of psychopathology are not significantly correlated to the longitudinal outcome of mental disorders.

Null hypothesis ten:

Socio-clinical measures are not significantly associated with the longitudinal outcome of mental disorders.

Where continuous measures are normally distributed, the Pearson correlations are used to examine bivariate correlations between variables. For variables which have a distribution significantly different from normality, non-parametric methods are used to calculate Spearman's correlation coefficient.

For the binary categorical variables (gender, diagnosis of autism, Down syndrome, visual impairment, hearing impairment, urinary incontinence, bowel incontinence and mobility problems) Student t-tests were used to examine whether there are significant between group differences in continuous variables with a normal distribution. The Mann-Whitney test was used to examine between group differences in continuous variables with distributions significantly different from normality.

For the categorical variables with more than two groups (level of intellectual disabilities and epilepsy), analysis of variance (ANOVA) is used to test whether there is a significant difference in the means of continuous variables with a normal distribution. Where there is a significant between group difference on the ANOVA, post-hoc Bonferroni comparison tests are used to examine which pairwise group differences are significant. For variables that do not have a normal distribution, the χ^2 from the Kruskall-Wallis test is used as the non-parametric equivalent to the ANOVA. Post-hoc Mann-Whitney tests are used to examine individual between group differences.

The parametric Student t-test and ANOVA are based on the assumption that there is homogeneity of variance in the data. Levene's test for equality of variances is used to examine if there is homogeneity of variance in data used in the Student t-test and ANOVA. If the result from the Levene's test is significant ($p < .05$) the results reported are for equal variances not assumed. In the case of ANOVA the *Welch F* statistic is reported if Levene's test indicates that the assumption of homogeneity of variance is violated.

For all bivariate analyses, associations with a significance value of $p < .05$ are highlighted in the results tables. However, to take account of multiple testing, inflating the risk of a *Type I* error, a Bonferroni correction was used to adjust the level of significance according to the number of groups, by dividing the accepted level of significance for single tests ($p < .05$) by the number of comparisons (one less than the number of groups). Each categorical group is used as the index variable against which the other categorical groups are compared in the post-hoc tests i.e. mild intellectual disabilities was used as the index variable against which moderate, severe and

profound intellectual disabilities are compared- then repeated with the moderate intellectual disabilities group as the index variable. Thus, the number of comparisons for each of the four groups defining the level of intellectual disabilities variable is three (mild-moderate, mild-severe, mild-profound etc). Therefore, the accepted level of significance is $p < .0167$ (.05/3). The accepted level of significance for the epilepsy variable- defined with three groups and therefore requiring two comparisons against each index categorical group (no epilepsy- well controlled seizures, no epilepsy- poorly controlled seizures) is $p < .025$.

3.5.5 Methods used to test null research hypotheses examining multivariate associations

Null hypothesis four:

There are no significant cross-sectional, multivariate relationships between measures of psychopathology and socio-clinical variables.

Null hypothesis seven:

There are no significant multivariate associations between dimensional measures of psychopathology, socio-clinical variables and measures of the severity of mental disorders.

Null hypothesis eight:

There are no significant differences in the associations of dimensional and categorical models of psychopathology with measures of the severity of mental disorders

Null hypothesis eleven:

Dimensional measures of psychopathology, and socio-clinical variables at baseline, are not independently associated with the longitudinal outcome of mental disorders.

Null hypothesis twelve:

There are no significant differences in the associations of dimensional and categorical models of psychopathology with the longitudinal outcome of mental disorders.

Since the dependent variables of interest are continuous variables (measures of psychopathology, severity and outcome) linear regressions were used to explore the independent relationships with the measures of psychopathology and socio-clinical variables. Given the exploratory nature of the analyses, measures of psychopathology and socio-clinical variables associated with the measures of outcome at a significance of $p < .1$ were included in the linear regression analyses.

Stepwise backward linear regression was used for all analyses. At each step of the analysis, the independent variable with the lowest correlation to the dependant variable is removed. However, a removal criterion was set in order that only those variables with of $p<.05$ were retained within the final model.

To include categorical variables in linear regression analysis dummy variables were used for any variables with more than two groups, such as the variables living circumstances, level of intellectual disabilities and epilepsy. All other categorical variables with two groups are already coded as binary measures and can be used in linear regression.

The number of dummy variables required is one less than the number of groups in the original variable. In the case of level of intellectual disabilities there are four groups (mild, moderate, severe and profound) so three dummy variables are required. These dummy variables are established against mild intellectual disabilities as the baseline variable, such that this group are recoded as 0 in all the dummy variables. Each other group is coded as 1 only once, for the dummy variable with the same name.

To examine if the assumption of homoscedasticity for linear regression is met, and check for cases which are outliers, plots of the residuals were examined for all the final regression models (Field 2005). Residuals are the values representing the difference between the value predicted by the regression model and the value observed in the sample. Therefore, the closer the regression model fits the data the closer to zero the residuals are.

To allow comparison of residuals across regression models that use different variables in the analyses, standardised residuals are calculated. This is achieved by converting

the residuals into z-scores, calculated by taking each residual value, subtracting the mean of all the residuals, and dividing by the standard deviation of all the residuals, This converts the residuals to a known distribution, with a mean of zero and a standard distribution of one. By calculating standardised residuals across regression models, rules based on the normal distribution can be set as to what constitutes an acceptable standardised residual (Field 2005b):

- standardised residuals greater than 3.29 are highly likely to be outliers
- if more than 1% of the sample have standardised residuals greater than 2.58 the level of error in the model is unacceptable
- if more than 5% of the sample have standardised residuals greater than 1.96 the regression model is a poor representation of the data.

In all cases plots of the standardised residuals against the standardised predicted values were made, examining the data points against the criteria above, and looking for evidence of heteroscedasticity on the basis that there unequal variance across the range of the standardised predicted values. In order to assist in the process of identifying outliers with standardised residuals greater than 1.96, case-wise diagnostics reporting the observed value, predicted value, residual and standardised residual are reported for all cases.

To test for strong correlations between significant predictors in the regression models (multicollinearity) the variance inflation factor (VIF) for each significant dependant variable is calculated. These are compared against the guidelines that suggest a VIF above 10 is indicative of significant multicollinearity (Field 2005b), and an average VIF for the dependant variables retained in the model greater than 1 is suggestive that multicollinearity is influencing the results of the regression.

For the final regression models, four test statistics are reported for each independent variable retained in the model:

- unstandardised coefficient (B)
- standard error of B
- standardised coefficient (β)
- significance (p).

For multiple linear regression, these statistics represent the effect of the independent variable on the dependent variable when the effects of all other variables are controlled for (Hair *et al.* 1998b). The unstandardised and standardised coefficients provide a measure of the extent to which a change in the independent variable affects the dependent variable (Hair *et al.* 1998b). The unstandardised coefficient represents the change in the dependant variable if the independent variable changes by a single unit. Since the standardised coefficients are comparable across variables, regardless of the unit of measurement, they are perhaps of greater relevance for regression models with multiple variables, as used here. The standardised coefficient is the number of standard deviations the independent variable increases by if the dependent variable changes by a single standard deviation (Hair *et al.* 1998b).

An overall statistic (R^2) is provided for each regression model to represent how well the model represents the data. The R^2 statistic is a measure of the proportion of the overall variance in the dependent variable explained by the final regression model. It can be converted to a percentage such that if $R^2 = .50$ then the model explains 50% of the variance in the dependent variable (Hair *et al.* 1998b).

3.5.5.1 Regression analyses using the measures of longitudinal outcome as the dependent variable

There is a recognized need to consider the potential influence on a measure of longitudinal outcome, calculated as a change score over time, of the baseline score on the measure at time 1 (Lord 1967). Since the baseline score and the longitudinal change score can be correlated, various methods of adjusting for the baseline value are described (Wainer 1991).

In this thesis, the regression analyses that used longitudinal change scores as the dependant variable were adjusted for the baseline score on the measure. This approach adopted is in keeping with previous studies examining the associations of dimensional and categorical models of psychopathology with longitudinal outcome (van Os *et al.* 1996; Dikeos *et al.* 2006).

3.5.6 Methods used to test null research hypotheses comparing dimensional and categorical models of psychopathology

Null hypothesis eight:

There are no significant differences in the associations of dimensional and categorical models of psychopathology with measures of the severity of mental disorders

Null hypothesis twelve:

There are no significant differences in the associations of dimensional and categorical models of psychopathology with the longitudinal outcome of mental disorders

A binary variable representing a categorical model of psychopathology was derived on the basis of whether or not an individual meets criteria for a DC-LD diagnosis of mental disorder. As shown in table 3.4, at baseline 96 (64%) individuals met the criteria for a DC-LD categorical diagnosis.

Comparisons are made between the relationships of dimensional and categorical models to the measures of the severity and the longitudinal outcome of mental disorders. To achieve this, the measures of severity and outcome are used as the dependant variables in three separate linear regression models using:

1. only the variables representing the dimensional of psychopathology
2. only the binary variable representing the categorical model of psychopathology
3. the variables representing both the dimensional and categorical models of psychopathology

The regression analyses, including the dimensional measures of psychopathology, are carried out in relation to null hypotheses seven and eleven. The same socio-clinical variables included in these analyses, on the basis of the results of the bivariate analyses, were included in the two other sets of linear regression described above. These separate analyses are run for each of the measures of severity and outcome.

The three regression models above with each measure of severity and outcome as the dependant variable are compared to examine if the variables representing the dimensional and categorical models are retained as significant (van Os *et al.* 1996). Two results from the regression analyses were examined to compare the dimensional and categorical models of psychopathology:

- the standardised coefficient (β)- representing the size of the effect of each psychopathology variable on the dependent variable
- R^2- the proportion of the variance of the dependent variable explained by the overall regression model.

Chapter 4: Results

This chapter is organised in relation to the 12 research hypotheses from chapter 2. For convenience, these are stated at the start of the relevant section.

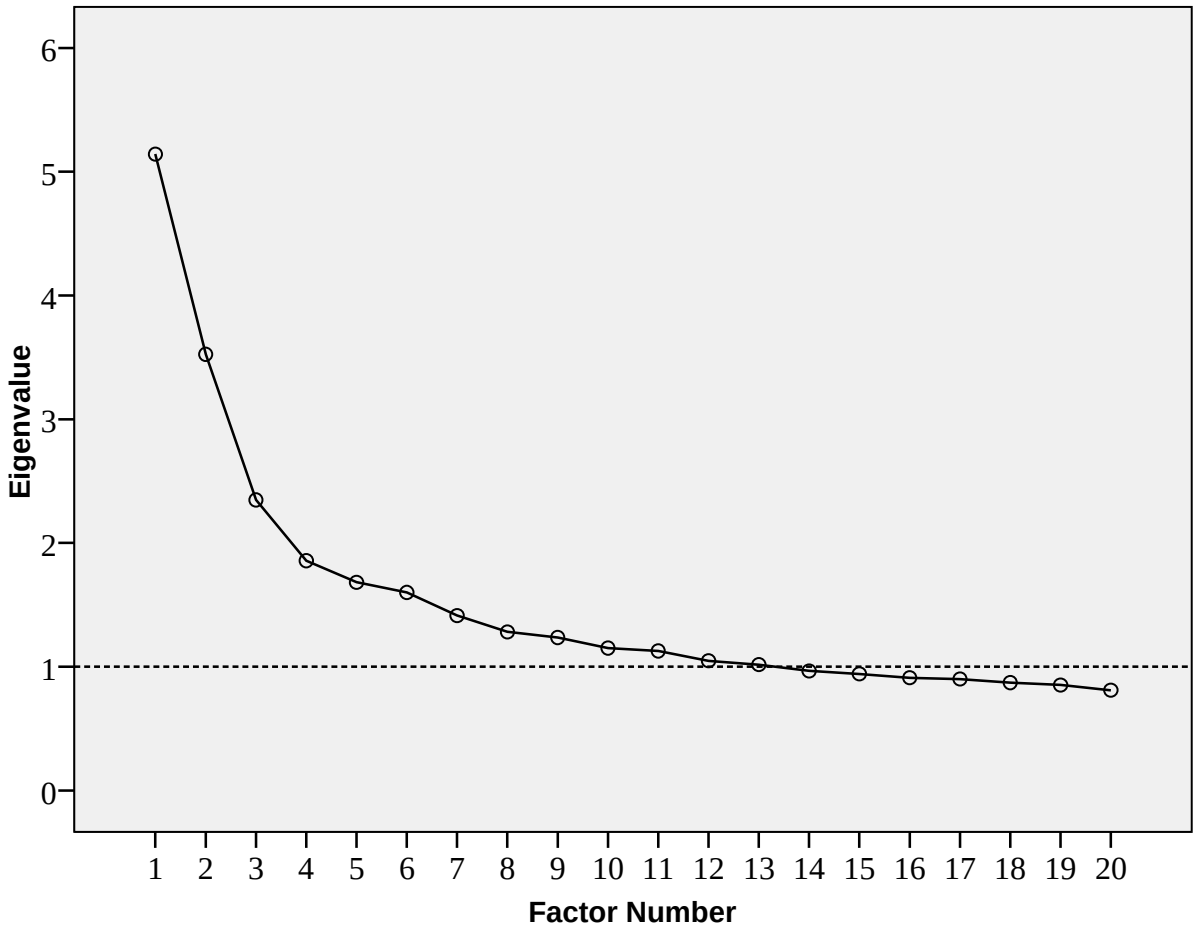
4.1 Identifying dimensions of psychopathology from the PPS-LD

Null hypothesis one:
There are no stable, identifiable dimensions of psychopathology experienced by adults with intellectual disabilities.

As described in section 3.5.2.4, problems can arise in EFA if there are items included which are not significantly correlated with any other items, or if variables are too highly correlated (multi-collinearity, defined as $r \geq .9$). This was checked in a correlation matrix. All items of psychopathology were significantly correlated with at least one other item and there were no items with correlation co-efficients above 0.9. Therefore, all 41 items were retained for the EFA.

The scree plot in figure 4.1 below was used as a guide to the predicted number of factors to extract from the EFA. From an initial EFA, the eigenvalues of the factors extracted were plotted and the scree plot examined to find the break point in the slope between the initial steep gradient- representing the initial factors with greater, more significant, eigenvalues- and the more gradual sloping gradient, with the smaller eigenvalues representing the vast majority of factors.

Figure 4.1: Scree plot of eigenvalues of first 20 factors extracted.



In figure 4.1, the eigenvalues of the first 20 factors extracted are plotted. It appears that the break point occurs at factor 4, suggesting that the final solution will have three extracted factors. Guidelines for EFA best practice (Costello & Osborne 2005) recommend examining the solutions with one more, and one less factors, than suggested by the scree plot. This allows consideration of the relevance and coherence of different factor solutions. Therefore, the factor solutions with two, three and four factors extracted were examined.

In tables 4.1, 4.2 and 4.3 below, the non-rotated and the rotated (Promax oblique rotation is used in all EFAs) solutions are shown for the two, three and four factor

solutions. The loading for each item of psychopathology to the specific factors is reported and loadings greater than or equal to 0.32 highlighted in bold.

Based on the number of items loading onto the factors and the size of the item loadings, all three solutions in tables 4.1, 4.2 and 4.3 have adequate stability. Since the four factor solution accounts for a greater percentage of the total variance, if the items loading onto the four factors seem coherent and interpretable then the four factor solution would be accepted as the final solution. To consider this further the four factors were examined in some detail.

The nature of EFA is such that as the number of factors extracted increases the percentage of the total variance explained by each additional factor decreases. Therefore, we might expect that there would be fewer items loading significantly onto these factors with lower percentage variances, and the actual items loadings would be smaller.

Table 4.1: Non-rotated and rotated two factor solutions for EFA with 41 items of psychopathology.

	Non-rotated solution		Rotated solution	
	Factor		Factor	
	1	2	1	2
worry	.145	.169	.225	-.102
generalised anxiety	.113	.220	.232	-.163
agoraphobia	.103	.062	.123	-.017
animal phobia	.034	.128	.107	-.110
specific phobia	-.091	-.054	-.109	.017
rituals	-.081	-.040	-.091	.005
orderliness	-.139	-.042	-.140	-.017
low mood	**.662**	.158	**.641**	.119
labile mood	**.343**	.260	**.445**	-.108
irritability	**.460**	.290	**.560**	-.089
social withdraw	**.631**	.082	**.567**	.178
anhedonia	**.707**	.019	**.589**	.269
talk loss	**.552**	-.209	.318	**.423**
talk gain	.091	.121	.151	-.078
tearfulness	**.469**	.193	**.506**	.006
reduced self care	**.663**	-.170	**.433**	**.431**
loss of energy	**.588**	-.190	**.359**	**.419**
increased energy	.074	.269	.231	-.226
loss of cognitive skills	**.322**	**-.651**	-.151	**.750**
name loss	.202	**-.575**	-.200	**.629**
place loss	.161	**-.666**	-.291	**.698**
reduced comprehension	**.336**	**-.653**	-.141	**.758**
loss of memory	.282	**-.694**	-.211	**.775**
change in personality	**.321**	**-.535**	-.077	**.639**
initial insomnia	.228	.257	**.349**	-.151
mid-insomnia	.276	.230	**.371**	-.107
early morning wakening	.195	.231	.306	-.140
increased daytime sleep	.255	-.052	.175	.153
loss of appetite	**.512**	.156	**.517**	.059
increased appetite	.069	-.058	.020	.083
weight loss	**.386**	.170	**.423**	-.005
weight gain	.023	.001	.020	.008
diurnal variation - evening	.161	.081	.183	-.011
diurnal variation -morning	.173	.187	.260	-.108
reduced concentration	**.534**	.071	**.481**	.149
increased verbal aggression	**.367**	.298	**.488**	-.135
increased physical aggression	**.332**	.311	**.469**	-.161
need for reassurance	**.490**	.131	**.483**	.074
self harm/ SIB	.214	.302	**.367**	-.201
somatic concerns	.226	.152	.281	-.053
sexual behaviour	.190	.147	.249	-.063
eigenvalue	5.16	3.51	4.84	4.03
% total variance	12.5	8.54	11.80	9.83

Table 4.2: Non-rotated and rotated three factor solution for the EFA of 41 items of psychopathology

	Non-rotated solution			Rotated solution		
	Factor			Factor		
	1	2	3	1	2	3
worry	.145	.169	-.026	.146	-.123	.112
generalised anxiety	.113	.220	-.085	.177	-.201	.073
agoraphobia	.103	.062	-.131	.187	-.079	-.046
animal phobia	.034	.128	.026	.018	.096	.097
specific phobia	-.091	-.054	-.076	-.009	-.006	-.127
rituals	-.081	-.040	.271	-.281	.122	.185
orderliness	-.139	-.042	.247	-.304	.098	.143
low mood	**.662**	.158	-.225	**.674**	-.048	.129
labile mood	**.343**	.260	.260	.070	-.035	**.477**
irritability	**.460**	.290	**.336**	.096	.000	**.601**
social withdraw	**.631**	.082	-.226	**.643**	.011	.080
anhedonia	**.707**	.019	-.313	**.758**	.054	.002
talk loss	**.552**	-.209	-.172	**.505**	.274	-.042
talk gain	.091	.121	**.353**	-.203	.057	**.397**
tearfulness	**.469**	.193	-.031	**.385**	-.057	.241
reduced self care	**.663**	-.170	-.068	**.505**	.311	.109
loss of energy	**.588**	-.190	-.296	**.633**	.217	-.127
increased energy	.074	.269	.254	-.117	-.121	.376
loss of cognitive skills	**.322**	**-.651**	.149	.024	**.737**	-.061
name loss	.202	**-.575**	.182	-.078	**.648**	-.041
place loss	.161	**-.666**	.207	-.139	**.729**	-.078
reduced comprehension	**.336**	**-.653**	.266	-.060	**.790**	.045
loss of memory	.282	**-.694**	.197	-.049	**.784**	-.054
change in personality	**.321**	**-.535**	.121	.061	**.621**	-.029
initial insomnia	.228	.257	.166	.063	-.102	**.352**
mid-insomnia	.276	.230	.076	.166	-.101	.278
early morning wakening	.195	.231	.158	.042	-.091	**.320**
increased daytime sleep	.255	-.052	-.120	.272	.070	-.033
loss of appetite	**.512**	.156	-.454	.751	-.180	-.127
increased appetite	.069	-.058	.295	-.196	.189	.254
weight loss	**.386**	.170	-.350	**.579**	-.186	-.078
weight gain	.023	.001	.253	-.187	.107	.229
diurnal variation - evening	.161	.081	-.057	.172	-.051	.049
diurnal variation -morning	.173	.187	.185	-.001	-.047	.315
reduced concentration	**.534**	.071	.176	.249	.155	**.387**
increased verbal aggression	**.367**	.298	**.496**	-.099	.031	**.709**
increased physical aggression	**.332**	.311	**.441**	-.078	-.013	**.655**
need for reassurance	**.490**	.131	.037	**.337**	.032	.278
self harm/ SIB	.214	.302	**.398**	-.128	-.055	**.569**
somatic concerns	.226	.152	.100	.101	-.034	.243
sexual behaviour	.190	.147	.199	-.005	-.001	.314
eigenvalue	5.16	3.51	2.32	4.16	3.61	3.30
% total variance	12.50	8.54	5.66	10.15	8.80	8.04

Table 4.3: Non-rotated and rotated four factor solution for EFA of 41 items of psychopathology

	Non-rotated solution				Rotated solution			
	Factor				Factor			
	1	2	3	4	1	2	3	4
worry	.145	.169	-.026	**.543**	.022	-.045	-.173	**.603**
generalised anxiety	.113	.220	-.085	**.513**	.056	-.126	-.193	**.570**
agoraphobia	.103	.062	-.131	**.365**	.104	-.027	-.223	**.378**
animal phobia	.034	.128	.026	.017	.007	-.093	.078	.052
specific phobia	-.091	-.054	-.076	-.019	-.002	-.009	-.105	-.055
rituals	-.081	-.040	.271	.108	-.293	.134	.108	.130
orderliness	-.139	-.042	.247	.153	-.325	.117	.047	.163
low mood	**.662**	.158	-.225	-.083	**.665**	-.055	.165	.016
labile mood	**.343**	.260	.260	-.047	.063	-.040	**.448**	.101
irritability	**.460**	.290	**.336**	-.031	.084	-.002	**.552**	.153
social withdraw	**.631**	.082	-.226	-.012	**.625**	.013	.086	.067
anhedonia	**.707**	.019	-.313	-.098	**.759**	.044	.063	-.035
talk loss	**.552**	-.209	-.172	-.094	**.524**	.260	.021	-.083
talk gain	.091	.121	**.353**	.313	-.269	.100	.194	**.410**
tearfulness	**.469**	.193	-.031	-.058	**.376**	-.061	.248	.050
reduced self care	**.663**	-.170	-.068	-.006	**.504**	.309	.111	.048
loss of energy	**.588**	-.190	-.296	-.045	**.637**	.211	-.078	-.043
increased energy	.074	.269	.254	.263	-.183	-.082	.199	**.374**
loss of cognitive skills	**.322**	**-.651**	.149	.039	.054	**.733**	-.063	-.030
name loss	.202	**-.575**	.182	-.106	-.020	**.625**	.025	-.173
place loss	.161	**-.666**	.207	.043	-.105	**.724**	-.082	-.045
reduced comprehension	**.336**	**-.653**	.266	.161	-.053	**.802**	-.030	.112
loss of memory	.282	**-.694**	.197	.028	-.013	**.777**	-.052	-.049
change in personality	**.321**	**-.535**	.121	.129	.065	**.631**	-.081	.082
initial insomnia	.228	.257	.166	**.350**	-.025	-.051	.136	**.469**
mid-insomnia	.276	.230	.076	.036	.141	-.093	.230	.140
early morning wakening	.195	.231	.158	.083	.011	-.077	.242	.188
increased daytime sleep	.255	-.052	-.120	-.132	.295	.052	.042	-.125
loss of appetite	**.512**	.156	-.454	.097	**.704**	-.161	-.154	.140
increased appetite	.069	-.058	.295	.309	-.251	.229	.071	**.355**
weight loss	**.386**	.170	-.350	.012	**.553**	-.179	-.070	.055
weight gain	.023	.001	.253	.263	-.236	.141	.070	**.339**
diurnal variation - evening	.161	.081	-.057	**.346**	.092	-.001	-.128	**.382**
diurnal variation -morning	.173	.187	.185	-.225	.034	-.077	**.392**	-.131
reduced concentration	**.534**	.071	.176	-.077	.255	.144	**.388**	.046
increased verbal aggression	**.367**	.298	**.496**	-.290	-.054	-.009	**.775**	-.096
increased physical aggression	**.332**	.311	**.441**	-.394	-.013	-.066	**.779**	-.212
need for reassurance	**.490**	.131	.037	.210	.278	.063	.147	**.321**
self harm/ SIB	.214	.302	**.398**	-.169	-.107	-.077	**.588**	-.011
somatic concerns	.226	.152	.100	.202	.048	-.005	.115	.287
sexual behaviour	.190	.147	.199	-.141	.015	-.020	**.350**	-.051
eigenvalue	5.16	3.51	2.32	1.85	4.02	3.57	3.06	2.23
% total variance	12.50	8.54	5.66	4.51	9.80	8.70	7.47	5.44

Although the labelling and interpretation of the dimensions extracted from EFA is a crucial part of the research process, this aspect is discussed less often in best practice guidelines (Costello & Osborne 2005), or textbooks on factor analysis. Since interpretation of the results of EFA is largely subjective researchers are recommended to fully consider alternative labels for extracted factors (Ford et al, 1986), aiming for a simple, recognisable label that adequately represents the items that load to the factor (Child, 2006).

Factor one in the rotated solution comprises nine items of psychopathology;

- low mood
- social withdrawal
- anhedonia
- reduced verbal communication
- tearfulness
- reduced self-care
- lower energy levels
- loss of appetite
- weight loss

Since eight of the nine items have loadings to the depressive dimension greater than 0.5, this dimension would be expected to have good reliability and stability (Hair *et al* 1998a). It is perhaps surprising that none of the four items relating to sleep load significantly to the depressive dimension. However, overall, the dimension appears coherent and is readily interpretable.

Several possible factor labels to represent this dimension of psychopathology were considered including *depressive, internalising psychopathology* and *bio-psycho-social withdrawal.*

Two main reasons to label this dimension of psychopathology with the term *depressive* were considered. The nine items of psychopathology extracted in this first dimension are included amongst criteria for depressive disorders in existing categorical diagnostic classification systems. There is overlap between the items of psychopathology extracted here from the PPS-LD data, and items of psychopathology

in dimensions labelled with the term *depressive* in studies in table 1.2. Thus, using the *depressive* label would be consistent with existing categorical diagnostic classification systems, previous studies and would be familiar to clinicians and researchers.

All nine items of psychopathology represent affective or behaviour changes that largely impact on the individual, rather than other people or the surrounding environment. Therefore, this dimension could be appropriately labelled with the term *internalising psychopathology*. However, as described in section 1.5.1, this is a term that is commonly used to describe a higher order dimension of psychopathology experienced by children and adolescents. The higher order internalising dimension of psychopathology represents a dimension that includes a broader range of psychopathology than the nine items extracted here, including affective, generalised anxiety, phobic and panic psychopathology. Since the *internalising* term is a distinct concept in the psychopathology literature, to avoid confusion it was decided not to use this as a label for the first dimension.

It was recognised that at least some of the items of psychopathology extracted in the first dimension were not directly related to changes in affect or mood. For example social withdrawal, reduced verbal communication and reduced self-care all represent changes in behaviour that can occur without any affective changes. The label *psycho-social withdrawal* was considered as it seemed to describe both the affective and behavioural change represented by the majority of items of psychopathology in the first factor. However, this label does not really capture three items of psychopathology that are often to be considered biological in nature- lower energy levels, loss of appetite and weight loss. Therefore, *bio-psycho-social withdrawal* may be a more comprehensive representation of the items of psychopathology extracted in the first factor.

Although the *depressive* and *bio-psycho-social withdrawal* labels both appear to adequately represent the nine items of psychopathology in the first dimension, it was decided to label this as a depressive dimension. The reason for this is that it is in keeping with the labelling of similar dimensions in previous intellectual disabilities studies, thus facilitating comparison with previous research.

The second dimension extracted from the PPS-LD data had six items:

- change in cognitive functioning
- forgetting the names of familiar people
- getting lost in familiar places
- reduced verbal comprehension
- memory problems
- change in personality.

Labels considered in naming this dimension of psychopathology included *confusion*, *organic* and *cognitive impairment*. Since the label *confusion* was felt to be non-specific, and could be interpreted as representing an individual's experience of brief periods of subjective uncertainty, it was discounted and *organic* and *cognitive* considered further.

Both these terms meet the criteria of being good descriptions of the six items of psychopathology in the second dimension of psychopathology extracted. Clinicians and researchers would be likely to readily accept that there is a relationship between the items of psychopathology and either of these terms. One issue considered was the fact that *change in cognitive functioning* was one of the items of psychopathology that loaded to the dimension. Since the term *organic* could encompass this and the five additional items it was decided that it was preferable as the label for this dimension.

One point of interest from the depressive and organic dimensions is that the item of psychopathology indicative of a reduction in self-care skills is primarily loaded onto the depressive dimension. Although the reduced self-care item has a loading of 0.309 to the organic dimension (accepted as significant by some of the studies in table 1.2), there is a stronger loading of 0.504 to the depressive dimension. Nonetheless, overall the organic dimension does appear coherent and relevant to the assessment of psychopathology and mental disorders.

The third dimension extracted in the EFA was more problematic to label. This dimension included eight individual items of psychopathology:

- increased mood lability
- increased irritability

- diurnal variation in mood-worse in the morning
- reduced concentration
- increased verbal aggression
- increased physical aggression
- increased self-injurious or self-harming behaviour
- a change in sexual behaviour.

Of the eight items of psychopathology that loaded to this dimension four represented changes in behaviour (verbal aggression, physical aggression, self-injurious and change in sexual behaviour) and three involved affective changes (mood lability, increased irritability, diurnal variation in mood-worse in the morning). Although the final item of psychopathology (reduced concentration) stood alone, it was recognised that it is often described by individuals experiencing affective changes. Therefore, this dimension was conceptualised as being made up of four items of behaviour change and four affective items.

Clearly, the labels *affective change* and *behaviour change* would only represent half of the items in the dimension, and so were discounted. However, the combined term *behaviour-affective* was considered, along with *instability*, and *externalising psychopathology*.

Similar to the term *internalising psychopathology* described above, the term externalising psychopathology is used to represent a higher order dimension of psychopathology. This dimension usually includes conduct, anti-social or problem behaviour psychopathology, hyperactivity and inattention. To avoid confusion with the construct represented by *externalising psychopathology* in the literature this label was not considered further.

The term *instability* encapsulates the fact that each of the items of psychopathology extracted in the third dimension represents a change from baseline. However, all items on the PPS-LD are only rated positively if there has been a change. Therefore, the concept of change could equally apply to all the dimensions. Furthermore, the term instability implies that an affect or behaviour is unstable, changing rapidly and frequently. Whilst this feature is likely to be true for mood lability, it is less likely to

be the case for other items of psychopathology loading to this dimension. For example, an individual may experience increased irritability or poor concentration as persistent changes that do not fluctuate over time. Due to these issues around the meaning of the term *instability*, it was discounted as a potential label for the third dimension. However, in section 5.1.5 the relevance of change or instability to the overall multi-dimensional model of psychopathology is discussed.

The label finally accepted for the third dimension was, therefore, *behaviour-affective*. It was felt that this label adequately describes the balance in the different items of psychopathology in the dimension. Importantly, *behaviour-affective* is a straightforward term, familiar to psychopathology researchers and the use of the term affective differentiates this dimension from the depressive dimension.

Finally, the fourth dimension included 10 items of psychopathology:

- worrying
- generalised anxiety
- agoraphobia
- increased verbal communication
- increased energy levels
- initial insomnia greater than one hour
- increased appetite
- weight gain
- diurnal mood variation- worse in the evening
- increased need for reassurance.

Terms considered as a potential label for this dimension included *over-arousal*, *over-activation* and *anxiety*.

An aspect of the terms *overarousal* and *overactivation* considered was their use in the literature to link psychopathology with a specific biologically-based system. For example, sympathetic *overarousal* and externalising behaviour in children, or hemispheric and temporal *overactivation* in schizophrenia. Although both these terms seem applicable to the items of psychopathology that loaded to this dimension, at this stage in researching the multi-dimensional model any label would ideally be

descriptive. Without further research investigating causative mechanisms it is preferable to avoid the use of terms that imply involvement of specific biological systems. Therefore, *overarousal* and *overactivation* were not considered appropriate labels for this dimension. However, the concepts of arousal and activation are further discussed in section 5.1.5, in relation to constructs of relevance to a multi-dimensional model of psychopathology.

Instead, the descriptive term *anxiety* was decided upon. Similar to labels used for the other dimensions it is simple and concisely describes the items that load to the fourth dimension. Each of the 10 items of psychopathology is readily associated to the label *anxiety*, and the label distinguishes this dimension from the previous three.

Perhaps the items rating increased verbal communication and increased energy levels need further consideration but overall, like the other three factors, the anxiety dimension is readily interpretable.

Although the scree plot in figure 4.1 suggested examining two, three and four factor solutions there are two specific reasons to look at additional solutions. Firstly, factor four in table 4.3 has 10 items loading above 0.32- significantly greater than the minimum of three suggested by best practice guidance. This suggests that there may well be additional stable factors that could be extracted. The second reason for extending the examination of solutions to those with more factors relates to the previous studies that have used EFA to examine the structure of psychopathology experienced by adults with intellectual disabilities (see section 1.6.1). Since there were eight dimensions of psychopathology identified across studies, the extraction of a greater number of factors than in the four dimensional model above might have been predicted. For these reasons, five and six factor solutions were examined to look at whether there are additional coherent dimensions that emerge from the data.

The rejection of the six factor solution is straightforward. In table 4.5, there are only two items with loadings greater than 0.32 to the sixth factor. Therefore, the six factor solution does not meet the requirement that there are at least three items loading onto a factor to ensure stability. A decision on which solution to accept as the final dimensional model in thus narrowed to between the four and five factor solutions. In

table 4.4, we can see that in the five factor solution all the factors meet the criterion for at least three items loading to each factor- with five items loading to factor five:

- increased verbal communication
- increased energy levels
- initial insomnia greater than one hour
- mid-insomnia greater than one hour
- early morning wakening greater than one hour.

Table 4.4: Non-rotated and rotated five factor solution for EFA of 41 items of psychopathology

	Non-rotated solution					Rotated solution				
	Factor					Factor				
	1	2	3	4	5	1	2	3	4	5
worry	.145	.169	-.026	.543	-.152	.009	-.081	-.162	**.623**	.096
generalised anxiety	.113	.220	-.085	.513	-.036	.046	-.136	-.209	**.549**	.179
agoraphobia	.103	.062	-.131	.365	-.208	.082	-.073	-.184	**.452**	-.074
animal phobia	.034	.128	.026	.017	-.181	-.011	-.128	-.120	-.114	-.116
specific phobia	-.091	-.054	-.076	-.019	-.034	-.010	-.016	-.087	-.028	-.081
rituals	-.081	-.040	.271	.108	.220	-.264	.180	.045	.003	.296
orderliness	-.139	-.042	.247	.153	.052	-.311	.127	.026	.105	.150
low mood	**.662**	.158	-.225	-.083	-.108	**.661**	-.080	.181	.078	-.087
labile mood	.343	.260	.260	-.047	-.115	.075	-.064	**.453**	.100	.056
irritability	**.460**	.290	**.336**	-.031	-.272	.091	-.061	**.589**	.202	-.035
social withdraw	**.631**	.082	-.226	-.012	-.037	**.625**	.002	.085	.099	-.020
anhedonia	**.707**	.019	-.313	-.098	.019	**.762**	.045	.054	-.006	-.033
talk loss	**.552**	-.209	-.172	-.094	-.122	**.523**	.230	.054	.001	-.179
talk gain	.091	.121	**.353**	.313	.266	-.231	.153	.100	.230	**.485**
tearfulness	**.469**	.193	-.031	-.058	-.004	**.385**	-.063	.234	.042	.060
reduced self care	**.663**	-.170	-.068	-.006	.020	**.521**	.308	.098	.052	.029
loss of energy	**.588**	-.190	-.296	-.045	-.179	**.626**	.168	-.030	.075	-.243
increased energy	.074	.269	.254	.263	**.531**	-.133	.029	.040	.092	**.703**
loss of cognitive skills	.322	**-.651**	.149	.039	.041	.081	**.733**	-.065	-.032	-.014
name loss	.202	**-.575**	.182	-.106	.117	.011	**.644**	.009	-.205	.018
place loss	.161	**-.666**	.207	.043	.185	-.068	**.756**	-.117	-.111	.112
reduced comprehension	**.336**	**-.653**	.266	.161	.100	-.015	**.813**	-.054	.064	.117
loss of memory	.282	**-.694**	.197	.028	.094	.021	**.789**	-.065	-.075	.030
change in personality	**.321**	**-.535**	.121	.129	-.114	.078	**.599**	-.051	.134	-.102
initial insomnia	.228	.257	.166	**.350**	.140	-.004	-.024	.070	**.352**	**.375**
mid-insomnia	.276	.230	.076	.036	**.406**	.179	-.008	.112	-.054	**.474**
early morning wakening	.195	.231	.158	.083	**.415**	.052	.010	.119	-.022	**.514**
increased daytime sleep	.255	-.052	-.120	-.132	.052	.300	.062	.033	-.122	-.021
loss of appetite	**.512**	.156	-.454	.097	.285	**.710**	-.103	-.231	.060	.235
increased appetite	.069	-.058	.295	.309	-.232	-.250	.176	.109	**.397**	-.014
weight loss	.386	.170	-.350	.012	.337	**.566**	-.108	-.158	-.055	.273
weight gain	.023	.001	.253	.263	-.532	-.261	.026	.184	**.478**	-.299
diurnal variation - evening	.161	.081	-.057	**.346**	-.048	.087	-.014	-.133	**.381**	.094
diurnal variation -morning	.173	.187	.185	-.225	-.104	.040	-.097	**.409**	-.111	-.053
reduced concentration	**.534**	.071	.176	-.077	.043	.281	.150	**.359**	.002	.138
increased verbal aggression	**.367**	.298	**.496**	-.290	-.039	-.021	-.016	**.760**	-.146	.122
increased physical aggression	**.332**	.311	**.441**	-.394	-.047	.015	-.073	**.772**	-.245	.062
need for reassurance	**.490**	.131	.037	.210	-.175	.278	.023	.166	**.362**	.010
self harm/ SIB	.214	.302	**.398**	-.169	.024	-.081	-.070	**.560**	-.080	.174
somatic concerns	.226	.152	.100	.202	-.157	.046	-.040	.134	.315	.019
sexual behaviour	.190	.147	.199	-.141	-.058	.026	-.031	**.353**	-.054	.014
eigenvalue	5.16	3.51	2.32	1.85	1.62	4.03	3.56	2.91	2.13	1.95
% total variance	12.50	8.54	5.66	4.51	3.95	9.83	8.68	7.10	5.20	4.476

Table 4.5: Non-rotated and rotated six factor solution for EFA of 41 items of psychopathology

	Non-rotated solution						Rotated solution					
	Factor						Factor					
	1	2	3	4	5	6	1	2	3	4	5	6
worry	.145	.169	-.026	**.543**	-.152	-.139	.012	-.066	-.186	**.619**	.143	-.085
generalised anxiety	.113	.220	-.085	**.513**	-.036	.226	.110	-.161	-.193	**.509**	.109	.264
agoraphobia	.103	.062	-.131	**.365**	-.208	.265	.136	-.103	-.165	**.419**	-.146	.240
animal phobia	.034	.128	.026	.017	.181	.128	.015	-.138	.122	.098	-.140	.116
specific phobia	-.091	-.054	-.076	-.019	-.034	-.011	-.021	-.015	-.087	-.029	-.077	-.030
rituals	-.081	-.040	.271	.108	.220	**.677**	-.122	.104	.118	-.047	.070	**.767**
orderliness	-.139	-.042	.247	.153	.052	**.680**	-.175	.051	.096	.059	-.069	**.746**
low mood	**.662**	.158	-.225	-.083	-.108	-.125	**.634**	-.068	.158	.079	-.035	-.237
labile mood	**.343**	.260	.260	-.047	-.115	.006	.087	-.066	**.445**	.118	.058	.018
irritability	**.460**	.290	**.336**	-.031	-.272	-.122	.082	-.049	**.562**	.240	.012	-.117
social withdraw	**.631**	.082	-.226	-.012	-.037	.037	**.633**	-.004	.081	.084	-.022	-.056
anhedonia	**.707**	.019	-.313	-.098	.019	-.002	**.758**	.042	.048	-.023	-.023	-.120
talk loss	**.552**	-.209	-.172	-.094	-.122	.053	**.530**	.221	.053	-.006	-.184	-.047
talk gain	.091	.121	.353	.313	.266	-.122	-.203	.166	.087	.236	**.502**	.058
tearfulness	**.469**	.193	-.031	-.058	-.004	-.047	**.381**	-.059	.223	.045	.079	-.087
reduced self care	**.663**	-.170	-.068	-.006	.020	.020	**.541**	.302	.094	.044	.025	-.020
loss of energy	**.588**	-.190	-.296	-.045	-.179	.163	**.646**	.147	-.021	.053	-.277	.025
increased energy	.074	.269	.254	.263	**.531**	-.065	-.095	.037	.038	.079	**.693**	.125
loss of cognitive skills	**.322**	**-.651**	.149	.039	.041	.008	.111	**.727**	-.064	-.028	-.023	.055
name loss	.202	**-.575**	.182	-.106	.117	.039	.038	**.635**	.016	-.199	-.004	.085
place loss	.161	**-.666**	.207	.043	.185	-.169	-.064	**.770**	-.130	-.094	.149	-.067
reduced comprehension	**.336**	**-.653**	.266	.161	.100	-.071	.017	**.816**	-.062	.074	.126	.037
loss of memory	.282	**-.694**	.197	.028	.094	-.012	.050	**.785**	-.065	-.067	.024	.057
change in personality	**.321**	**-.535**	.121	.129	-.114	-.004	.101	**.595**	-.056	.141	-.100	.022
initial insomnia	.228	.257	.166	**.350**	.140	.007	.034	-.025	.066	**.341**	**.363**	.112
mid-insomnia	.276	.230	.076	.036	**.406**	-.224	.168	.017	.091	-.052	**.525**	-.135
early morning wakening	.195	.231	.158	.083	**.415**	-.222	.046	.035	.100	-.017	**.562**	-.101
increased daytime sleep	.255	-.052	-.120	-.132	.052	.062	.306	.054	.039	-.132	-.038	.007
loss of appetite	**.512**	.156	-.454	.097	.285	.002	**.716**	-.104	-.231	.017	.232	-.065
increased appetite	.069	-.058	.295	.309	-.232	-.294	-.274	.207	.070	**.434**	.079	-.201
weight loss	**.386**	.170	-.350	.012	**.337**	.124	**.591**	-.122	-.143	-.099	.228	.077
weight gain	.023	.001	.253	.263	-.532	-.131	-.276	.040	.156	**.514**	-.241	-.116
diurnal variation - evening	.161	.081	-.057	**.346**	-.048	-.219	.069	.009	-.161	**.384**	.163	-.182
diurnal variation -morning	.173	.187	.185	-.225	-.104	.126	.055	-.111	**.417**	-.099	-.087	.096
reduced concentration	**.534**	.071	.176	-.077	.043	.209	**.335**	.125	**.374**	-.006	.072	.210
increased verbal aggression	**.367**	.298	**.496**	-.290	-.039	-.040	-.017	-.012	**.749**	-.106	.133	.000
increased physical aggression	**.332**	.311	**.441**	-.394	-.047	.035	.022	-.077	**.769**	-.210	.052	.042
need for reassurance	**.490**	.131	**.037**	.210	-.175	.204	**.331**	-.002	.175	**.345**	-.045	.183
self harm/ SIB	.214	.302	**.398**	-.169	.024	-.033	-.074	-.066	**.552**	-.052	.180	.022
somatic concerns	.226	.152	.100	.202	-.157	.075	.073	-.049	.132	.312	.001	.087
sexual behaviour	.190	.147	.199	-.141	-.058	.177	.058	-.051	**.367**	-.050	-.039	.169
eigenvalue	5.16	3.51	2.32	1.85	1.62	1.61	4.05	3.52	2.86	2.10	1.98	1.67
% total variance	12.50	8.54	5.66	4.51	3.95	3.90	9.88	8.59	6.98	5.12	4.83	4.07

This suggests that the factors have adequate stability. For the first time in any of the factor solutions, there is cross-loading of an item across factors. The initial insomnia item loads significantly to factors four and five. An overlap between factors four and five is also supported by the finding that two items that loaded onto factor four, in the four factor solution in table 4.3, now load onto factor five- increased verbal communication and increased energy.

The rotated four factor solution accounts for 31.4% of the total variance, whilst the rotated five factor solution accounts for 35.3%, suggesting that the fifth factor may make a significant contribution to the overall dimensional model. However, some issues arise when the coherence and interpretability of factor five is considered. It is possible to conceptualise the five items in factor five as a mania/ hypomania dimension of psychopathology. The increased verbal communication and energy items of psychopathology are often experienced by individuals with hypomania. Similarly, the three sleep problem items could be conceptualised as part of a mania/ hypomania dimension.

Although factor five is interpretable and makes a sizeable contribution to the five factor solution explaining a greater proportion of the total variance, there are reasons to be cautious over accepting the five factor solution. Three of the items in factor five (increased verbal communication, increased energy levels and initial insomnia) load significantly onto the anxiety dimension in the four factor solution. Therefore, it could be argued that the only additional contribution to the overall dimensional model is the inclusion of the mid-insomnia and early morning wakening items.

Perhaps of greatest relevance is the fact that for the first time cross-loading of an item of psychopathology appears in the five factor solution. The cross-loading of initial insomnia across the anxiety and mania/ hypomania dimension could be interpreted as evidence that the dimensional model based on the five factor solution is less coherent and reliable. It is certainly recognised that it is preferable to have no cross-loading of items across factors in a rotated solution (Costello & Osborne 2005).

Overall, there are arguments for and against using the five factor solution as the basis of the dimensional model of psychopathology. However, since there is cross-loading

within the five factor solution, the four factor solution is chosen as the final solution on which to base the proposed dimensional model of psychopathology.

In order to examine the stability of the four factor solution, two separate random samples were selected from the sample used for the EFA (n= 330). To maintain the minimum case:item ratio of 5:1 each sample would need a minimum of 205 cases.

SPSS was used to examine a random sample of 205 cases from the 330 used in the EFA. The EFA extracting four factors was run for this first random sample. A second random sample of 205 cases was selected and the EFA run again. The results are shown in tables 4.6 and 4.7 below.

Table 4.6: Non-rotated and rotated four factor solution from EFA of 41 items of psychopathology for random sample 1 (n=205)

	Non-rotated solution				Rotated solution			
	Factor				Factor			
	1	2	3	4	1	2	3	4
worry	.158	-.128	.004	**.504**	.090	-.027	-.210	**.550**
generalised anxiety	.174	-.218	-.004	.267	.110	-.143	-.040	**.336**
agoraphobia	.173	-.088	-.166	.162	.236	-.128	-.091	.171
animal phobia	.036	-.080	-.019	-.112	.040	.079	-.095	-.095
specific phobia	-.109	.056	.005	-.001	-.085	-.051	.041	-.025
rituals	-.038	-.016	**.343**	-.273	-.252	.071	**.423**	-.188
orderliness	-.166	-.063	**.346**	-.168	-.365	.027	**.337**	-.093
low mood	**.691**	-.101	-.212	.021	**.683**	-.081	.074	.097
labile mood	**.365**	-.248	.234	.044	.107	-.087	**.349**	.209
irritability	**.485**	-.223	**.364**	.075	.115	.003	.461	.285
social withdraw	**.675**	.007	-.245	-.003	**.704**	.001	.023	.038
anhedonia	**.692**	.023	-.294	-.135	**.757**	-.019	.065	-.104
talk loss	**.489**	.279	-.273	-.043	**.601**	.210	-.120	-.094
talk gain	.157	-.107	**.538**	.135	-.255	.141	**.418**	.311
tearfulness	**.587**	-.144	.029	.041	**.432**	-.041	.229	.168
reduced self care	**.641**	.200	-.100	-.053	**.597**	.220	.094	-.022
loss of energy	**.563**	.212	-.282	-.034	**.659**	.156	-.088	-.062
increased energy	.096	-.230	**.331**	.061	-.172	-.066	**.323**	.205
loss of cognitive skills	.218	**.595**	.228	.006	.071	**.657**	.052	-.033
name loss	.055	**.635**	.175	-.198	-.009	**.626**	.070	-.281
place loss	.054	**.671**	.158	.162	-.010	**.701**	-.172	.062
reduced comprehension	.200	**.655**	**.341**	.159	-.019	**.773**	.022	.130
loss of memory	.122	**.608**	.313	.093	-.065	**.701**	.031	.056
change in personality	.223	**.562**	.039	.059	.199	**.565**	-.114	-.019
initial insomnia	.239	-.155	.121	.303	.081	-.025	.036	**.398**
mid-insomnia	**.381**	-.119	.043	.148	.257	-.024	.102	.241
early morning wakening	.231	-.082	.106	.083	.101	.005	.131	.160
increased daytime sleep	.165	.247	-.162	-.029	.265	.182	-.134	-.097
loss of appetite	**.603**	-.091	-.399	.119	**.736**	-.139	-.161	.131
increased appetite	-.030	-.001	.246	**.542**	-.213	.160	-.146	**.590**
weight loss	**.472**	-.085	-.288	-.088	**.567**	-.137	.007	-.067
weight gain	-.068	-.076	.304	**.474**	-.287	.099	-.048	**.547**
diurnal variation - evening	.133	-.128	-.061	**.365**	.120	-.074	-.184	**.393**
diurnal variation -morning	.182	-.097	.231	-.373	-.005	-.030	**.492**	-.263
reduced concentration	**.578**	.012	.226	-.101	.311	.155	**.415**	.041
increased verbal aggression	**.443**	-.196	**.416**	-.248	.063	-.001	**.673**	-.034
increased physical aggression	**.453**	-.193	**.370**	-.353	.106	-.028	**.704**	-.147
need for reassurance	**.509**	-.042	.092	-.158	**.332**	.082	.150	.265
self harm/ SIB	.266	-.272	**.357**	-.139	-.050	-.100	**.531**	.049
somatic concerns	.279	-.131	.183	.141	.107	-.008	.128	.286
sexual behaviour	.139	-.103	.204	-.291	-.025	-.040	**.410**	-.194
eigenvalue	5.49	3.11	2.58	1.87	4.72	3.09	3.06	2.28
% total variance	13.39	7.58	6.29	4.56	11.5	7.54	7.46	5.56

Table 4.7: Non-rotated and rotated four factor solution for EFA of 41 items of psychopathology for random sample 2 (n=205)

	Non-rotated solution				Rotated solution			
	Factor				Factor			
	1	2	3	4	1	2	3	4
worry	.027	-.103	-.038	**.345**	.088	-.054	-.142	**.337**
generalised anxiety	-.002	-.174	-.121	**.378**	.122	-.152	-.206	**.354**
agoraphobia	.072	.009	-.202	.170	.205	-.033	-.193	.124
animal phobia	.024	-.120	.035	-.013	-.010	-.091	.087	.018
specific phobia	-.063	.184	-.037	.055	-.012	.147	-.146	.010
rituals	-.067	.003	.246	.208	-.187	.121	.056	.266
orderliness	-.165	-.007	.250	.075	-.284	.076	.084	.136
low mood	**.671**	-.142	-.241	-.041	**.672**	-.105	.172	-.039
labile mood	**.341**	-.247	.272	-.125	.065	-.061	**.490**	.031
irritability	**.508**	-.262	.244	-.208	.202	-.066	**.584**	-.043
social withdraw	**.615**	.014	-.255	.067	**.656**	.034	.033	.027
anhedonia	**.714**	.011	-.289	.053	**.753**	.033	.057	.010
talk loss	**.511**	.234	-.223	-.121	**.535**	.196	.023	-.189
talk gain	.083	-.047	**.333**	**.556**	-.084	.190	.038	**.642**
tearfulness	**.482**	-.145	.032	-.105	**.338**	-.039	**.327**	-.032
reduced self care	**.637**	.207	-.122	.012	**.583**	.256	.098	-.020
loss of energy	**.538**	.234	-.391	-.063	**.674**	.140	-.117	-.183
increased energy	.052	-.253	**.435**	**.549**	-.182	.042	.176	**.701**
loss of cognitive skills	.265	**.661**	.195	.054	.101	**.726**	-.002	.008
name loss	.198	**.637**	.142	-.022	.074	**.659**	-.025	-.081
place loss	.094	**.717**	.262	.047	-.076	**.770**	-.040	-.001
reduced comprehension	.186	**.734**	.256	.159	.015	**.817**	-.064	.107
loss of memory	.249	**.703**	.245	.114	.064	**.790**	-.015	.071
change in personality	.212	**.629**	.044	.013	.153	**.620**	-.106	-.074
initial insomnia	.201	-.251	**.325**	.221	-.035	-.019	.310	**.367**
mid-insomnia	.293	-.175	**.322**	.234	.042	.066	.314	**.370**
early morning wakening	.178	-.172	.282	.200	-.025	.025	.251	.318
increased daytime sleep	**.381**	.080	-.134	.019	**.389**	.091	.024	-.010
loss of appetite	**.512**	-.184	-.368	**.363**	**.683**	-.167	-.163	.303
increased appetite	.046	.157	.286	.032	-.145	.271	.161	.091
weight loss	**.459**	-.200	-.257	**.361**	**.568**	-.146	-.096	.154
weight gain	.055	.123	.120	.182	-.057	.144	.154	**.334**
diurnal variation - evening	.068	-.126	-.041	**.367**	.125	-.064	-.129	**.364**
diurnal variation -morning	.270	-.143	.059	-.351	.123	-.101	**.371**	-.272
reduced concentration	**.597**	-.102	.014	.020	**.456**	.031	.287	.082
increased verbal aggression	**.418**	-.230	**.505**	-.311	-.052	.040	**.776**	-.074
increased physical aggression	**.429**	-.278	**.379**	-.408	.025	-.067	**.749**	-.195
need for reassurance	**.524**	-.100	-.039	.047	**.438**	.001	.205	.087
self harm/ SIB	.294	-.291	**.463**	-.121	-.099	-.028	**.626**	.096
somatic concerns	.233	-.149	.062	.018	.139	-.060	.188	.079
sexual behaviour	.310	-.119	.264	-.083	.054	.051	**.407**	.042
eigenvalue	5.28	3.78	2.57	2.04	4.37	3.63	3.31	2.25
% total variance	12.88	9.22	6.27	4.98	10.66	8.85	8.07	5.49

To examine the stability of the four factor solution the correlations between item loadings from the rotated factors from the EFA using the two random samples were calculated. In table 4.8, the Pearson correlations and level of significance are shown.

Table 4.8: Correlation of items loadings from rotated four factor solution, using two random samples

	Pearson correlation	**Level of significance**
Factor 1- depression	0.954	p< 0.001
Factor 2- organic	0.968	p< 0.001
Factor 3- behaviour- affective	0.809	p< 0.001
Factor 4- anxiety	0.591	p= .003

The significant correlations in table 4.8 suggest that the extracted four factor solution has good stability. However, whilst the factor solutions in table 4.6 and table 4.7 remain coherent to a dimensional model of psychopathology, with dimensions labelled as depressive, organic, behaviour-affective and anxiety, there are differences in the loadings of individual items, compared to the four factors in the original EFA (table 4.3). To allow comparison, table 4.9 below lists the items with loadings greater than 0.32 from the four factor solutions, extracted from the three EFAs.

In table 4.9, any changes in the EFAs using the two random samples, in comparison to the original EFA are highlighted in bold. One further point to note is that the item rating agoraphobia loads significantly to the anxiety dimension only in the original EFA.

Table 4.9: Item loadings to the four factor solutions from the three separate EFAs.

	Factor 1- depressive	Factor 2- organic	Factor 3- behaviour-affective	Factor 4- anxiety
Original EFA (n=330)	low mood social withdrawal anhedonia reduced verbal communication tearfulness reduced self-care lower energy levels loss of appetite weight loss	change in cognitive functioning forgetting the names of familiar people getting lost in familiar places reduced verbal comprehension memory problems change in personality	increased mood lability increased irritability diurnal variation in mood- worse in the morning reduced concentration increased verbal aggression increased physical aggression increased self harming or self-injurious behaviour inappropriate sexual behaviour	worrying generalised anxiety agoraphobia increased verbal communication increased energy levels initial insomnia greater than one hour increased appetite weight gain diurnal mood variation- worse in the evening increased need for reassurance
Random sample 1 (n=205)	low mood social withdrawal anhedonia reduced verbal communication tearfulness reduced self-care lower energy levels loss of appetite weight loss **increased need for reassurance**	change in cognitive functioning forgetting the names of familiar people getting lost in familiar places reduced verbal comprehension memory problems change in personality	**rituals** **excessive orderliness** increased mood lability increased irritability diurnal variation in mood- worse in the morning reduced concentration increased verbal aggression increased physical aggression increased self harming or self-injurious behaviour inappropriate sexual behaviour	worrying generalised anxiety increased verbal communication increased energy levels initial insomnia greater than one hour increased appetite weight gain diurnal mood variation- worse in the evening
Random sample 2 (n=205)	low mood social withdrawal anhedonia reduced verbal communication tearfulness reduced self-care lower energy levels **increased daytime sleeping** loss of appetite weight loss **reduced concentration** **increased need for reassurance**	change in cognitive functioning forgetting the names of familiar people getting lost in familiar places reduced verbal comprehension memory problems change in personality	increased mood lability increased irritability **tearfulness** diurnal variation in mood- worse in the morning increased verbal aggression increased physical aggression increased self harming or self-injurious behaviour inappropriate sexual behaviour	worrying generalised anxiety increased verbal communication increased energy levels initial insomnia > one hour **mid-insomnia> one hour** increased appetite weight gain diurnal mood variation- worse in the evening increased need for reassurance

Although some differences exist, overall it appears from table 4.9 that the items loading to the four factors are largely unchanged across the three EFAs. The items loading to the depressive dimension in the original EFA load significantly to the depressive dimension in the EFAs using the two random samples. However, two additions to the item loadings to the depressive dimension are noted with an item moving from the original behaviour-affective dimension (concentration) and the original anxiety dimension (increased need for reassurance).

Perhaps the most interesting changes in the loadings are the four items that appear for the first time in the EFAs using the random samples- increased daytime sleeping loads to the depressive dimension, rituals and excessive orderliness load to the behaviour-affective dimension, and mid-insomnia loads to the anxiety dimension.

Despite these minor differences in the dimensions identified, the strong correlations between dimensions in the three, separate four factor solutions indicate that this dimensional model of psychopathology is statistically stable. Therefore, null hypothesis one is rejected.

4.2 The correlations between the four dimensions of psychopathology

Null hypothesis two:
There are no significant correlations between the individual dimensions of psychopathology experienced by adults with intellectual disabilities.

The correlations between the four factors from the rotated solution from the original EFA are shown in table 4.10. There were no significant correlations between the four dimensions of psychopathology. On the one hand this is a positive finding as it demonstrates the four factors stand alone as independent dimensions of psychopathology. However, from studies involving children, adolescents and adults who do not have intellectual disabilities it might have been expected to find greater correlations between the depressive and anxiety dimensions of psychopathology. Thus it would appear that the dimensions are independent, with no evidence for any higher order dimensions. Therefore, the null hypothesis is accepted.

Table 4.10: The correlations between the dimensions of psychopathology from the four factor solution.

	Depressive	Organic	Behavioural-affective	Anxiety
Depressive	1.000	.194	.261	.227
Organic	.194	1.000	.079	.014
Behavioural-affective	.261	.079	1.000	.256
Anxiety	.227	.014	.256	1.000

4.3 The bivariate relationship between psychopathology and socio-clinical variables

Null hypothesis three:
There are no significant cross-sectional, bivariate relationships between dimensional measures of psychopathology and socio-clinical variables.

Prior to considering the specific hypotheses relevant to dimensional models of psychopathology and socio-clinical variables, the distributions of the variables are explored.

4.3.1 The distribution of the measures of psychopathology

Descriptive data and the normal distribution statistics for the measures representing the dimensional model of psychopathology (see section 3.5.1) are reported in table 4.11 below:

- imension factor scores for depressive, organic, behavioural-affective and anxiety
- the total dimension factor score
- dimension symptom counts for depressive, organic, behavioural-affective and anxiety
- the total dimension symptom count
- the EFA PPS-LD symptom count- 41.

From table 4.11, the z-scores for skewness and kurtosis and the Shapiro-Wilk test results suggest that the three overall measures of psychopathology (total dimension factor score, total dimension symptom count and EFA PPS-LD symptom count- 41) have normal distributions. Visual confirmation of this was provided in the histograms with superimposed normal distribution curves and the normal probability plots for these variables. Given that these overall measures of psychopathology have a normal distribution, the use of parametric statistical tests is considered valid for these variables.

As well as informing a decision on whether or not to use parametric statistics, examining the distribution of each of the three overall measures allows consideration of whether psychopathology experienced by adults with intellectual disabilities has a continuous or bimodal distribution. To illustrate this, the histogram for the total dimension factor score is shown in figure 4.2. Examining figure 4.2, there do not appear to be any clear break points in the distribution, or a two peaked distribution suggestive of bimodality. Thus, along with the evidence to support a normal distribution in table 4.11, it appears that psychopathology assessed using the PPS-LD is best considered as a continuous measure. This suggests that a dimensional rather than categorical model of psychopathology may be appropriate.

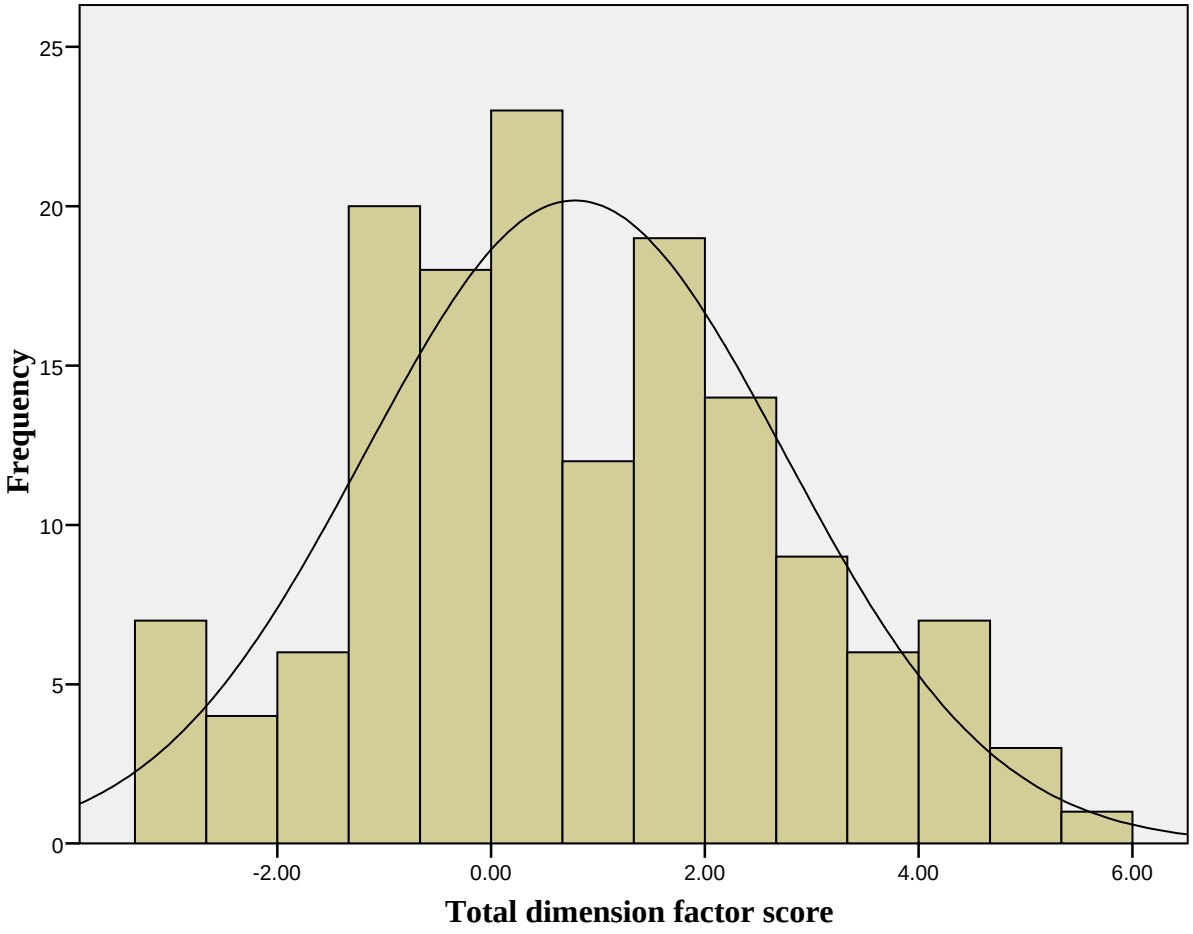
Table 4.11: Summary and normality data of the dimensional and overall measure of psychopathology

		Mean	Min	Max	SD	Skewness		Kurtosis		Normality test	
						S	z-score§	K	z-score§	Shapiro-Wilk	p
Dimension factor scores	Depressive	.16	-1.92	2.14	.99	.067	.337	-.909	2.301*	.978*	.018
	Organic	.08	-.91	4.48	1.00	1.914	9.618***	3.668	9.286***	.748***	.000
	Behaviour-affective	.31	-1.40	2.77	.94	.442	2.221*	-.518	1.311	.972**	.004
	Anxiety	.24	-1.77	3.44	1.05	.487	2.447*	.204	.516	.981*	.039
	Total	.78	-3.32	5.88	1.96	.204	1.01	-.35	.89	.99	.216
Dimension symptom counts	Depressive	3.63	0	9.00	2.50	.169	.849	-1.02	2.582**	.944***	.000
	Organic	.67	0	6.00	1.31	2.011	10.106***	3.517	8.904***	.582***	.000
	Behaviour-affective	2.79	0	8.00	1.88	.433	2.176*	-.540	1.367	.940***	.000
	Anxiety	2.57	0	7.00	1.69	.554	2.784**	-.154	.390	.932***	.000
	Total	9.66	1	19.0	3.96	.17	.85	-.52	1.32	.98	.05
EFA PPS-LD symptom count-41		11.12	2	22	4.13	.33	1.66	-.31	.78	.98	.050

§ z-score values are calculated by dividing the statistic score by the standard errors 0.199 for skewness and 0.395 for kurtosis.

* $p < .05$
** $p < .01$
*** $p < .001$

Figure 4.2: A histogram showing the distribution of the total dimension factor score



In contrast to the three overall measures of psychopathology, the Shapiro-Wilk tests in table 4.11 suggest that all eight measures of psychopathology (the four individual dimension factor scores and symptom counts) differ significantly from the normal distribution. The distribution of all variables is positively skewed to different extents- the depressive dimension factor scores are the least positively skewed, and the organic dimension factor scores have the greatest positive skew. To try and move the distribution of the variables closer to normality, initially a square root and logarithmic transformation were applied separately to the dimensional measures of psychopathology. The statistical results of the distributions of the transformed variables are shown in table 4.12 below. It appears that the square root transformation has moved the distribution of the depressive, behaviour-affective and anxiety factor scores closer to normality. For all three variables, the skewness and kurtosis z-scores,

and Shapiro-Wilk test are no longer significant, suggesting that the distributions no longer differ from normality. This was confirmed in the histograms and normal probability plots for square root transformed depressive, behaviour-affective and anxiety factor scores.

However, neither the square root nor logarithmic transformations moved the organic dimension factor score closer to a normal distribution on the statistical measures in table 4.12. Therefore, an inverse transformation was tried and lead to some improvement in the skewness (-.499; z-score= 2.508) and kurtosis (-.550; z-score= 1.392). However, the Shapiro-Wilk score (.949; $p < .001$) suggested that the distribution was still significantly different from normality. Overall, none of the transformations moved the distribution of the organic dimension factor score closer to normality. Therefore, non-parametric methods were used in subsequent analyses using the organic dimension factor score.

In table 4.12, it is apparent that the square root and logarithmic transformations did not move the distribution of the four dimension symptom counts towards normality. The Shapiro-Wilk test remains significant for the transformed depressive, organic, behaviour-affective and anxiety dimension symptom counts. Therefore, the inverse transformation of these was carried out there but there was no significant shift in the skewness and kurtosis, and the Shapiro-Wilk score in table 4.13 confirms that the distributions of the dimension symptom count variables differed significantly from normality.

Table 4.12: Statistical tests of skewness, kurtosis and normality for square root and logarithmic transformed measures of psychopathology

		Square root transformation						Logarithmic transformation					
		Skewness		Kurtosis		Normality test		Skewness		Kurtosis		Normality test	
		S	z-score§	K	z-score§	Shapiro-Wilk	p	S	z-score§	K	z-score§	Shapiro-Wilk	p
Dimension factor scores	Depressive	-.231	1.161	-.736	1.863	.982	.160	-.585	2.940**	-.165	.418	.975*	.035
	Organic	1.496	7.517***	1.619	4.099***	.845***	.000	1.144	5.749***	.438	1.109	.893***	.000
	Behaviour-affective	.103	.518	-.658	1.666	.983	.193	-.274	1.377	-.419	1.061	.986	.342
	Anxiety	-.015	.075	-.088	.414	.992	.759	-.549	2.759**	.315	.797	.967**	.008
Dimension symptom counts	Depressive	-.256	1.286	-1.036	2.623**	.942***	.000	-.709	3.563***	-.600	1.519	.931***	.000
	Organic	1.659	8.337***	1.544	3.909***	.655***	.000	1.433	7.201***	.483	1.223	.655***	.000
	Behaviour-affective	-.040	.201	-.796	2.015*	.952**	.001	-.554	2.784**	-.433	1.096	.906***	.000
	Anxiety	.038	.191	-.596	1.509	.950***	.000	-.509	2.558*	-.286	.724	.947***	.000

§ z-score values are calculated by dividing the statistic score by the standard errors 0.199 for skewness and 0.395 for kurtosis.

* $p < .05$
** $p < .01$
*** $p < .001$

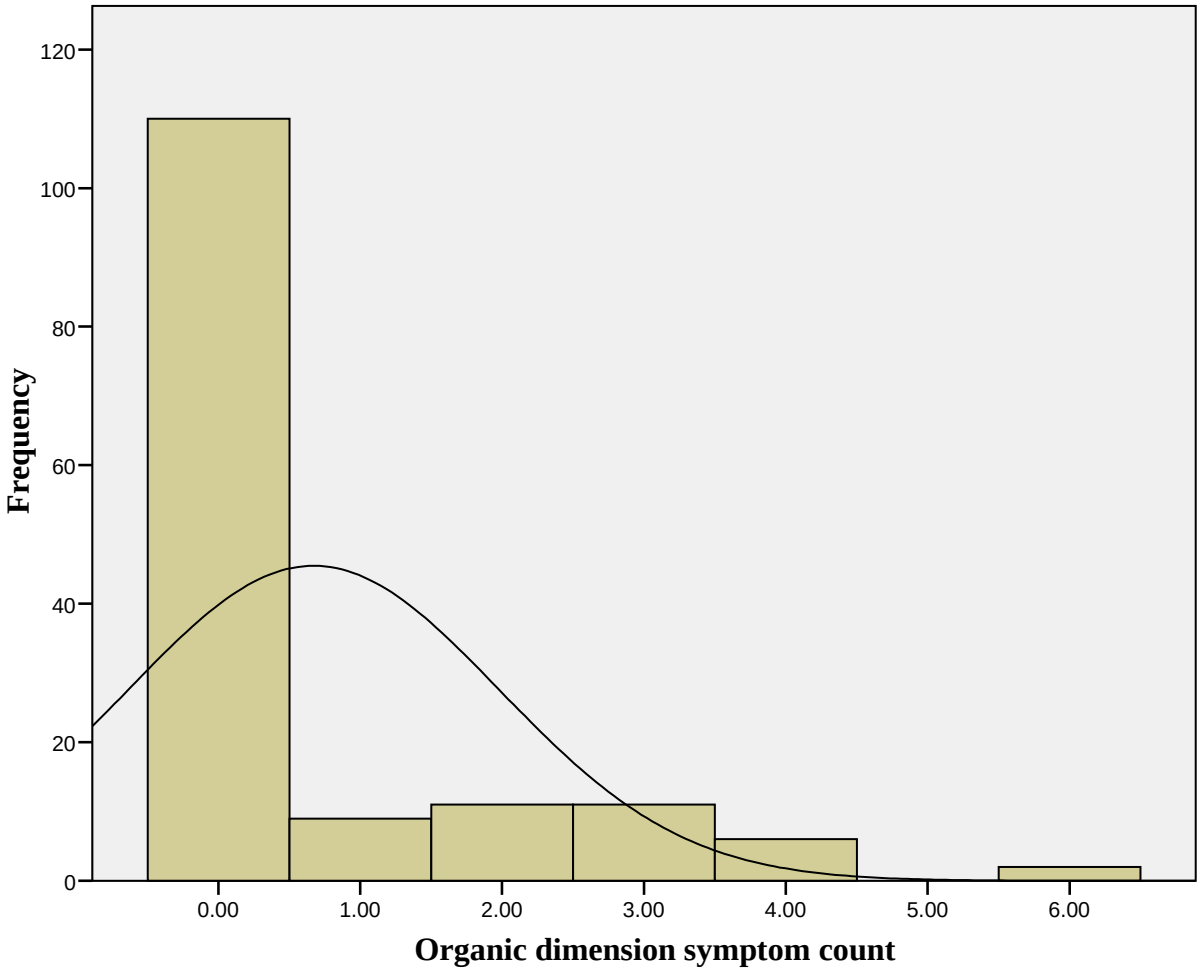
Table 4.13: Statistical tests of skewness, kurtosis and normality for the inverse transformation of the symptom counts of the four dimensions of psychopathology

	Inverse transformation					
	Skewness		Kurtosis		Normality test	
Symptom count	**stat**	**z-score**	**stat**	**z-score**	**S-W**	**p**
Depressive	1.546	7.769***	1.153	2.919**	.723***	.000
Organic	-1.208	6.056***	-.405	1.025	.589***	.000
Behaviour-affective	1.618	8.131***	1.960	4.962***	.761***	.001
Anxiety	1.673	8.407***	2.458	6.223***	.768***	.000

Z-score values are calculated by dividing the statistic score by the standard errors .199 for skewness and .395 for kurtosis.
* $p < 0.05$
** $p < 0.01$
*** $p < 0.001$

All of the distributions remain positively skewed, most obviously for the organic dimension symptom count, illustrated in figure 4.3. Part of the reason for this is the number of cases with zero scores on each the specific symptom count. This effect has been described previously for research using symptom count distributions (Melzer, 2002). Therefore, as for the organic dimension factor score, the analyses involving the individual dimension symptom counts will use non-parametric statistical methods.

Figure 4.3: The histogram showing the distribution of the organic dimension symptom count



4.3.2 Distribution of age

The mean age of sample 2 is 43.5 years (range= 17-74; SD ± 13.1). Although, the Shapiro-Wilk test statistic approaches significance (.982; p= 0.053), the non-significant skewness z-score of 0.317, and a non-significant kurtosis z-score of 1.56 (z-score $\geq \pm$ 1.96, is significant at $p < 0.05$) suggest there is a slightly flat distribution unlikely to be improved by transformation. Since, age in years has a distribution which is close to normality, it is assumed that it can be reliably used in parametric analyses.

4.3.3 The association of psychopathology with gender

The descriptive statistics and results of statistical analyses examining the relationship between gender and psychopathology are shown in table 4.14. In the final two columns, the results of the Student t-tests and non-parametric Mann-Whitney tests suggest that there are no significant gender differences in any of the dimensional measures of psychopathology.

Table 4.14: The relationship between gender and dimensional measures of psychopathology

		Gender	Mean	Min - Max	SD	statistic	p
Dimension factor scores	Depressive‡	male	.14	-1.85 - 2.12	1.06	-.458	.647
		female	.19	-1.92 - 2.14	.92		
	Organic	male	.113	-.91 - 4.48	1.02	.614†	.539
		female	.032	-.86 - 4.03	.98		
	Behaviour-affective‡	male	.35	-1.40 - 2.77	.99	.459	.647
		female	.25	-1.22 - 2.57	.88		
	Anxiety‡	male	.18	-1.77 - 2.69	1.00	-.685	.494
		female	.30	-1.71 - 3.44	1.10		
	Total	male	.78	-3.32 - 5.05	2.07	.010	.992
		female	.78	-3.08 - 5.88	1.84		
Dimension symptom counts	Depressive	male	3.57	0 - 9	2.65	-.384†	.701
		female	3.71	0 - 9	2.33		
	Organic	male	.73	0 - 6	1.35	.678†	.497
		female	.60	0 - 6	1.26		
	Behaviour-affective	male	2.88	0 - 8	2.02	.547†	.584
		female	2.68	0 - 7	1.71		
	Anxiety	male	2.44	0 - 8	1.54	-.534†	.593
		female	2.72	0 - 7	1.86		
	Total	male	9.62	1 - 18	4.23	-.135	.892
		female	9.71	2 -19	3.65		
EFA PPS-LD symptom count- 41		male	11.27	2 -20	4.28	.274	.785
		female	11.09	2 - 22	3.8		

‡ The square root transformed variable was used in the statistic analysis
† Non- parametric z-score from Mann-Whitney test

4.3.4 The relationship between psychopathology and age

The dimensional measures of psychopathology are examined against continuous and categorical measures of age, and the correlations reported in table 4.15.

Table 4.15: The relationship between age and measures of psychopathology.

		Age in years	
	Measure of psychopathology	**R**	**p**
Dimension factor scores	Depressive‡	.214**	.009
	Organic	.098†	.234
	Behaviour-affective‡	-.217**	.008
	Anxiety‡	-.210*	.010
	Total	-.016	.850
Dimension symptom counts	Depressive	.171†*	.038
	Organic	.174†*	.034
	Behaviour-affective	-.230†**	.005
	Anxiety	-.215†**	.009
	Total	-.018	.829
EFA PPS-LD symptom count- 41		-.035	.669

* significant at the p< .05 level
** significant at the p< .01 level
‡ the square root transformed variable is used in the analyses
† Non-parametric Spearman's correlation co-efficient
§ Non- parametric z-score from Mann-Whitney test

Some interesting results were seen in table 4.15. Age in years is significantly correlated to the depressive, behaviour-affective and anxiety factor scores, and all four dimension symptom counts. However, the direction of the correlation is not the same for all four dimensions of psychopathology. The depressive factor score, depressive symptom count and the organic dimension symptom count, are positively correlated with age in years i.e. the factor score and symptom counts increase as age increases. In contrast, there is an inverse correlation between age and the factor scores, and symptom counts, for the behaviour-affective and anxiety dimensions.

4.3.5 Psychopathology and living circumstances

Table 4.16 shows that only the organic and behaviour-affective dimension factor scores were significantly associated with living circumstances.

A Bonferroni correction was used to take account of the multiple comparisons in the post-hoc tests. Since there are two separate comparisons for each variable the accepted levels of significance are $p < .025$, $p < .005$ and $p < .0005$. Mann-Whitney tests were used for the post-hoc tests for the organic dimension factor score. There are significant differences between individuals living independently compared to individuals with support from family carers ($z=-3.201$, $p=.001$) and individuals living with support from family carers against paid carers ($z=-2.635$, $p=.008$) Post hoc Bonferroni tests found that the only significant difference in the behaviour-affective factor score was between individuals living independently and with paid carers (mean difference= 0.1744, $p= .014$).

Table 4.16: The relationship between living circumstances and psychopathology

		Living circumstances	Mean	SD	Min	Max	F	p
Dimension factor scores	Depressive‡	Independent	1.79	.30	1.00	2.25	.846	.431
		Family carer	1.69	.29	1.13	2.16		
		Paid carer	1.73	.29	1.03	2.24		
	Organic	Independent	-.20	.75	-.91	2.18	11.26†**	.004
		Family carer	.35	1.01	-.59	2.82		
		Paid carer	.052	1.04	-.86	4.48		
	Behaviour-affective‡	Independent	1.48	.21	1.00	1.84	4.176*	.017
		Family carer	1.63	.26	1.18	2.20		
		Paid carer	1.66	.30	1.01	.27		
	Anxiety‡	Independent	1.78	.28	-1.68	2.64	1.409	.248
		Family carer	1.65	.29	-1.25	3.44		
		Paid carer	1.71	.31	-1.77	1.95		
	Total	Independent	.46	1.97	-2.97	5.88	.573	.565
		Family carer	.72	1.81	-3.32	4.54		
		Paid carer	.91	2.03	-3.08	5.05		
Dimension symptom counts	Depressive	Independent	4.00	2.43	0	8	1.241†	.538
		Family carer	3.29	2.56	0	8		
		Paid carer	3.66	2.51	0	9		
	Organic	Independent	.41	.89	0	3	3.206†	.201
		Family carer	.97	1.44	0	4		
		Paid carer	.63	1.35	0	6		
	Behaviour-affective	Independent	2.04	1.37	0	4	4.513†	.105
		Family carer	2.86	1.87	0	6		
		Paid carer	2.99	1.98	0	8		
	Anxiety	Independent	2.89	1.85	0	7	1.844†	.398
		Family carer	2.29	1.66	0	6		
		Paid carer	2.59	1.66	0	7		
	Total	Independent	9.33	4.10	2	19	.277	.758
		Family carer	9.40	4.13	1	17		
		Paid carer	9.86	3.89	2	18		
EFA PPS-LD symptom count- 41		Independent	10.70	4.11	1.23	2.44	.361	.698
		Family carer	11.00	4.09	1.02	2.34		
		Paid carer	11.41	4.07	1.00	2.49		

* significant at the p< .05 level
** significant at the p< .01 level
† Non-parametric Kruskall-Wallis test
‡ square root transformed variable used in the analyses

4.3.6 Psychopathology and level of intellectual disabilities

The descriptive statistics for the measures of psychopathology are shown for participants with mild to profound intellectual disabilities in table 4.17.

Post hoc, Bonferroni test results in table 4.18 clarify the nature of the between group differences for the psychopathology variables with significant differences from the initial ANOVA tests. Mann-Whitney tests were used as the post-hoc tests for the organic dimension factor score and behaviour-affective symptom count, which were initially examined using the non-parametric Kruskall-Wallis test and the results shown in table 4.19.

Several of the analyses in table 4.18 and 4.19 would be significant if the accepted minimum level of significance was $p < .05$. However, to take account of the multiple comparisons a Bonferroni correction is used. Since there are three separate comparisons for each variable the accepted levels of significance are $p < .0167$, $p < .003$ and $p < .0003$.

4.3.7 Psychopathology and categorical clinical variables

Tables 4.20-4.24 show the results of analyses examining the associations between the dimensional measures of psychopathology and categorical social variables- epilepsy, diagnosis of autism, Down syndrome, visual impairment, hearing impairment, mobility problems, urinary incontinence and bowel incontinence.

The only variable that was significantly associated with epilepsy was the anxiety dimension factor score. Post hoc Bonferroni tests found that the only significant between group difference was between the non-epilepsy group and individuals with poorly controlled seizures (mean difference= 0.29, p=.001).

Table 4.17: The relationship between intellectual disabilities and psychopathology

		Intellectual disabilities	Mean	SD	Min	Max	F	p
Dimension factor scores	Depressive‡	mild	.05	.96	-1.92	2.14	.521	.669
		moderate	.34	.92	-1.50	2.01		
		severe	.13	.97	-1.69	2.06		
		profound	.15	1.08	-1.85	2.12		
	Organic	mild	-.13	.74	-.91	2.18	8.255†*	.041
		moderate	.24	1.26	-.63	4.48		
		severe	.42	1.13	-.86	2.82		
		profound	-.11	.81	-.71	2.55		
	Behaviour-affective‡	mild	-.11	.62	-1.25	1.61	3.712*	.013
		moderate	.51	.93	-.70	2.57		
		severe	.22	1.09	-1.36	2.77		
		profound	.52	.94	-1.40	2.45		
	Anxiety‡	mild	.26	1.05	-1.68	2.64	4.116**	.008
		moderate	.72	1.10	-1.25	3.44		
		severe	-.16	.91	-1.77	1.95		
		profound	.19	1.00	-1.71	2.60		
	Total	mild	.07	1.99	-3.08	4.64	4.750**	.003
		moderate	1.81	1.95	-.68	5.88		
		severe	.62	1.58	-2.89	4.05		
		profound	.74	1.98	-3.32	5.05		
Dimension symptom counts	Depressive	mild	3.38	2.44	0	8	1.393†	.707
		moderate	4.06	2.38	0	9		
		severe	3.55	2.36	0	9		
		profound	3.59	2.74	0	8		
	Organic	mild	.47	.90	0	3	4.895†	.180
		moderate	.84	1.70	0	6		
		severe	1.09	1.51	0	4		
		profound	.43	1.06	0	4		
	Behaviour-affective	mild	2.06	1.46	0	6	10.077†*	.018
		moderate	3.19	1.70	0	7		
		severe	2.55	2.14	0	8		
		profound	3.18	1.94	0	7		
	Anxiety	mild	2.62	1.88	0	7	7.003†	.072
		moderate	3.26	1.79	0	7		
		severe	2.09	1.31	0	5		
		profound	2.43	1.64	0	7		
	Total	mild	8.53	4.19	2	17	3.038*	.031
		moderate	11.35	3.77	7	19		
		severe	9.27	3.28	3	17		
		profound	9.63	4.09	1	18		
EFA PPS-LD symptom count- 41		mild	9.8	4.20	2	17	3.554*	.016
		moderate	12.94	4.12	7	22		
		severe	10.70	3.34	4	18		
		profound	11.35	4.06	2	19		

Table 4.18: Post hoc Bonferroni tests of ANOVA between group differences for level of intellectual disabilities and measures of psychopathology

	Dependent Variable	(I) Reference level of intellectual disability category	(J) Comparison level of intellectual disability categories	Mean Difference (I-J)	Std. Error	p	95% Confidence Interval	
Dimension factor scores	Behaviour affective‡	mild	moderate	-.184	.069	.050	-.369	.0001
			severe	-.087	.068	1.000	-.268	.095
			profound	-.183	.062	.020	-.348	-.019
	Anxiety‡	moderate	mild	.135	.073	.407	-.061	.331
			severe	.258*	.074	.004	.060	.456
			profound	.154	.067	.141	-.026	.334
	Total	mild	moderate	-1.74**	.470	.002	-2.999	-.484
			severe	-.547	.463	1.000	-1.784	.690
			profound	-.671	.419	.668	-1.793	.450
Dimension symptom counts	Behaviour-affective	mild	moderate	-1.13	.457	.085	-2.356	.0868
			severe	-.487	.449	1.000	-1.689	.715
			profound	-1.11	.407	.041	-2.207	-.0286
	Total	mild	moderate	-2.825	.965	.024	-5.406	-.245
			severe	-.743	.949	1.000	-3.283	1.796
			profound	-1.098	.860	1.000	-3.399	1.203
EFA PPS-LD symptom count- 41		mild	moderate	-3.112*	.984	.011	-5.743	-.481
			severe	-.873	.968	1.000	-3.462	1.716
			profound	-1.529	.878	.500	-3.876	.817

* significant at the p< .0167 level ** significant at the p < .003
‡ the square root transformed variable is used in the analyses

Table 4.19: The non-parametric post hoc tests for the between group differences for level of intellectual disabilities and the organic dimension factor score and behaviour-affective and anxiety symptom counts

	Dependent Variable	(I) Reference level of intellectual disability category	(J) Comparison level of intellectual disability categories	Mann-Whitney U	z	p
Dimension factor scores	Organic	moderate	mild	410	-1.537	.124
			severe	486	-.343	.732
			profound	559	-2.214	.027
		severe	mild	400	-2.019	.043
			moderate	486	-.343	.732
			profound	606	-2.157	.031
Dimension symptom counts	Behaviour-affective	mild	moderate	326	-2.693*	.007
			severe	518	-552	.581
			profound	571	-2.696*	.007
	Anxiety	mild	moderate	1332	-2.366	.018
			severe	1541	-1.740	.082
			profound	2361	-.563	.574

* significant at the p< .0167 level

Table 4.20: The relationship between epilepsy and psychopathology

		Epilepsy	Mean	SD	Min	Max	F	p
Dimension factor scores	Depressive‡	no	.24	1.00	-1.92	2.14	1.394	.251
		good control	-.12	.93	-1.20	1.88		
		poor control	.15	.99	-1.12	2.12		
	Organic	no	.05	.93	-.91	2.82	2.846†	.241
		good control	-.002	1.06	-.69	4.48		
		poor control	.43	1.31	-.59	4.02		
	Behaviour-affective ‡	no	.25	.93	-1.39	2.57	.765	.467
		good control	.46	1.00	-1.07	2.77		
		poor control	.43	.90	-.80	1.78		
	Anxiety ‡	no	.40	1.04	-1.77	3.44	7.020**	.001
		good control	.02	.82	-1.56	2.27		
		poor control	-.49	1.14	-1.72	1.70		
	Total	no	.94	1.86	-2.96	5.88	1.118	.330
		good control	.36	2.20	-3.32	4.96		
		poor control	.53	2.16	-3.08	4.27		
Dimension symptom counts	Depressive	no	3.86	2.49	0	9	3.294†	.193
		good control	2.93	2.36	0	8		
		poor control	3.40	2.75	0	8		
	Organic	no	.66	1.24	0	4	3.798†	.150
		good control	.48	1.30	0	6		
		poor control	1.13	1.73	0	6		
	Behaviour-affective	no	2.64	1.82	0	7	2.133†	.344
		good control	3.10	2.04	0	8		
		poor control	3.20	1.97	0	6		
	Anxiety	no	2.77	1.72	0	7	5.588†	.061
		good control	2.24	1.48	0	6		
		poor control	1.80	1.66	0	5		
	Total	no	9.92	3.76	2	19	.990	.374
		good control	8.76	4.28	1	17		
		poor control	9.53	4.69	1	17		
EFA PPS-LD symptom count-41		no	11.44	3.91	4	22	.724	.487
		good control	10.44	4.40	2	19		
		poor control	10.87	4.52	2	18		

* significant at the p< .01 level
‡ square root transformed variable used
† Non- parametric χ^2 from Kruskall-Wallis test

Table 4.21: The relationship between autism, Down syndrome and psychopathology.

		Autism						Down syndrome					
		Yes (n=19)		No (n=131)		statistic	p	Yes (n=24)		No (n=126)		statistic	p
		Mean	SD	Mean	SD			Mean	SD	Mean	SD		
Dimension factor scores	Depression ‡	-.07	1.05	.20	.98	1.130	.260	.35	.99	.13	.99	-1.000	.319
	Organic	-.31	.39	.13	1.05	-1.337†	.181	.74	1.14	-.05	.92	-3.388**†	.001
	Behaviour-affective‡	.30	1.14	.31	.91	.209	.835	-.0002	.91	.36	.93	1.824	.070
	Anxiety ‡	.40	.46	.21	1.11	-1.895§	.063	.20	.99	.24	1.06	.166	.868
	Total	.33	2.12	.85	1.94	1.086	.279	1.29	1.67	.68	2.00	-1.385	.168
Dimension symptom counts	Depressive	2.95	2.63	3.73	2.48	-1.367†	.172	4.33	2.44	3.50	2.50	1.625†	.104
	Organic	.16	.50	.75	1.37	-1.779†	.075	1.50	1.64	.51	1.18	3.263**†	.001
	Behaviour-affective	3.00	2.24	2.75	1.83	-.286†	.775	1.96	1.81	2.94	1.86	-2.371*†	.018
	Anxiety	3.00	1.15	2.51	1.75	-1.749†	.080	2.25	1.54	2.63	1.72	-.847†	.397
	Total	9.11	4.67	9.74	3.87	.649	.517	10.04	3.51	9.58	4.05	-.517	.606
EFA PPS-LD symptom count- 41		10.58	4.57	11.28	3.99	.698	.486	11.75	3.57	11.08	4.16	-.739	.461

** significant at the p< .01 level
‡ the square root transformed variable is used in the analyses
§ Levene's test found the between group variance is significant so the t-test results are for equal variances not assumed
† Non- parametric z score from Mann-Whitney test

Table 4.22: The relationship between sensory impairments and psychopathology.

		Visual impairment						Hearing impairment					
		Yes (n=27)		No (n=122)		statistic	p	Yes (n=12)		No (n=137)		statistic	p
		Mean	SD	Mean	SD			Mean	SD	Mean	SD		
Dimension factor scores	Depressive‡	.26	.97	.14	1.00	-.636	.526	.10	.98	.17	.99	.213	.831
	Organic	-.25	.58	.15	1.06	-2.198*†	.028	.04	1.08	.08	.99	-.467†	.640
	Behaviour-affective‡	.28	.88	.31	.95	.090	.929	.30	.75	.31	.95	-.085	.932
	Anxiety ‡	.11	.98	.27	1.06	.640	.523	.46	1.31	.22	1.02	-.653	.515
	Total	.41	1.58	.87	2.04	1.101	.273	.90	1.36	.77	2.01	-.210	.834
Dimension symptom counts	Depressive	3.93	2.51	3.57	2.51	-.638†	.524	3.50	2.32	3.64	2.53	-.063†	.950
	Organic	.37	.74	.74	1.40	-.826†	.409	.67	1.56	.67	1.29	-.506†	.613
	Behaviour-affective	2.59	1.78	2.83	1.91	-.495†	.621	2.50	1.62	2.81	1.90	-.478†	.633
	Anxiety	2.26	1.63	2.64	1.71	-1.047†	.295	2.75	2.01	2.55	1.67	-.341†	.733
	Total	9.15	3.22	9.77	4.11	.737	.462	9.42	2.91	9.68	4.05	.219	.827
EFA PPS-LD symptom count- 41		10.78	3.50	11.28	4.18	.578	.564	11.25	2.34	11.18	4.19	-.088§	.931

** significant at the p< 0.01 level
‡ the square root transformed variable is used in the analyses
§ Levene's test found the between group variance is significant so the t-test results are for equal variances not assumed
† Non- parametric z-score from Mann-Whitney test

Table 4.23: The relationship between mobility problems and psychopathology.

		Mobility problems					
		Yes (n=37)		No (n=113)		statistic	p
		Mean	SD	Mean	SD		
Dimension factor scores	Depressive‡	.17	1.03	.16	.98	-.020	.984
	Organic	.16	1.12	.05	.96	-.009†	.993
	Behaviour-affective‡	.20	.89	.34	.95	.790	.431
	Anxiety‡	-.27	1.01	.40	1.01	3.755***	.000
	Total	.25	1.79	.96	2.00	1.912	.058
Dimension symptom counts	Depressive	3.62	2.74	3.64	2.43	-.031†	.975
	Organic	.76	1.46	.64	1.26	-.230†	.818
	Behaviour-affective	2.46	1.79	2.89	1.90	-1.146†	.252
	Anxiety	1.79	1.53	2.83	1.67	-3.360**†	.001
	Total	8.62	3.91	10.00	3.94	1.849	.067
EFA PPS-LD symptom count- 41		10.24	3.70	11.50	4.14	1.641	.103

* significant at the p< .05 level
** significant at the p< .01 level
*** significant at the p< .001 level
‡ the square root transformed variable is used in the analyses
† Non- parametric z score from Mann-Whitney test

Table 4.24: The relationship between incontinence and psychopathology.

		Urinary incontinence						Bowel incontinence					
		Yes (n=53)		No (n=97)		statistic	p	Yes (n=38)		No (n=112)		statistic	p
		Mean	SD	Mean	SD			Mean	SD	Mean	SD		
Dimension factor scores	Depressive ‡	.26	.98	.11	1.00	-.946	.346	.25	1.02	.13	.98	-.600	.549
	Organic	.23	1.23	-.01	.83	-.345†	.730	.17	1.14	.04	.95	-.100†	.920
	Behaviour-affective‡	.55	.94	.17	.91	-2.383*	.018	.45	.94	.26	.94	-1.073	.285
	Anxiety ‡	-.03	1.06	.38	1.02	2.475*	.014	-.17	1.08	.38	1.00	3.142**	.002
	Total	1.00	2.08	.66	1.89	-1.040	.300	.69	2.09	.81	1.93	.332	.741
Dimension symptom counts	Depressive	4.00	2.67	3.43	2.40	-1.306†	.192	3.87	2.70	3.55	2.44	-.735†	.463
	Organic	.83	1.57	.58	1.14	-.598†	.550	.74	1.43	.65	1.27	-.113†	.910
	Behaviour-affective	3.11	1.90	2.60	1.86	-1.577†	.115	2.89	1.93	2.75	1.87	-.473†	.636
	Anxiety	2.17	1.67	2.79	1.67	-2.362*†	.018	1.97	1.71	2.77	1.64	-2.687**†	.007
	Total	10.11	4.05	9.41	3.92	-1.042	.299	9.47	4.15	9.72	3.92	.331	.741
EFA PPS-LD symptom count- 41		11.75	4.11	10.88	4.02	-1.268	.207	11.05	4.26	11.23	4.01	.237	.813

* significant at the p< .05 level
** significant at the p< .01 level
‡ the square root transformed variable is used in the analyses
† Non- parametric z score from Mann-Whitney test

Since there are several significant associations between measures of psychopathology and socio-clinical variables the null hypothesis is rejected.

4.4 Multivariate associations between measures of psychopathology and socio-clinical variables

Null hypothesis four:
There are no significant cross-sectional, multivariate relationships between dimensional measures of psychopathology and socio-clinical variables.

Several of the socio-clinical variables may be correlated, such as level of intellectual disabilities and epilepsy. To take account of such cross-correlations, multiple linear regression was used to explore whether any socio-clinical variables associated with the measures of psychopathology in the bivariate analyses are independently associated.

Tables 4.25 and 4.26 give the results of the multivariate analyses for the dimension factor scores and dimension symptom counts. Each table provides the p value from the bivariate analyses in section 4.3, and the results of the multiple linear regression analysis for those variables retained in the final model. Since level of intellectual disabilities was the only socio-clinical variable significantly associated with the overall measure of psychopathology, EFA PPS-LD symptom count- 41, in the bivariate analyses, there is no requirement for a multivariate analysis.

Table 4.25: Multivariate associations of socio-clinical variables with dimension factor scores

Dimension of psychopathology	Bivariate associations (p< .1)		Multivariate associations					
	Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive ‡	Continuous measure of age (years)	.009**		.005	.002	.214	.009**	.046
Organic	Living circumstances	.004**	Independent-family carer	Not retained in the model				
			Independent-paid carer	Not retained in the model				
	Categorical measure of intellectual disabilities	.041*	Mild- moderate	Not retained in the model				
			Mild-severe	.467[a]	.192	.195	.016*	.156
			Mild- profound	Not retained in the model				
	Down syndrome	.001**		.800	.208	.296	.000***	
	Visual impairment	.028*		Not retained in the model				
Behaviour-affective ‡	Continuous measure of age (years)	.008**		-.005	.002	-.208	.010*	.141
	Living circumstances	.017*	Independent-family carer	Not retained in the model				
			Independent-paid carer	Not retained in the model				
	Categorical measure of intellectual disabilities	.013*	Mild-moderate	.181	.067	.258	.008**	
			Mild-severe	.136	.067	.198	.046*	
			Mild-profound	.195	.060	.326	.001**	
	Down syndrome	.070		-.135	.061	-.175	.028*	

	Visual impairment	.090		Not retained in the model				
	Urinary incontinence	.018*		Not retained in the model				
Anxiety‡	Continuous measure of age (years)	.010*		-.004	.002	-.163	.035*	.232
	Categorical measure of intellectual disabilities	.013*	Mild-moderate	.148	.060	.198	.015*	
			Mild-severe	Not retained in the model				
			Mild-profound	Not retained in the model				
	Diagnosis of autism	.063		Not retained in the model				
	Urinary incontinence	.014*		Not retained in the model				
	Bowel incontinence	.002**		-.143	.063	-.205	.024*	
	Epilepsy	.001**	No epilepsy-poor seizure control	-.215	.077	-.213	.006**	
			No epilepsy-good seizure control	Not retained in the model				
	Mobility problems	.000***		-.115	.057	-.163	.048*	
Total	Categorical measure of intellectual disabilities	.003**	Mild-moderate	1.298	.383	.269	.001**	.073
			Mild-severe	Not retained in the model				
			Mild-profound	Not retained in the model				
	Mobility problems	.058		Not retained in the model				

* significant at the p< .05 level ** significant at the p< .01 level *** significant at the p< .001 level
‡ the square root transformed variable is used in the analyses

Table 4.26: Multivariate associations of socio-clinical variables with dimension symptom counts

Dimension of psychopathology	Bivariate associations (p< .1)		Multivariate associations					
	Variable	p	Dummy variable	B	*SE* B	β	p	R^2
Depressive	Continuous measure of age (years)	.038*		.032	.016	.166	.043*	.028
Organic	Continuous measure of age (years)	.034*		.020	.008	.199	.012*	.117
	Down syndrome	.001**		.987	.276	.278	.000***	
	Autism	.075		Not retained in the model				
Behaviour-affective	Continuous measure of age (years)	.005**		-.027	.012	-.188	.021*	.141
	Categorical measure of intellectual disabilities	.018*	Mild-moderate	1.116	.440	.242	.012*	
			Mild-severe	Not retained in the model				
			Mild-profound	1.229	.396	.311	.002**	
	Down syndrome	.018*		-1.112	.401	-.218	.006**	
Anxiety	Continuous measure of age (years)	.009**		-.022	.010	-.172	.031*	.127
	Categorical measure of intellectual disabilities	.072	Mild-moderate	.656	.328	.158	.048	
			Mild-severe	Not retained in the model				
			Mild-profound	Not retained in the model				
	Diagnosis of autism	.080		Not retained in the model				
	Urinary incontinence	.018*		Not retained in the model				

	Bowel incontinence	.007**		Not retained in the model				
	Epilepsy	.061		Not retained in the model				
	Mobility problems	.001**		-.816	.313	-.209	.010	
Total	Categorical measure of intellectual disabilities	.031*	Mild-moderate	2.143	.783	.220	.007**	.048
			Mild-severe	Not retained in the model				
			Mild-profound	Not retained in the model				
	Mobility problems	.067		Not retained in the model				

* significant at the p< .05 level

** significant at the p< .01 level

*** significant at the p< .001 level

Although the final regression models for the factor score and symptom count for a specific dimension of psychopathology are similar overall, there are some interesting differences. For example, older age is independently associated with higher scores on the organic dimension symptom count, but not the organic dimension factor score. A final point to note is that the three overall measures of psychopathology are only independently associated with level of intellectual disabilities. These points of note and others are considered fully in the discussion in chapter 5.

With specific reference to null hypothesis four, there are socio-clinical variables independently associated with each of the eight dimension factor scores and symptom counts, and the overall measures of psychopathology. Therefore, the null hypothesis is rejected.

4.5 The cross-sectional relationship between psychopathology and measures of the severity of mental disorders

Null hypothesis five:
There are no significant cross-sectional, bivariate relationships between dimensional measures of psychopathology and the severity of mental disorders.

This section examines the relationships between the dimensional and overall measures of psychopathology and the six measures of the severity of mental disorders.

Prior to investigating the hypothesis, Table 4.27 reports the descriptive statistics and results of tests examining the skewness, kurtosis and overall distribution of the six measures of severity, in comparison to the normal distribution. It appears that the HONOS-LD total score, CGI rating, CANDID met needs and CANDID total needs have a distribution that does not differ significantly from normal. Therefore, it is appropriate to use parametric statistical tests in analyses including these variables.

However, results from table 4.27 suggest that the distribution of GAF and the CANDID unmet needs scores differ significantly from normality. The difference from normality in

the distribution of the GAF scores is accounted for by the significant kurtosis score, indicative of a flat distribution. Since transforming the data has more of an effect on a skewed distribution, than an abnormal kurtosis, it is unlikely to move the GAF distribution closer to the normal distribution. Therefore, any analyses using the GAF scores will make use of non-parametric tests.

The distribution of the CANDID-R unmet needs scores in table 4.27 is positively skewed. Square root and logarithmic transformations were used in an attempt to move the distribution closer to normality, and the results shown in table 4.28. The distribution of the square root transformed CANDID-R unmet needs scores still differ significantly from normality due to a significant positive skew, in table 4.28. A logarithmic transformation has a greater effect on a positive skew than a square root transformation; however in table 4.28 we can see that it has flipped the distribution to a significant negative skew. An inverse transformation was not carried out, since it would further increase the negative skew seen in the logarithmic transformed variable. Since none of the transformations have moved the CANDID-R unmet needs scores closer to the normal distribution, the original CANDID-R unmet needs variable will be used in analyses, using non-parametric statistical tests.

As described previously, the CANDID-R total needs variable was not included in analyses as it is simply a composite measure of the unmet and met needs. Statistical analyses examining the correlations between the five variables representing the measures of severity of mental disorder and the dimensional factor scores, dimensional symptom counts and overall measures of psychopathology are given in table 4.29-4.31.

Table 4.27: Summary and normality data of the measures of severity at baseline.

Outcome measure	Mean	Min	Max	SD	Skewness		Kurtosis		Normality test	
					S	z-score§	K	z-score§	Shapiro-Wilk	p
HoNOS-LD total	23.64	6	48	8.85	.380	1.910	-.410	1.038	.986	.08
GAF	49.36	18	73	13.33	-.080	.402	-.952	2.41*	.973**	.005
CGI	3.71	1	6	1.029	.039	.452	-.417	1.056	.991	.335
CANDID- unmet	5.80	0	16	3.13	.946	4.754***	1.091	2.762**	.933***	.000
CANDID- met	9.38	2	18	3.36	-.355	1.784	-.161	.408	.980	.050
CANDID- total	15.19	9	21	2.561	-.322	1.618	-.356	.901	.990	.203

§ z-score values are calculated by dividing the statistic score by the standard errors 0.199 for skewness and 0.395 for kurtosis.
* $p < .05$
** $p < .01$
*** $p < .001$

Table 4.28: Statistical tests of skewness, kurtosis and normality for square root and logarithmic transformed CANDID-R unmet needs scores

	Square root transformation						Logarithmic transformation					
	Skewness		Kurtosis		Normality test		Skewness		Kurtosis		Normality test	
	S	z-score§	K	z-score§	Shapiro-Wilk	p	S	z-score§	K	z-score§	Shapiro-Wilk	p
CANDID-R unmet needs	.393	1.975*	.036	.091	.967**	.001	-.410	2.060*	.515	1.058	.962***	.000

§ z-score values are calculated by dividing the statistic score by the standard errors 0.199 for skewness and 0.395 for kurtosis.
* $p < .05$
** $p < .01$
*** $p < .001$

Although there is some variation across the measures of psychopathology, certain commonalities can be identified. In all cases where a significant correlation exists, a higher level of psychopathology is correlated with a greater score on the measure of severity of mental disorder indicative of a poorer outcome. Whilst there are differences between the results when dimension factor scores and symptom counts are used in the analyses, the factor scores and symptom counts for all four dimensions of psychopathology are correlated with at least one measure of the severity of mental disorders. The three overall measures of psychopathology- total dimension factor score, total dimension symptom count and EFA PSS-LD symptom count-41- are correlated with all the measures of severity of mental disorder.

Given the strong correlations between the measures of psychopathology and severity of mental disorder at baseline the null hypothesis is rejected.

Table 4.29: The correlations between measures of severity of mental disorder and dimension factor scores.

	Depressive factor score‡		Organic factor score		Behaviour-affective factor score‡		Anxiety factor score‡		Total factor score	
	R	**p**	**R†**	**p**	**R**	**p**	**R**	**p**	**R**	**p**
HoNOS-LD total score	.421***	.000	.104	.207	.348***	.000	.098	.236	.551***	.000
GAF†	-.475***	.000	-.258**	.001	-.243**	.003	-.055	.506	-.583***	.000
CGI	.494***	.000	.245**	.003	.220**	.007	.082	.319	.562***	.000
CANDID-R unmet needs†	.158	.054	.143	.082	.175*	.033	.125	.130	.326***	.000
CANDID-R met needs	-.153	.063	-.057	.490	.106	.200	-.206*	.012	-.185*	.024

* significant at the p< .05 level
** significant at the p< .01 level
*** significant at the p< .001 level
‡ The square root transformed variable was used in the statistic analysis
† Non-parametric Spearman's correlation co-efficient

Table 4.30: The correlations between measures of severity of mental disorder and dimension symptom counts

	Depressive symptom count		Organic symptom count		Behaviour-affective symptom count		Anxiety symptom count		Total symptom count	
	R†	p	R†	p	R†	p	R†	p	R	p
HoNOS-LD total score	.416***	.000	.207*	.011	.359***	.000	.135	.101	.585***	.000
GAF	-.500***	.000	-.318***	.000	-.262**	.001	-.050	.546	-.587†***	.000
CGI	.543***	.000	.227**	.001	.254**	.002	.072	.386	.590***	.000
CANDID-R unmet needs	.165*	.044	.243**	.003	.206*	.012	.117	.157	.322†***	.000
CANDID-R met needs	-.139	.090	-.144	.080	.075	-.363	-.184*	.025	-.184*	.025

* significant at the p< .05 level
** significant at the p< .01 level
*** significant at the p< .001 level
† Non-parametric Spearman's correlation co-efficient

Table 4.31: The correlations between measures of severity of mental disorder and the overall PPS-LD symptom count

	EFA PPS-LD symptom count - 41	
	R	**p**
HoNOS-LD total score	.576*	.000
GAF	-.590***	.000
CGI	.568***	.000
CANDID-R unmet needs	.308**	.003
CANDID-R met needs	-.163*	.047

* significant at the p< 0.05 level

** significant at the p< 0.01 level

*** significant at the p< 0.001 level

† Non-parametric Spearman's correlation co-efficient

4.6 Bivariate associations between socio-clinical variables and the severity of mental disorders

Null hypothesis six:
There are no significant bivariate relationships between socio-clinical variables and measures of the severity of mental disorders.

4.6.1 The association between gender and measures of severity of mental disorder

The descriptive statistics and results of Student t-tests and Mann-Whitney tests, examining the relationship between gender and measures of severity of mental disorder are shown in table 4.32. There are no significant gender differences in any of the measures of severity of mental disorder.

Table 4.32: The relationship between gender and measures of severity of mental disorder

	Gender	Mean	SD	statistic	p
HoNOS-LD total score	male	23.67	9.86	.045§	.964
	female	23.60	7.55		
GAF	male	50.10	14.452	-.827†	.408
	female	48.47	11.904		
CGI	male	3.70	1.078	-.099	.921
	female	3.72	.975		
CANDID-R unmet needs	male	5.84	2.777	-.697†	.486
	female	5.75	3.534		
CANDID-R met needs	male	9.32	3.320	-.243	.808
	female	9.46	3.431		

† Non- parametric z-score from Mann-Whitney test

§ Levene's test found the between group variance is significant so the t-test results are for equal variances not assumed

4.6.2 The association between age and measures of severity of mental disorder

The correlation between the continuous measure of age and measures of age were examined and results shown in table 4.33. There is a significant indirect correlation between CANDID-R unmet needs and age, suggesting that younger participants have higher level of unmet needs. Although its does not reach statistical significance, the opposite result is found for met needs- with a direct correlation between age and met needs suggesting older participants have higher met needs.

Table 4.33: The relationship between age and measures of severity of mental disorder

	Continuous measure (age in years)	
	R	p
HoNOS-LD total score	-.093	.260
GAF	-.060†	.468
CGI	.075	.364
CANDID-R unmet needs	-.177†*	.031
CANDID-R met needs	.153	.062

* significant at the p< 0.05 level

† Non-parametric Spearman's correlation co-efficient

4.6.3 Living circumstances and measures of severity of mental disorder

In table 4.34 there are significant between group differences in the CANDID-R unmet, and met needs. For the CANDID-R unmet needs post hoc Mann-Whitney tests found significant between group differences for individuals living independently against participants living with family carers (z=-2.53, p=.012), and living independently against living with support from paid carers (z=-2.876, p=.004). All three between group comparisons for the CANDID-R met needs were significant on the post hoc Bonferroni

tests- independent against family carer (mean difference=-3.174, p< .000), independent against paid carer (mean difference=-4.960, p<.000) and family against paid carer (mean difference=-1.787, p=.005).

Table 4.34: The relationship between living circumstances and measures of severity of mental disorder

	Living circumstances	Mean	SD	Min	Max	F	p
HoNOS-LD	Independent	22.56	7.62	6	35	2.700	.071
	Family carer	21.11	8.47	8	42		
	Paid carer	24.99	9.17	8	48		
GAF	Independent	52.67	10.00	36	72	2.995†	.224
	Family carer	50.69	15.13	18	73		
	Paid carer	47.79	13.36	23	72		
CGI	Independent	3.41	.84	1	5	2.217	.113
	Family carer	3.60	1.17	2	6		
	Paid carer	3.85	1.01	2	6		
CANDID-R unmet needs	Independent	8.00	4.81	0	16	9.317†**	.009
	Family carer	5.34	2.84	2	13		
	Paid carer	5.30	2.21	1	11		
CANDID-R met needs	Independent	5.74	3.44	2	13	32.702***	.000
	Family carer	8.91	3.03	3	14		
	Paid carer	10.70	2.49	5	18		

* significant at the p< 0.05 level

** significant at the p< 0.01 level

† Non-parametric Kruskall-Wallis test

4.6.4 The association between level of intellectual disabilities and measures of severity of mental disorder

The descriptive statistics for the measures of severity of mental disorder and results for the initial analyses using ANOVA are shown for participants with mild, moderate, severe and profound intellectual disabilities in table 4.35. There are significant associations between level of intellectual disabilities and the HoNOS-LD score, CGI, and CANDID-R met needs. The result of the ANOVA for the CANDID-R unmet needs approaches significance (F=6.788, p=.079) and therefore level of intellectual disabilities will be included in the multivariate analysis for all measures of severity of mental disorder

Post hoc, Bonferroni test results in table 4.36 and non-parametric Mann Whitney tests for the CANDID-R unmet needs in table 4.37 clarify the nature of the between group differences for the measures of severity of mental disorder with significant with significant between group differences from the initial ANOVA tests.

Table 4.35: The relationship between level of intellectual disabilities and measures of severity of mental disorder

	Level of intellectual disabilities	Mean	SD	Min	Max	F	p
HoNOS-LD total score	mild	19.65	7.511	6	35	4.036**	.009
	moderate	24.42	8.245	8	42		
	severe	23.12	7.672	11	40		
	profound	26.16	9.908	8	48		
GAF	mild	54.47	11.08	36	73	6.222†	.101
	moderate	47.42	13.03	23	70		
	severe	47.73	11.44	28	68		
	profound	48.18	15.36	18	72		
CGI	mild	3.32	.88	1	5	2.964*	.034
	moderate	4.06	1.03	2	6		
	severe	3.73	.88	2	5		
	profound	3.75	1.15	2	6		
CANDID-R unmet needs	mild	5.65	4.07	-1.68	2.64	6.788†	.079
	moderate	7.13	3.54	-1.25	3.44		
	severe	5.36	2.16	-1.77	1.95		
	profound	5.37	2.50	-1.71	2.60		
CANDID-R met needs	mild	7.26	3.50	2	13	12.086***	.000
	moderate	8.23	3.20	3	14		
	severe	10.48	2.59	6	18		
	profound	10.78	2.87	3	16		

* significant at the p< 0.05 level

** significant at the p< 0.01 level

*** significant at the p< 0.001 level

† Non-parametric Kruskall-Wallis test

Table 4.36: Post hoc Bonferroni tests of ANOVA between group differences for level of intellectual disabilities and measures of severity of mental disorder

Dependent Variable	(I) Reference level of intellectual disability category	(J) Comparison level of intellectual disability categories	Mean Difference (I-J)	Std. Error	p	95% Confidence Interval	
HoNOS-LD total	mild	moderate	-4.77	2.13	.161	-10.48	.93
		severe	-3.47	2.10	.600	-9.09	2.14
		profound	-6.51*	1.90	.005	-11.60	-1.42
CGI	mild	moderate	-.74*	.25	.022	-1.41	-.07
		severe	-.40	.25	.622	-1.06	.26
		profound	-.42	.22	.366	-1.02	.18
CANDID-R met needs	mild	moderate	-.96	.75	1.000	-2.98	1.06
		severe	-3.22***	.74	.000	-5.20	-1.24
		profound	-3.52***	.67	.000	-5.32	-1.72
	moderate	mild	.96	.75	1.000	-1.06	2.98
		severe	-2.26	.76	.021	-4.29	-.23
		profound	-2.56*	.69	.002	-4.41	-.71

* significant at the p< .0167 level

** significant at the p < .003

*** significant at the p < .0003

Table 4.37: The non-parametric post hoc tests for the between group differences for level of intellectual disabilities and the CANDID-R unmet needs measure

Dependent Variable	(I) Reference level of intellectual disability category	(J) Comparison level of intellectual disability categories	Mann-Whitney U	z	p
CANDID-R unmet needs	mild	moderate	378	-1.968	.049
		severe	520	-.519	.604
		profound	827	-.368	.713
	moderate	mild	378	-1.968	.049
		severe	362	-2.032	.042
		profound	543	-2.388*	.016

* significant at the p< .0167 level

** significant at the p < .003

*** significant at the p < .0003

Although these results are of interest, the exact relationship between level of intellectual disabilities and the measures of severity of mental disorder is not a straightforward linear effect. To understand this further plots of the mean scores on the measures of severity of mental disorder against level of intellectual disabilities are shown in figures 4.4- 4.8.

Figure 4.4: Plot of mean baseline HoNOS-LD score against level of intellectual disabilities

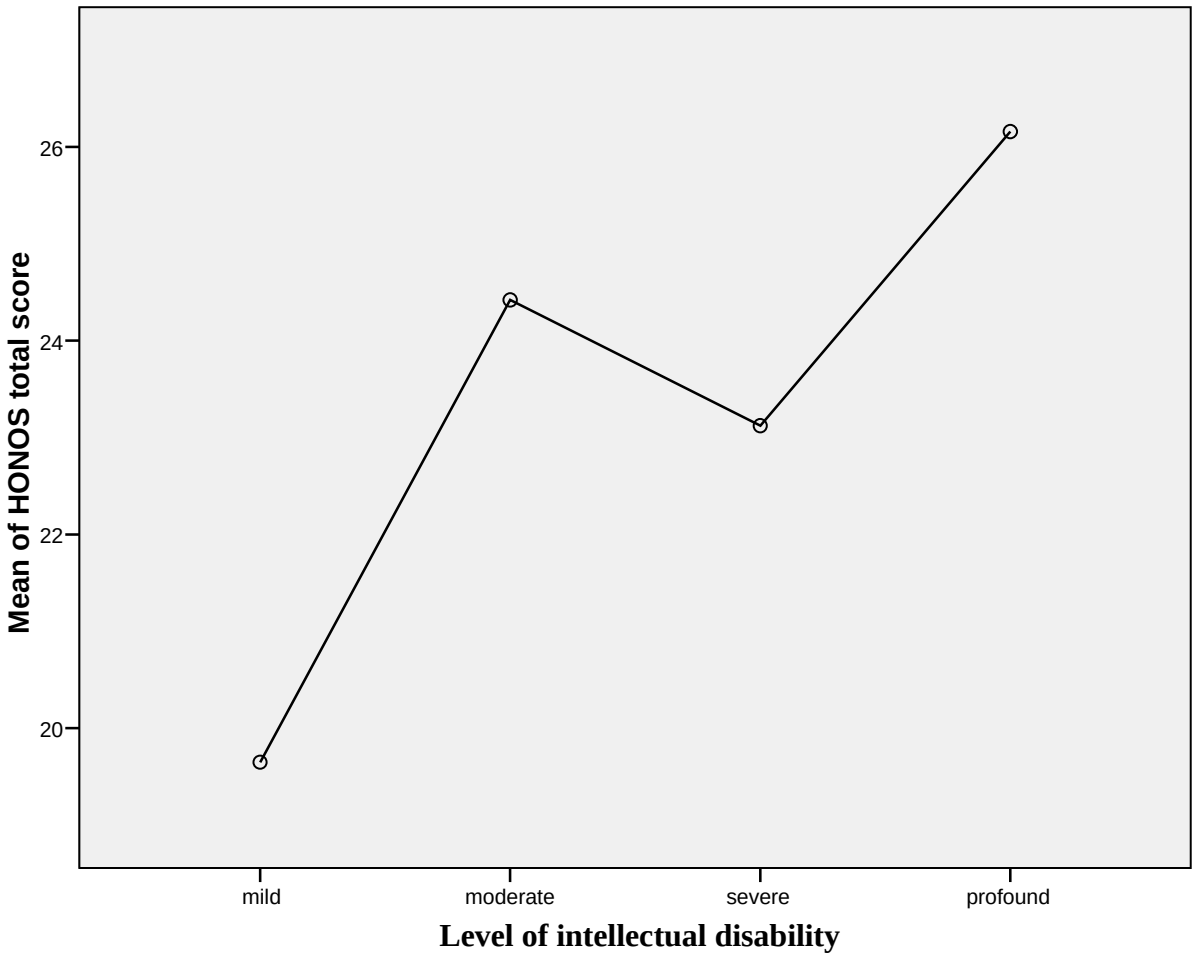


Figure 4.5: Plot of mean baseline GAF score against level of intellectual disabilities

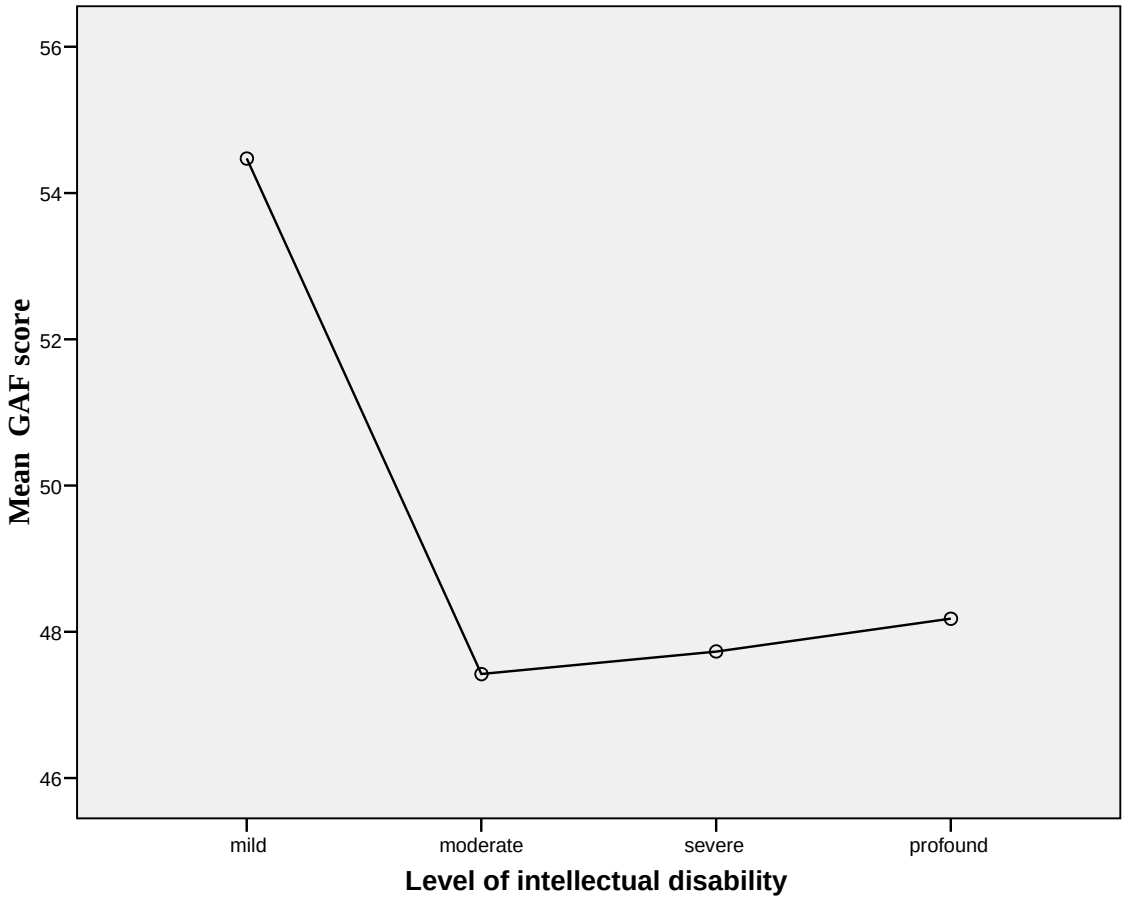


Figure 4.6: Plot of mean baseline CGI score against level of intellectual disabilities

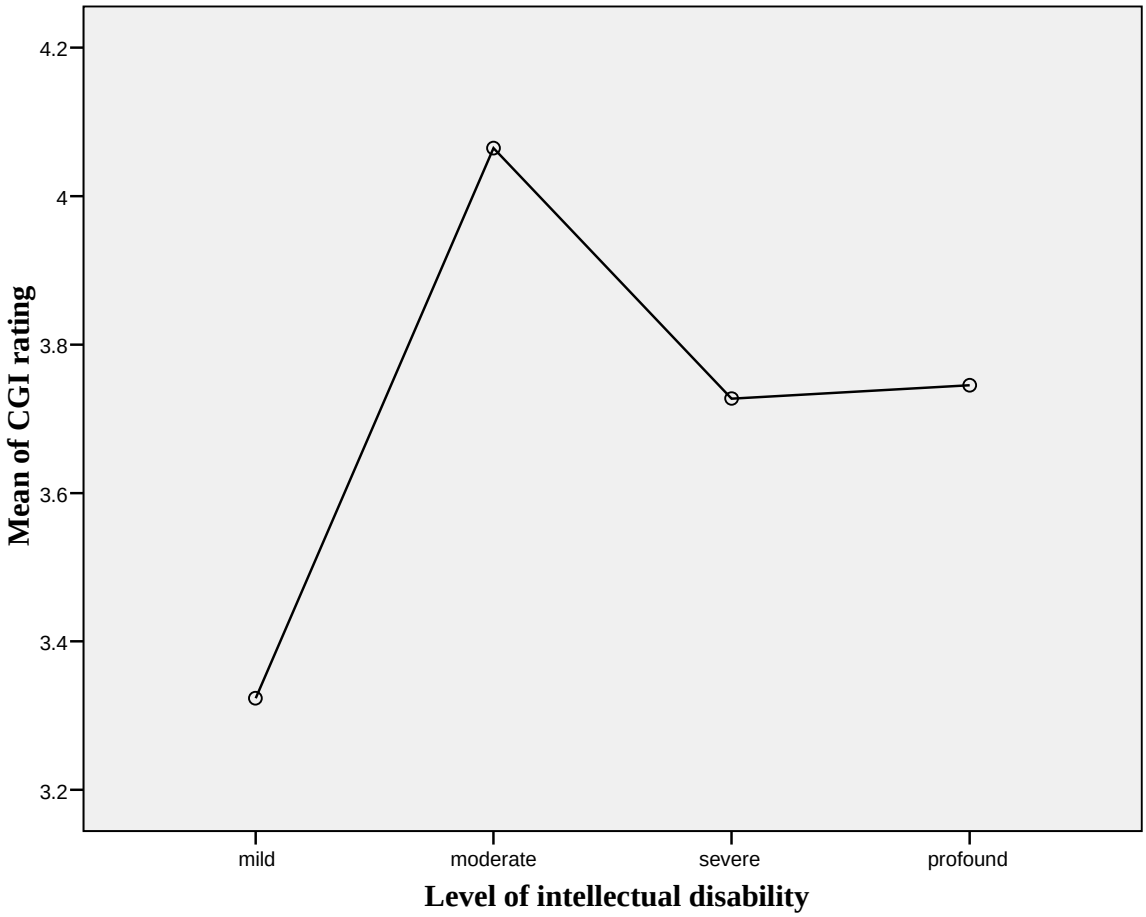


Figure 4.7: Plot of mean baseline CANDID-R unmet against level of intellectual disabilities

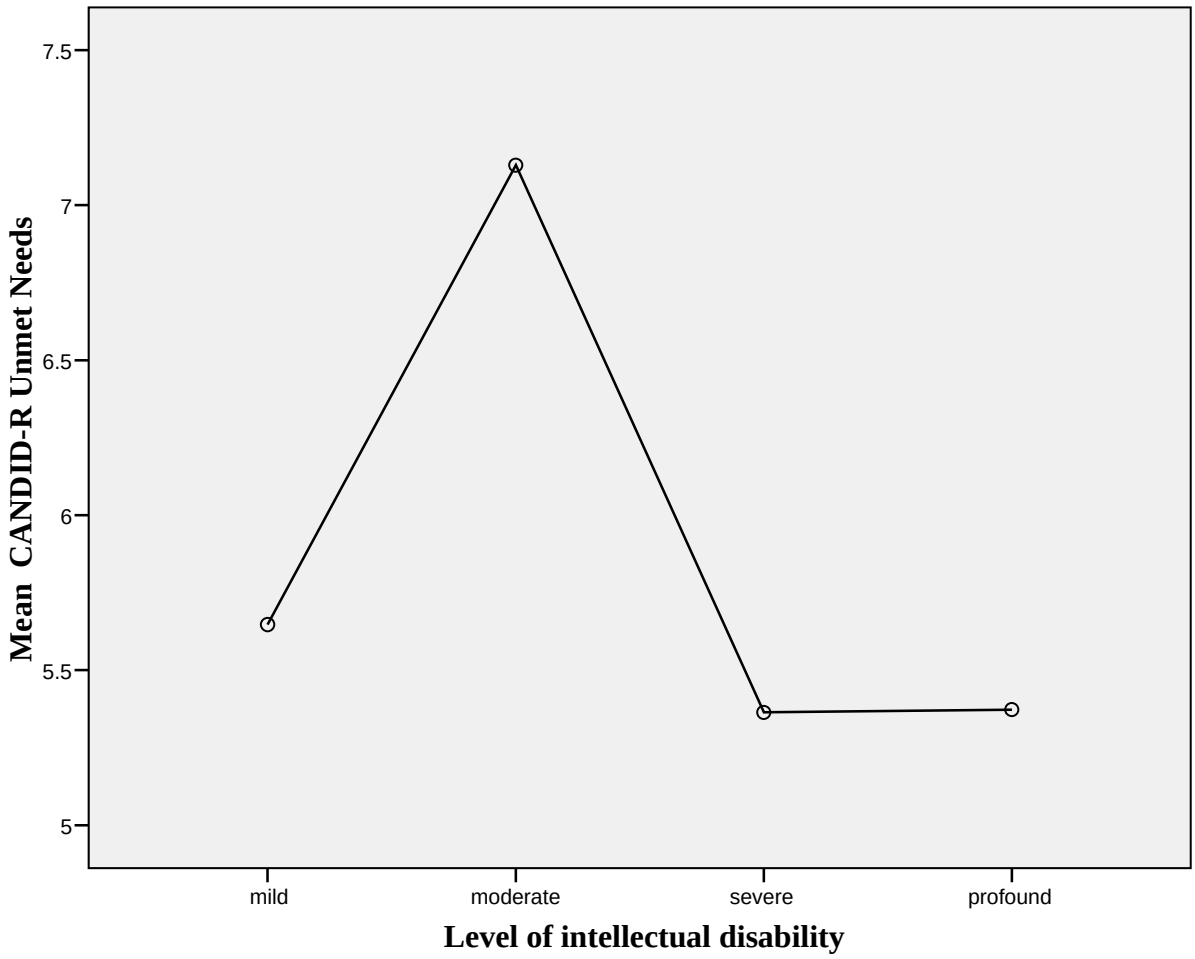
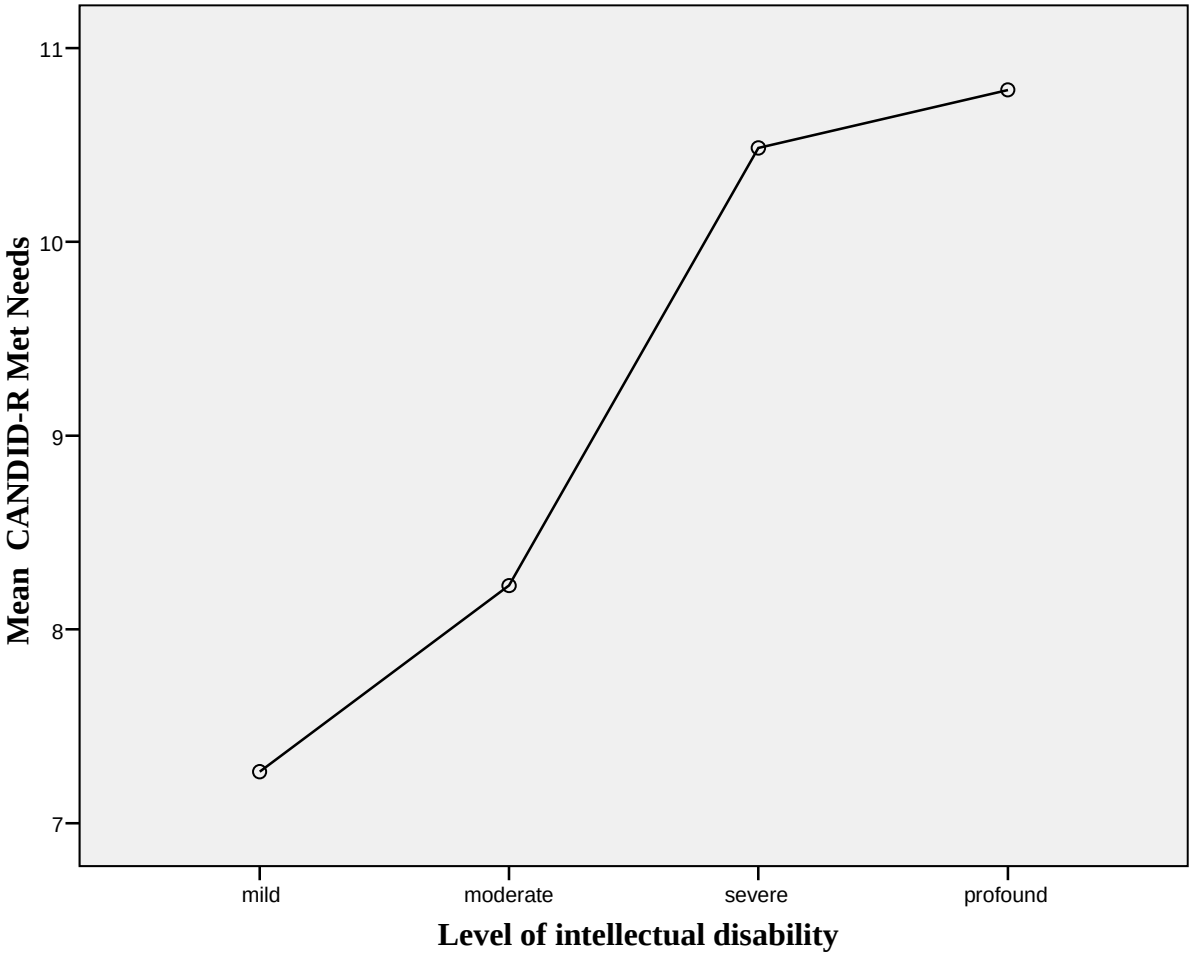


Figure 4.8: Plot of mean baseline CANDID-R met against level of intellectual disabilities



It appears from figures 4.4- 4.8, that there is only a linear relationship between level of intellectual disabilities and CANDID-R met needs. For the other measures, the mean scores for the participants with moderate intellectual disabilities stands out as possibly discrepant with the overall relationship. Possible reasons for these varying and complex relationships between level of intellectual disabilities and measures of severity of mental disorder are considered further in chapter 5.

4.6.5 The association between categorical socio-clinical variables and measures of severity of mental disorder

Table 4.38 shows the results of the ANOVA examining the associations between the measures of severity of mental disorder and epilepsy. From the post-hoc Bonferroni tests the only results of significant is that individuals with well controlled seizures (less than one/ month) have higher levels of met needs (mean difference= -2.502, p= .001) on the CANDID-R, compared to people who do not have epilepsy.

There are no significant differences in measures of severity of mental disorder related to whether an individual has Down syndrome or a diagnosis of autism (table 4.39). However, some other categorical socio-clinical variables are significantly associated with the measures of need on the CANDID-R:

- individuals with visual impairment have higher unmet and met needs (table 4.40)
- having mobility problems is associated with higher met needs (table 4.41)
- participants with either urinary incontinence or bowel incontinence have significantly higher CANDID-R met needs (table 4.42).

Table 4.38: The relationship between epilepsy and measures of severity of mental disorder

	Epilepsy	Mean	SD	Min	Max	F	p
HoNOS-LD total score	no	23.27	8.87	6	48	.656	.521
	good control	23.72	7.37	10	36		
	poor control	26.07	11.26	8	42		
GAF	no	48.68	12.90	18	72	3.187†	.203
	good control	53.03	13.45	23	72		
	poor control	47.00	15.59	27	73		
CGI	no	3.78	1.01	1	6	.970	.381
	good control	3.48	.99	2	6		
	poor control	3.67	1.23	2	5		
CANDID-R unmet needs	no	6.06	3.31	0	16	1.532	.465
	good control	5.21	2.46	1	11		
	poor control	5.13	2.97	0	10		
CANDID-R met needs	no	8.70	3.23	2	14	8.104***	.000
	good control	11.21	2.76	6	18		
	poor control	10.60	3.85	4	16		

** significant at the p< .01 level

† Non- parametric χ^2 from Kruskall-Wallis test

Table 4.39: The relationship between autism, Down syndrome and measures of severity of mental disorder

	Autism						Down syndrome					
	Yes (n=19)		No (n=131)		statistic	p	Yes (n=24)		No (n=126)		statistic	p
	Mean	SD	Mean	SD			Mean	SD	Mean	SD		
HoNOS-LD total score	25.58	12.38	23.35	8.23	-.759§	.456	22.50	9.49	23.86	8.74	.686	.494
GAF	48.26	16.49	49.52	12.87	-.219†	.827	47.96	12.39	49.62	13.53	-.677†	.499
CGI	3.74	1.15	3.71	1.02	-.115	.909	3.75	.90	3.70	1.06	-.200	.842
CANDID-R unmet needs	6.00	3.09	5.77	3.15	-.691†	.489	5.13	2.29	5.93	3.26	-1.125†	.261
CANDID-R met needs	9.32	3.15	9.39	3.40	.092	.927	10.25	2.67	9.22	3.46	-.200	.842

§ Levene's test found the between group variance is significant so the t-test results are for equal variances not assumed

† Non- parametric z score from Mann-Whitney test

Table 4.40: The relationship between sensory impairments and measures of severity of mental disorder

	Visual impairment						Hearing impairment					
	Yes (n=27)		No (n=123)		statistic	p	Yes (n=12)		No (n=133)		statistic	p
	Mean	SD	Mean	SD			Mean	SD	Mean	SD		
HoNOS-LD total	23.78	10.11	23.61	8.59	-.091	.928	20.00	8.42	23.96	8.842	1.491	.138
GAF	51.63	12.67	48.85	13.47	-1.080†	.280	51.08	13.15	49.20	13.38	-.440†	.660
CGI	3.56	.93	3.75	1.05	.869	.386	3.50	1.00	3.73	1.03	.741	.460
CANDID-R unmet needs	4.52	2.59	6.08	3.18	-2.390†*	.017	5.33	3.73	5.84	3.09	-.774†	.439
CANDID-R met needs	11.11	2.81	9.00	3.36	-3.035**	.003	10.50	4.48	9.28	3.25	-1.203	.231

* significant at the p< .05 level
** significant at the p< .01 level
† Non- parametric z-score from Mann-Whitney test

Table 4.41: The relationship between mobility problems and measures of severity of mental disorder

	Mobility problems					
	Yes (n=37)		No (n=113)		statistic	p
	Mean	SD	Mean	SD		
HoNOS-LD total	22.97	8.60	23.86	8.96	.526	.600
GAF	48.65	14.71	49.59	12.91	-1.501†	.133
CGI	3.70	1.15	3.71	.99	.059	.953
CANDID-R unmet needs	5.22	2.56	5.99	3.29	-1.029†	.303
CANDID-R met needs	10.92	3.13	8.88	3.29	-3.314**	.001

** significant at the p< .01 level

† Non- parametric z-score from Mann-Whitney test

Table 4.42: The relationship between incontinence and measures of severity of mental disorder

	Urinary incontinence						Bowel incontinence					
	Yes (n=53)		No (n=97)		statistic	p	Yes (n=38)		No (n=112)		statistic	p
	Mean	SD	Mean	SD			Mean	SD	Mean	SD		
HONOS-LD total	26.06	8.94	22.30	8.55	-2.524*	.013	26.74	9.43	22.58	8.43	-2.548*	.012
GAF	47.55	13.99	50.35	12.92	-1.127†	.260	47.61	14.53	49.95	12.91	-.889†	.374
CGI	3.83	1.07	3.65	1.01	-1.048	.297	3.79	1.19	3.68	.97	-.541	.590
CANDID-R unmet needs	5.38	2.40	6.03	3.47	-.822†	.411	5.11	1.98	6.04	3.42	-.1.106†	.269
CANDID-R met needs	11.04	2.77	8.47	3.32	-4.787***	.000	11.00	2.59	8.83	3.42	-3.572***	.000

* significant at the p< 0.05 level
** significant at the p< 0.01 level
*** significant at the p< 0.001 level
† Non- parametric z-score from Mann-Whitney test
§ Levene's test found the between group variance is significant so the t-test results are for equal variances not assumed

The only measure of severity of mental disorder other than CANDID-R significantly related to any of these categorical socio-clinical variables is the HONOS-LD- individuals with urinary or bowel incontinence have significantly higher scores, suggestive of a greater severity of mental disorder.

The complex relationships between the baseline measures of severity of mental disorders and socio-clinical variables need further clarification in multivariate statistical tests. However, the findings that there are significant bivariate associations between the measures of severity of mental disorder at baseline and the socio-clinical variables in this section means that null hypothesis six is rejected.

4.7 Multivariate associations between measures of psychopathology, socio-clinical variables and severity of mental disorder

Null hypothesis seven:

There are no significant multivariate associations between dimensional measures of psychopathology, socio-clinical variables and measures of the severity of mental disorders.

This section examines which variables, found to be associated with the measures of severity of mental disorder in bivariate analyses in section 4.6, are independently associated in multivariate linear regression. The variables that are significantly associated with the measures of severity of mental disorder ($p<.05$), and variables with associations approaching significance ($.05 < p < .1$) are included in separate linear regression analyses, using each of the measures of severity of mental disorder as the dependant variable. Separate regression analyses are shown for psychopathology dimension factor scores and symptom counts, and the three overall measures of psychopathology.

4.7.1 Psychopathology and socio-clinical variables independently associated with HoNOS-LD

There was only one difference between the regression models using the HoNOS-LD total score as the dependant variable in the linear regression analyses that include the

dimension factor scores (table 4.43) and dimension symptom counts (table 4.44). The regression model that includes the factor scores includes two dimensions of psychopathology- depressive and behaviour-affective- whilst the symptom count model has three- depressive, organic and behaviour-affective. Otherwise the models are similar:

- both multivariate analyses retain only the mild- profound intellectual disabilities between group difference in the HoNOS-LD as independently significant
- urinary and bowel incontinence were excluded from both models.

It is likely that the reason that urinary and bowel incontinence are excluded from both models, in table 4.43 and 4.44, is that they are strongly correlated with the level of intellectual disabilities i.e. individuals with profound intellectual disabilities are more likely to experience urinary and bowel incontinence than individuals with mild intellectual disabilities.

The overall measures of psychopathology based on the results of the EFA dimensions of psychopathology, the total dimension factor score and total dimension symptom count, are also independently associated with the HoNOS-LD score (table 4.45 and 4.46).

Table 4.43: Multivariate associations of dimension factor scores and socio-clinical variables with baseline HoNOS-LD scores

Bivariate associations (p<0.1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension factor score‡	.000***		13.120	2.068	.431	.000***	.330
Behaviour-affective dimension factor score‡	.000***		10.297	2.135	.332	.000***	
Categorical measure of intellectual disabilities	.009**	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	2.983	1.280	.160	.021*	
Urinary incontinence	.013*		Not retained in the model				
Bowel incontinence	.012*		Not retained in the model				

‡ the square root transformed variable is used in the analyses
* significant at the p< .05 level
** significant at the p< .01 level
*** significant at the p< .001 level

Table 4.44: Multivariate associations of dimension symptom counts and socio-clinical variables with baseline HoNOS-LD scores

Bivariate associations (p<0.1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension symptom count	.000***		1.360	.241	.385	.000***	.378
Organic dimension symptom count	.011*		1.390	.469	.205	.004**	
Behaviour-affective dimension symptom count	.000***		1.554	.318	.330	.000***	
Categorical measure of intellectual disabilities	.009**	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	3.501	1.243	.188	.006**	
Urinary incontinence	.013*		Not retained in the model				
Bowel incontinence	.012*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.45: Multivariate associations of total dimension factor score, and socio-clinical variables with baseline HoNOS-LD scores

Bivariate associations (p<0.1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension factor score	.000***		2.512	.298	.557	.000***	.366
Categorical measure of intellectual disabilities	.009**	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	2.545	1.437	.137	.049*	
Urinary incontinence	.013*		Not retained in the model				
Bowel incontinence	.012*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.46: Multivariate associations of total dimension symptom count and socio-clinical variables with baseline HoNOS-LD scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension symptom count	.000***		1.317	.143	.590	.000***	.404
Categorical measure of intellectual disabilities	.009**	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	2.398	1.394	.129	.048*	
Urinary incontinence	.013*		Not retained in the model				
Bowel incontinence	.012*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Contrasting results for the overall measure of psychopathology based on the symptom count from the PPS-LD are shown in table 4.47. Whilst the EFA PPS-LD symptom count- 41 measures of psychopathology was retained as significant in the regression model, the results for the socio-clinical variables were different to the results for the regression analyses that were done for overall the measures of psychopathology related to the dimensional model of psychopathology (tables 4.45 & 4.46 above).

Table 4.47: Multivariate associations of EFA PPS-LD symptom count- 41, and socio-clinical variables with baseline HoNOS-LD scores

Bivariate associations (p< .1)		**Multivariate associations**					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
EFA PPS-LD symptom count-41	.000***		1.264	.142	.580	.000***	.379
Categorical measure of intellectual disabilities	.009**	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	Not retained in the model				
Urinary incontinence	.013*		Not retained in the model				
Bowel incontinence	.012*		4.390	1.320	.217	.001**	

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

4.7.2 Psychopathology and socio-clinical variables independently associated with GAF scores

None of the socio-clinical variables were significantly associated with the GAF score in the bivariate analyses reported in section 4.6. Therefore, the results in this section are only for GAF regression models for analyses with factor scores, and symptom counts for the depressive, organic and behaviour-affective dimensions of psychopathology.

Table 4.48: Multivariate associations of dimension factor scores with baseline GAF scores

Bivariate associations (p<0.1)		Multivariate associations				
Variable	**p**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension ‡	.000***	-19.272	3.020	-.420	.000***	.387
Organic dimension	.001**	-4.359	.884	-.326	.000***	
Behaviour-affective dimension ‡	.003**	-13.373	3.051	-.286	.000***	

‡ the square root transformed variable is used in the analyses

Table 4.49: Multivariate associations of dimension symptom counts with baseline GAF scores

Bivariate associations (p<0.1)		Multivariate associations				
Variable	**p**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension	.000***	-2.183	.358	-.410	.000***	.392
Organic dimension	.000**	-3.123	.692	-.306	.000***	
Behaviour-affective dimension	.001**	-1.988	.468	-.280	.000***	

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

The results in tables 4.48 and 4.49 using the factor score and symptom count measures representing the three dimensions of psychopathology are very similar- with strong correlations with the GAF scores. The reasons why only the anxiety dimension of psychopathology is not significantly correlated with the GAF scores will be considered further in chapter 5.

There are no potential covariates to include in a regression analysis with the overall measures of psychopathology. To allow comparison, table 4.50 shows the statistics from simple regression analyses with each of the three overall measures of psychopathology.

Table 4.50: Simple regression statistics for the overall measures of psychopathology with GAF scores at baseline

Bivariate associations (p<.1)		**Multivariate associations**				
Variable	**p**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension factor score	.000***	-3.910	.458	-.576	.000***	.332
Total dimension symptom count	.000***	-1.969	.225	-.585	.000***	.343
EFA PPS-LD symptom count- 41	.000***	-1.900	.221	-.579	.000***	.335

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

4.7.3 Psychopathology and socio-clinical variables independently associated with CGI scores

Although the categorical measure of level of intellectual disabilities was associated with the CGI scores in the bivariate analysis, it was not retained in any of the final multivariate regression models. The dummy categorical variables representing level of intellectual disabilities are shown in the models including individual dimensions of psychopathology factor scores and dimension counts in table 4.51 & 4.52. Although the dummy categorical variables were included in the separate analyses for the overall measures of psychopathology, they are not shown in table 4.53.

Table 4.51: Multivariate associations of dimension factor scores and level of intellectual disabilities with baseline CGI scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension ‡	.000***		1.616	.237	.457	.000***	.366
Organic dimension	.003**		.275	.069	.266	.000***	
Behaviour-affective dimension ‡	.003**		.914	.239	.253	.000***	
Categorical measure of intellectual disabilities	.034*	Mild- moderate	Not retained in the model				
		Mild- severe	Not retained in the model				
		Mild- profound	Not retained in the model				

‡ the square root transformed variable is used in the analyses

Table 4.52: Multivariate associations of dimension symptom counts and level of intellectual disabilities with baseline CGI scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension	.000***		.192	.028	.468	.000***	.386
Organic dimension	.001**		.183	.054	.232	.001**	
Behaviour-affective dimension	.002**		.135	.036	.248	.000***	
Categorical measure of intellectual disabilities	.034*	Mild- moderate	Not retained in the model				
		Mild- severe	Not retained in the model				
		Mild- profound	Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.53: Multivariate associations for the overall measures of psychopathology with baseline CGI scores

Bivariate associations (p< .1)		Multivariate associations				
Variable	**p**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension factor score	.000***	.295	.036	.562	.000***	.316
Total dimension symptom count	.000***	.153	.017	.590	.000***	.349
EFA PPS-LD symptom count- 41	.000***	.144	.017	.568	.000***	.322

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

4.7.4 Psychopathology and socio-clinical variables independently associated with the number of CANDID-R unmet needs at baseline

The results for the multivariate analyses examining variables associated with the CANDID-R unmet needs, and including the dimensional factor scores and symptom counts are shown in table 4.54 and 4.55 respectively. From table 4.54, none of the psychopathology dimension factor scores are independently associated with the number of unmet needs on the CANDID-R. However, the organic and behaviour-affective dimension symptom counts are retained in the final regression model in table 4.55.

As for the HoNOS-LD and the GAF and regression models for the three overall measures of psychopathology are very similar with retention of the measure of psychopathology and the same socio-clinical variables- age, living circumstances, level of intellectual disabilities and visual impairment- in each model (tables 4.56 -4.58).

Table 4.54: Multivariate associations of dimension factor scores and socio-clinical variables with baseline CANDID-R unmet needs

Bivariate associations (p<0.1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Behaviour-affective dimension factor score‡	.033*		Not retained in the model				.263
Age	.031*		-.035	.020	-.147	.048*	
Living circumstance	.009**	Independent-family carer	-4.045	.795	-549	.000***	
		Independent-paid carer	-3.772	.794	-.595	.000***	
Categorical measure of intellectual disabilities	.079	Mild- moderate	2.233	.747	.290	.003**	
		Mild-severe	1.783	.811	.237	.030*	
		Mild- profound	1.510	.755	.229	.047*	
Visual impairment	.017*		-1.701	.610	-.210	.006**	

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level
‡ the square root transformed variable is used in the analyses

Table 4.55: Multivariate associations of dimension symptom counts and socio-clinical variables with baseline CANDID-R unmet needs

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension	.044*		Not retained in the model				
Organic dimension	.003**		.433	.190	.181	.024*	
Behaviour-affective dimension	.012*		.296	.124	.178	.018*	
Age	.031*		-.050	.019	-.208	.010*	
Living circumstances	.009**	Independent- family carer	-4.417	.761	-.599	.000***	.339
		Independent- paid carer	-3.740	.749	-.590	.000***	
Categorical measure of intellectual disabilities	.079	Mild- moderate	1.908	.715	.248	.008**	
		Mild-severe	1.413	.777	.188	.041*	
		Mild- profound	1.425	.719	.216	.030*	
Visual impairment	.017*		-1.546	.582	-.191	.009**	

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.56: Multivariate associations of total dimension factor score and socio-clinical variables with baseline CANDID-R unmet needs

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension factor score	.000***		.477	.116	.299	.000***	.328
Age	.031*		-.042	.018	-.176	.023*	
Living circumstances	.009**	Independent-family carer	-3.906	.755	-.530	.000***	
		Independent-paid carer	-3.623	.745	-.572	.000***	
Categorical measure of intellectual disabilities	.079	Mild- moderate	1.642	.731	.213	.026*	
		Mild-severe	1.632	.776	.217	.037*	
		Mild- profound	1.373	.721	.209	.048*	
Visual impairment	.017*		-1.559	.584	-.192	.009**	

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.57: Multivariate associations of total dimension symptom count and socio-clinical variables with baseline CANDID-R unmet needs

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension factor score	.000***		.226	.057	.285	.000***	.328
Age	.031*		-.042	.018	-.176	.023*	
Living circumstances	.009**	Independent-family carer	-3.817	.758	-.518	.000***	
		Independent-paid carer	-3.539	.747	-.558	.000***	
Categorical measure of intellectual disabilities	.079	Mild- moderate	1.801	.726	.234	.014*	
		Mild-severe	1.674	.778	.222	.033*	
		Mild- profound	1.403	.723	.213	.046*	
Visual impairment	.017*		-1.615	.585	-.199	.007**	

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.58: Multivariate associations of EFA PPS-LD symptom count-41 and socio-clinical variables with baseline CANDID-R unmet needs

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
EFA PPS-LD symptom count-41	.000***		.210	.056	.272	.000***	.316
Age	.031*		-.042	.018	-.173	.026*	
Living circumstances	.009**	Independent-family carer	-3.841	.762	-.521	.000***	
		Independent-carer	-3.535	.751	-.558	.000***	
Categorical measure of intellectual disabilities	.079	Mild- moderate	1.780	.733	.231	.016*	
		Mild-severe	1.647	.783	.219	.037*	
		Mild- profound	1.329	.729	.202	.049*	
Visual impairment	.017*		-1.646	.588	-.203	.006**	

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

4.7.5 Psychopathology and socio-clinical variables independently associated with the number of CANDID-R met needs at baseline

The results of the multivariate analyses examining the relationships between the dimensional measures of psychopathology, socio-clinical variables and the met needs on the CANDID-R are shown in tables 4.59 and 4.60. This was the first measure of severity of mental disorder for which there was no bivariate association with the behaviour-affective dimension of psychopathology.

Interestingly, the anxiety dimension factor score and symptom counts are not retained in either regression model, respectively. However, the other dimensions of psychopathology are retained and remain indirectly associated with the CANDID-R met needs. Furthermore, more socio-clinical variables are associated with the CANDID-R met needs than any other measure of severity of mental disorder- age, level of intellectual disabilities, epilepsy, visual impairment, mobility problems, urinary incontinence and bowel incontinence.

We can see in tables 4.61-4.63, below that including the overall measures of psychopathology in the regression models results in the same socio-clinical variables being retained in the model as for the analyses that use the measures representing the individual dimensions of psychopathology in tables 4.59 and 4.60. Overall, whilst the results for the regression analyses using the different measures of psychopathology in tables 4.59-4.63 are very similar, the results are very different than for the other measures of severity of mental disorder. Potential reasons for this difference will be explored in the discussion in chapter 5.

Table 4.59: Multivariate associations of dimension factor scores and socio-clinical variables with at baseline CANDID-R met needs

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension ‡	.063		-1.788	.747	-.155	.018*	
Anxiety dimension ‡	.012*		Not retained in the model				
Age	.062		.041	.018	.160	.021*	
Living circumstances	.000***	Independent-family carer	2.969	.680	.376	.000***	
		Independent-paid carer	3.862	.619	.568	.000***	
Categorical measure of intellectual disabilities	.000***	Mild- moderate	1.609	.701	.195	.023*	
		Mild-severe	2.948	.690	.365	.000***	.482
		Mild- profound	2.794	.678	.396	.000***	
Epilepsy	.000***	No-well controlled	2.040	.578	.241	.001**	
		No-poor control	1.492	.760	.134	.032	
Visual impairment	.003**		1.947	.555	.224	.001**	
Mobility problems	.001**		Not retained in the model				
Urinary incontinence	.000***		1.163	.478	.166	.016*	
Bowel incontinence	.000***		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level
‡ the square root transformed variable is used in the analyses

Table 4.60: Multivariate associations of dimension symptom counts and socio-clinical variables with baseline CANDID-R met needs

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension	.063		-.176	.087	-.131	.045*	
Organic dimension	.080		-.400	.169	-.156	.019*	
Anxiety dimension	.012*		Not retained in the model				
Age	.062		.048	.017	.187	.007**	
Living circumstances	.000***	Independent-family carer	3.214	.674	.407	.000***	
		Independent-paid carer	3.896	.606	.573	.000***	
Categorical measure of intellectual disabilities	.000***	Mild- moderate	1.609	.701	.195	.023*	.491
		Mild-severe	2.948	.690	.365	.000***	
		Mild- profound	2.794	.678	.396	.000***	
Epilepsy	.000***	No-well controlled	1.663	.535	.197	.002**	
		No-poor control	1.423	.703	.128	.045*	
Visual impairment	.003**		1.832	.547	.211	.001**	
Mobility problems	.001**		Not retained in the model				
Urinary incontinence	.000***		1.279	.472	.183	.008**	
Bowel incontinence	.000***		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.61: Multivariate associations of total dimension factor score and socio-clinical variables with baseline CANDID-R met needs

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension factor score	.024*		-.308	.119	-.180	.011*	
Age	.062		.042	.018	.162	.019*	
Living circumstances	.000***	Independent-family carer	3.152	.668	.399	.000***	
		Independent-paid carer	4.206	.606	.619	.000***	
Categorical measure of intellectual disabilities	.000***	Mild- moderate	1.609	.701	.195	.023*	
		Mild-severe	2.948	.690	.365	.000***	
		Mild- profound	2.794	.678	.396	.000***	.482
Epilepsy	.000***	No-well controlled	2.040	.578	.241	.001**	
		No-poor control	1.492	.760	.134	.032	
Visual impairment	.003**		1.646	.584	.189	.006**	
Mobility problems	.001**		Not retained in the model				
Urinary incontinence	.000***		1.287	.539	.184	.018*	
Bowel incontinence	.000***		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.62: Multivariate associations of total dimension symptom count and socio-clinical variables with baseline CANDID-R met needs

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension symptom count	.024*		-.149	.058	-.176	.011*	
Age	.062		.042	.018	.162	.019*	
Living circumstances	.000***	Independent-family carer	3.077	.670	.389	.000***	
		Independent-paid carer	4.130	.607	.608	.000***	
Categorical measure of intellectual disabilities	.000***	Mild- moderate	1.500	.691	.182	.032*	
		Mild-severe	2.895	.689	.359	.000***	
		Mild- profound	2.758	.677	.391	.000***	.478
Epilepsy	.000***	No-well controlled	2.037	.578	.241	.001**	
		No-poor control	1.556	.759	.140	.042*	
Visual impairment	.003**		1.680	.583	.193	.005**	
Mobility problems	.001**		Not retained in the model				
Urinary incontinence	.000***		1.278	.539	.183	.019*	
Bowel incontinence	.000***		Not retained in the model				

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

Table 4.63: Multivariate associations of EFA PPS-LD symptom count-41 and socio-clinical variables with baseline CANDID-R met needs

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
EFA PPS-LD symptom count- 41	.047*		-.141	.057	-.171	.014*	
Age	.062		.041	.018	.160	.021*	
Living circumstances	.000***	Independent-family carer	3.107	.672	.393	.000	
		Independent-paid carer	4.145	.609	.610	.000	
Categorical measure of intellectual disabilities	.000***	Mild- moderate	1.520	.695	.184	.003**	
		Mild-severe	2.915	.690	.361	.000***	
		Mild- profound	2.805	.679	.397	.000***	.475
Epilepsy	.000***	No-well controlled	2.063	.578	.244	.001**	
		No-poor control	1.532	.760	.138	.041*	
Visual impairment	.003**		1.697	.584	.195	.004**	
Mobility problems	.001**		Not retained in the model				
Urinary incontinence	.000***		1.278	.540	.183	.019**	
Bowel incontinence	.000***		Not retained in the model				

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

Since there are dimensional and overall measures of psychopathology, and socio-clinical variables independently associated with all five measures of the severity of mental disorders, the null hypothesis is rejected.

4.8 Comparing the contribution of dimensional and categorical models of psychopathology to the severity of mental disorders

Null hypothesis eight:
There are no significant differences in the associations of dimensional and categorical models of psychopathology with measures of the severity of mental disorders

In section 4.3.4, dimensional measures of psychopathology were shown to be independently related to measures of the severity of mental disorders. This section examines whether categorical diagnoses from DC-LD are related to the severity of mental disorders.

4.8.1 Examining the relationship of a categorical diagnosis to severity of mental disorder

The binary variable of whether or not an individual meets the criteria for a DC-LD categorical diagnosis replaces the dimensional measures in the regression analyses in section 4.7. The variable for categorical diagnosis was retained as significant in the regression analyses for the HoNOS-LD total score table 4.64.

Although no socio-clinical variables were associated with the GAF score at baseline simple linear regression was run to examine if there was a significant association between having a categorical diagnosis. The association approached significance (B=4.108, SE B= 2.348, β=.143, p= 0.082) but did not meet the accepted level of significance ($p < .05$). Similarly, having a categorical diagnosis was not associated with the CGI, baseline number of unmet or met needs on the CANDID-R (tables 4.65-4.67).

Table 4.64: Multivariate associations of categorical DC-LD diagnosis and socio-clinical variables with baseline HoNOS-LD scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Categorical diagnosis of mental disorder on DC-LD (Y/N)	N/A		3.405	1.516	.178	.026*	.108
Categorical measure of intellectual disabilities	.009**	Mild- moderate	4.750	2.104	.219	.025*	
		Mild-severe	4.017	2.084	.189	.046*	
		Mild- profound	6.610	1.876	.356	.001* *	
Urinary incontinence	.013*		Not retained in the model				
Bowel incontinence	.012*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level

Table 4.65: Multivariate associations of categorical DC-LD diagnosis and socio-clinical variables with baseline CGI scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Categorical diagnosis of mental disorder on DC-LD (Y/N)	N/A		Not retained in the model				.080
Categorical measure of intellectual disabilities	.034*	Mild- moderate	4.750	2.104	.219	.025*	
		Mild-severe	Not retained in the model				
		Mild- profound	Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.66: Multivariate associations of categorical DC-LD diagnosis and socio-clinical variables with CANDID-R unmet needs at baseline

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Categorical diagnosis of mental disorder on DC-LD (Y/N)	N/A		Not retained in the model				
Age	.031*		-.035	.020	-.147	.048*	
Living circumstance	.009**	Independent-family carer	-4.045	.795	-.549	.000***	
		Independent-paid carer	-3.772	.794	-.595	.000***	
Categorical measure of intellectual disabilities	.079	Mild- moderate	2.233	.747	.290	.003**	.263
		Mild-severe	1.783	.811	.237	.030*	
		Mild- profound	1.510	.755	.229	.047*	
Visual impairment	.017*		-1.701	.610	-.210	.006**	

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.67: Multivariate associations of categorical DC-LD diagnosis and socio-clinical variables with CANDID-R met needs at baseline

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Categorical diagnosis of mental disorder on DC-LD (Y/N)	N/A		Not retained in the model				
Age	.062		.030	.018	.118	.044*	
Living circumstances	.000***	Independent-family carer	2.803	.716	.355	.000***	
		Independent-paid carer	3.660	.678	.539	.000***	
Categorical measure of intellectual disabilities	.000***	Mild- moderate	Not retained in the model				
		Mild-severe	1.156	.620	.143	.048*	
		Mild- profound	1.309	.552	.185	.019*	.453
Epilepsy	.000***	No- well controlled	1.935	.550	.229	.001**	
		No- poor control	1.619	.714	.145	.025*	
Visual impairment	.003**		1.821	.565	.209	.002**	
Mobility problems	.001**		Not retained in the model				
Urinary incontinence	.000***		1.163	.478	.166	.016*	
Bowel incontinence	.000***		Not retained in the model				

* significant at the p< .05 level ** significant at the p< .01 level **** significant at the p< .001 level

4.8.2 Examining whether dimensional and categorical models of psychopathology are both retained as independently associated with the severity of mental disorders

Since having a DC-LD categorical diagnosis was only retained as significantly associated with the HoNOS-LD total score this was the only measure for which the final regression analysis, including both models of psychopathology, could be examined. However, the variable representing the categorical model was not retained as significant in the regression models for the dimension factor scores and symptom counts in tables 4.68 and 4.69.

This suggests that no additional variance in the HoNOS-LD total score was explained by the categorical model, over and above the variance accounted for by the dimensional model of psychopathology. Therefore, it was concluded that the dimensional model of psychopathology was more strongly related to the severity of mental disorder. The null hypothesis is rejected.

Table 4.68: Regression model examining dimension factor scores, DC-LD categorical diagnosis and socio-clinical variables with baseline HoNOS-LD scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension factor score‡	.000***		13.120	2.068	.431	.000***	.330
Behaviour-affective dimension factor score‡	.000***		10.297	2.135	.332	.000***	
Categorical diagnosis of mental disorder on DC-LD (Y/N)	N/A		Not retained in the model				
Categorical measure of intellectual disabilities	.009**	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	2.983	1.280	.160	.021*	
Urinary incontinence	.013*		Not retained in the model				
Bowel incontinence	.012*		Not retained in the model				

‡ the square root transformed variable is used in the analyses
* significant at the p< .05 level

** significant at the p< .01 level

**** significant at the p< .001 level

Table 4.69: Regression model examining dimension symptom counts, DC-LD categorical diagnosis and socio-clinical variables with baseline HoNOS-LD scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension symptom count	.000***		1.360	.241	.385	.000***	.378
Organic dimension symptom count	.011*		1.390	.469	.205	.004**	
Behaviour-affective dimension symptom count	.000***		1.554	.318	.330	.000***	
Categorical diagnosis of mental disorder on DC-LD (Y/N)	N/A		Not retained in the model				
Categorical measure of intellectual disabilities	.009**	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	3.501	1.243	.188	.006**	
Urinary incontinence	.013*		Not retained in the model				
Bowel incontinence	.012*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

4.9 The association of psychopathology and the longitudinal outcome of mental disorders

Null hypothesis nine:
Dimensional measures of psychopathology are not significantly correlated to the longitudinal outcome of mental disorders.

This section considers the relationship between psychopathology and outcome. Whereas the cross-sectional relationships are better conceptualised at looking at the relationships of psychopathology and socio-clinical variables with severity of mental disorders, by following up individuals with intellectual disabilities and mental disorders, the extent to which psychopathology and other variables at baseline are a significant predictor of outcome is examined.

As described in chapter 3.4.3.5, the longitudinal outcome was taken as the change in the measure of outcome between baseline and follow up. Since higher scores on the GAF and CANDID-R met needs variables represents a better outcome, the sign of the longitudinal outcome score was reversed for these variables in order that all five outcome measures can be compared.

4.9.1 Change in the measures of outcome over time

Prior to addressing the null hypothesis, table 4.70 shows the mean scores and standard deviation of the measures of outcome at baseline and follow-up, and the results of statistical tests to examine if there is a significant change in the measures over time. There is a significant change in all the measures of outcome over time.

Table 4.70: The significance of change in measures of outcome over time

	Baseline		Follow-up		Change over time		Wilcoxon signed ranks test	
Outcome measure	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Z**	**p**
HoNOS-LD total	25.50	8.93	16.68	11.28	-8.82	13.85	-3.442	.001**
GAF	44.40	11.547	57.75	17.86	-13.35	13.33	-3.552	.000***
CGI	3.93	1.02	2.85	1.48	-1.08	1.65	-3.579	.000***
CANDID-unmet	6.35	3.09	3.40	3.947	-2.95	4.19	-3.778	.000***
CANDID-met	9.80	2.92	12.85	4.07	-3.05	3.82	-4.261	.000***

* $p < .05$
** $p < .01$
*** $p < .001$

4.9.2 Examining the distribution of the longitudinal measures of outcome

Table 4.71 shows the results of tests examining the skewness, kurtosis and overall distribution of the six longitudinal measures of outcome, in comparison to the normal distribution. None of the measures are significantly different from the normal distribution and therefore parametric tests are used in the analyses.

4.9.3 The correlations of baseline psychopathology and longitudinal measures of outcome

To examine whether baseline psychopathology dimension factor scores and symptom counts are significant predictors of longitudinal outcome, correlations are shown in table 4.72 and 4.73. The correlations of the EFA PPS-LD symptom count- 41 overall measure of psychopathology with the measures of longitudinal outcome are shown in table 4.74.

The dimensional and overall measures of psychopathology are significantly correlated with the longitudinal change in the HoNOS-LD, GAF and CGI scores. However, only the three overall measures of psychopathology at baseline are correlated with the change in the CANDID-R unmet needs, and there are no significant correlations between baseline psychopathology and change in the CANDID-R met needs.

Null hypothesis nine is rejected.

Table 4.71 Summary and normality data of the longitudinal measures of outcome

Outcome measure	Mean	Min	Max	SD	Skewness		Kurtosis		Normality test	
					S	z-score§	K	z-score§	Shapiro-Wilk	p
HONOS-LD total	8.82	-21	33	13.85	-.236	.63	-.598	.815	.978	.605
GAF	13.35	-17	49	13.33	.035	.009	-.973	1.327	.954	.104
CGI	1.08	-2	5	1.65	.018	.048	-.442	.603	.951	.084
CANDID- unmet	2.95	-6	10	4.19	-.336	.898	-.912	1.244	.942	.051
CANDID- met	-3.05	-11	4	3.82	-.183	.489	-.950	1.296	.958	.148
CANDID- total	-.25	-6	10	3.00	.924	2.47*	2.63	3.588***	.923	.010*

§ z-score values are calculated by dividing the statistic score by the standard errors 0.374 for skewness and 0.733 for kurtosis.
* $p < .05$
** $p < .01$
*** $p < .001$

Table 4.72: The correlations between psychopathology dimension factor scores and longitudinal outcomes

	Depressive factor score‡		Organic factor score		Behaviour-affective factor score‡		Anxiety factor score‡		Total factor score	
Outcome variable change	**R**	**p**	**R†**	**p**	**R**	**p**	**R**	**p**	**R**	**p**
HONOS-LD total score	.373*	.018	-.216	.180	.518**	.001	.167	.303	.414**	.008
GAF	.460**	.003	.039	.813	.437**	.005	.121	.456	.555***	.000
CGI	.420**	.007	.062	.705	.446**	.004	.032	.846	.457**	.003
CANDID-R unmet needs	.227	.159	.106	.515	.253	.115	.086	.599	.378*	.016
CANDID-R met needs	.047	.772	-.043	.792	.005	.978	.105	.518	.107	.513

* significant at the p< .05 level
** significant at the p< .01 level
*** significant at the p< .001 level
‡ The square root transformed variable was used in the statistical analysis
† Non-parametric Spearman's correlation co-efficient

Table 4.73: The correlations between psychopathology dimension symptoms counts and longitudinal outcomes

	Depressive symptom count		Organic symptom count		Behaviour-affective symptom count		Anxiety symptom count		Total symptom count	
Outcome change variable	**R†**	**p**	**R†**	**p**	**R†**	**p**	**R†**	**p**	**R**	**p**
HoNOS-LD total score	.409**	.009	-.266	.097	.432**	.005	.135	.407	.450**	.004
GAF	.556***	.000	.006	.971	.361*	.022	.033	.841	.562***	.000
CGI	.509**	.001	-.051	.757	.365*	.020	.025	.880	.504**	.001
CANDID-R unmet needs	.299	.060	.052	.750	.193	.234	.045	.784	.329*	.038
CANDID-R met needs	.034	.835	.060	.713	.061	.711	.075	.645	.090	.581

* significant at the p< .05 level
** significant at the p< .01 level
*** significant at the p< .001 level
† Non-parametric Spearman's correlation co-efficient

Table 4.74: The correlations between baseline EFA PPS-LD symptom count- 41 and longitudinal outcome

	EFA PPS-LD symptom count - 41	
Outcome change variable	**R**	**p**
HoNOS-LD total score	.485**	.002
GAF	.581***	.000
CGI	.516**	.001
CANDID-R unmet needs	.367*	.020
CANDID-R met needs	.063	.700

* significant at the p< .05 level
** significant at the p< .01 level
*** significant at the p< .001 level

4.10 Baseline socio-clinical variables as predictors of longitudinal outcome

Null hypothesis ten:
Socio-clinical measures are not significantly associated with the longitudinal outcome of mental disorders.

4.10.1 Gender as a predictor of longitudinal outcome

In table 4.75, there is no significant difference in longitudinal outcome between women and men. However, as the result for the CGI measure approaches significance (.05 < p < .1), gender will be included as a dependant variable in the linear regression to examine the interaction of covariates in the prediction of longitudinal change in the CGI.

Table 4.75: The relationship between gender and measures of longitudinal outcome

	Gender	Mean	SD	statistic	p
HoNOS-LD total score	male	11.28	12.04	1.014	.317
	female	6.82	15.15		
GAF	male	16.94	20.75	1.050	.300
	female	10.41	18.57		
CGI	male	1.56	1.58	1.701	.097
	female	.68	1.64		
CANDID-R unmet needs	male	4.06	3.86	1.534	.133
	female	2.05	4.33		
CANDID-R met needs	male	3.50	4.37	.669	.508
	female	2.68	3.37		

4.10.2 Age as a predictor of longitudinal outcome

No significant correlation was found between age and longitudinal outcome in table 4.76.

Table 4.76: The relationship between age and measures of longitudinal outcome.

	Age in years	
	R	p
HoNOS-LD total score	.005	.975
GAF	-.064	.696
CGI	-.033	.839
CANDID-R unmet needs	.054	.742
CANDID-R met needs	.091	.271

4.10.3 Living circumstances and longitudinal outcome

Table 4.77 shows the correlations between baseline living circumstances and longitudinal outcome. From the post hoc Bonferroni tests, the only significant between group differences were for individuals living independently against with support from paid carers for GAF (mean difference= -25.31, p=.021) and CGI (mean difference= -2.28, p= .011). There were no significant between group differences for the HoNOS-LD.

4.10.4 Level of intellectual disabilities as a predictor of longitudinal outcome

The descriptive statistics for the measures of longitudinal outcome and results for the initial analyses using ANOVA are shown for participants with mild, moderate, severe and profound intellectual disabilities in table 4.78. The only measure of longitudinal outcome for which there are no significant between group differences is the change in the CANDID-R met needs over time.

Post hoc Bonferroni test results in table 4.79 clarify the nature of the between group differences for the measures of longitudinal outcome that showed significant between group differences from the initial ANOVA tests. Since there are four variables and three comparisons, the appropriate conservative level of significance is used ($p < .0167$) for the post-hoc analysis.

Table 4.77: The relationship between living circumstances and longitudinal measures of outcome

	Living circumstances	Mean	SD	Min	Max	F	p
HoNOS-LD	Independent	-3.00	3.39	-7.00	2.00	4.204	.023
	Family carer	3.00	14.81	-15.00	31.00		
	Paid carer	12.74	13.17	-21.00	33.00		
GAF	Independent	-7.60	9.74	-16.00	3.00	4.113	.024
	Family carer	11.75	23.37	-17.00	44.00		
	Paid carer	17.70	17.61	-16.00	49.00		
CGI	Independent	-.80	.84	-2.00	1.00	4.900	.013
	Family carer	.88	1.64	-1.00	3.00		
	Paid carer	1.48	1.55	-2.00	5.00		
CANDID-R unmet needs	Independent	6.22	6.04	-6.00	16.00	2.315	.102
	Family carer	4.43	3.47	-3.00	12.00		
	Paid carer	4.66	2.51	-3.00	10.00		
CANDID-R met needs	Independent	6.22	6.04	-6.00	16.00	1.084	.341
	Family carer	4.43	3.47	-3.00	12.00		
	Paid carer	4.66	2.51	-3.00	10.00		

* significant at the p< .05 level

** significant at the p< .01 level

Table 4.78: The relationship between level of intellectual disabilities and measures of longitudinal outcome

	Level of intellectual disabilities	Mean	SD	Min	Max	F	p
HoNOS-LD Total score	mild	-7.33	7.39	-17	2	5.432**	.003
	moderate	8.38	15.08	-11	33		
	severe	7.90	14.18	-21	23		
	profound	15.69	9.90	-1	31		
GAF	mild	-7.50	8.34	-16	3	3.837*	.018
	moderate	14.00	24.69	-17	44		
	severe	12.60	14.32	-16	29		
	profound	21.31	18.07	-14	49		
CGI	mild	-.83	.75	-2	0	4.827**	.006
	moderate	1.13	1.64	-1	3		
	severe	1.00	1.41	-2	3		
	profound	1.81	1.56	-1	5		
CANDID-R unmet needs	mild	4.24	4.81	-6	14	6.994**	.001
	moderate	6.19	4.23	-2	16		
	severe	4.64	2.42	-3	10		
	profound	4.69	2.82	-3	12		
CANDID-R met needs	mild	5.50	4.17	-3	12	1.933	.142
	moderate	5.45	5.43	-6	14		
	severe	6.21	7.75	-11	18		
	profound	6.33	7.63	-10	16		

* significant at the p< .05 level

** significant at the p< .01 level

*** significant at the p< .001 level

Table 4.79: Post hoc Bonferroni tests of ANOVA between group differences for level of intellectual disabilities and measures of longitudinal outcome

Dependent Variable	(I) Reference level of intellectual disability category	(J) Comparison level of intellectual disability categories	Mean Difference (I-J)	Std. Error	p	95% Confidence Interval	
HoNOS-LD total	mild	moderate	-15.71	6.46	.121	-33.74	2.32
		severe	-15.23	6.17	.111	-32.47	2.01
		profound	-23.02**	5.72	.002	-39.00	-7.04
GAF	mild	moderate	-21.50	9.59	.188	-48.28	5.28
		severe	-20.10	9.17	.210	-45.71	5.51
		profound	-28.81*	8.50	.010	-52.55	-5.07
CGI	mild	moderate	-1.96	.79	.104	-4.15	.23
		severe	-1.83	.75	.118	-3.93	.26
		profound	-2.65*	.70	.003	-4.59	-.70
CANDID-R unmet needs	mild	moderate	-6.50*	1.87	.008	-11.73	-1.27
		severe	-7.10**	1.79	.002	-12.10	-2.10
		profound	-7.19**	1.66	.001	-11.82	-2.55

* significant at the p< .0167 level
** significant at the p < .003
*** significant at the p < .0003

4.10.5 Categorical socio-clinical variables as predictors of longitudinal outcome

The only longitudinal measure of outcome, in table 4.80, significantly different across the three categories within the epilepsy variable is the CGI. Although the post hoc Bonferroni tests do not show any significant between group differences, the epilepsy variable will be included in the linear regression analyses for the CGI.

Table 4.80: The relationship between epilepsy and measures of longitudinal outcome

	Epilepsy	Mean	SD	Min	Max	F	p
HoNOS-LD total score	no	8.25	13.36	-21	31	.714	.496
	good control	13.38	14.17	-15	33		
	poor control	3.75	18.04	-17	26		
GAF	no	12.54	18.55	-17	49	1.791	.181
	good control	22.50	20.09	-11	48		
	poor control	.75	22.71	-16	34		
CGI	no	.96	1.48	-2	5	3.305*	.048
	good control	2.13	1.55	-1	4		
	poor control	-.25	2.22	-2	3		
CANDID-R unmet needs	no	2.86	4.08	-4	2.86	2.131	.133
	good control	4.88	3.56	-2	4.88		
	poor control	-.25	5.06	-6	-.25		
CANDID-R met needs	no	3.25	3.90	-11	2	.357	.702
	good control	3.13	4.42	-8	4		
	poor control	1.50	1.91	-3	1		

* significant at the p< .05 level

A diagnosis of autism, Down syndrome (table 4.81), visual impairment (table 4.82) and mobility problems (table 4.83) are not associated with any of the longitudinal measures of outcome. The significant associations for the variables representing hearing impairment (table 4.82), urinary incontinence and bowel incontinence (table 4.84) are solely with the longitudinal change in the HoNOS-LD, GAF and CGI.

Table 4.81: The relationship between autism, Down syndrome and measures of longitudinal outcome

	Autism						Down syndrome					
	Yes (n=6)		No (n=34)		statistic	p	Yes (n=6)		No (n=34)		statistic	p
	Mean	SD	Mean	SD			Mean	SD	Mean	SD		
HoNOS-LD total score	7.33	9.69	9.09	14.56	.283	.779	3.33	16.16	9.79	13.44	1.055	.298
GAF	8.17	21.17	14.26	19.51	.698	.490	15.00	26.84	13.06	18.56	-.221	.826
CGI	.67	1.37	1.15	1.71	.651	.519	.67	1.97	1.15	1.62	.651	.519
CANDID-R unmet needs	1.33	4.08	3.24	4.21	1.025	.312	3.83	3.19	2.79	4.37	-.555	.582
CANDID-R met needs	1.67	3.14	3.29	3.92	.960	.343	2.67	4.03	3.12	3.84	.263	.794

Table 4.82: The relationship between sensory impairments and measures of longitudinal outcome

	Visual impairment						Hearing impairment					
	Yes (n=5)		No (n=35)		statistic	p	Yes (n=5)		No (n=35)		statistic	p
	Mean	SD	Mean	SD			Mean	SD	Mean	SD		
HoNOS-LD total	6.00	15.51	9.23	13.79	.483	.632	-4.60	13.07	10.74	13.02	2.464*	.018
GAF	4.00	23.22	14.69	19.05	1.145	.260	-12.00	5.43	16.97	18.15	7.404§***	.000
CGI	.20	1.79	1.20	1.62	1.274	.210	-.80	.84	1.34	1.57	2.968**	.005
CANDID-R unmet needs	1.20	5.17	3.20	4.06	.997	.325	.80	3.11	3.26	4.27	1.234	.225
CANDID-R met needs	2.20	3.96	3.17	3.85	.527	.602	1.20	4.15	3.31	3.76	1.162	.252

* significant at the p< .05 level
** significant at the p< .01 level
*** significant at the p< .001 level
† Non- parametric z-score from Mann-Whitney test
§ Levene's test found the between group variance is significant so the t-test results are for equal variances not assumed

Table 4.83: The relationship between mobility problems and measures of longitudinal outcome

	Mobility problems					
	Yes (n=7)		No (n=33)		statistic	p
	Mean	SD	Mean	SD		
HoNOS-LD total	9.29	16.59	8.73	13.49	-.096	.924
GAF	14.71	25.90	13.06	18.50	-.200	.842
CGI	1.29	2.56	1.03	1.45	-.255§	.806
CANDID-R unmet needs	3.43	3.55	2.85	4.36	-.329	.744
CANDID-R met needs	3.57	3.87	2.94	3.86	.393	.697

** significant at the p< .01 level

§ Levene's test found the between group variance is significant so the t-test results are for equal variances not assumed

Table 4.84: The relationship between incontinence and measures of longitudinal outcome

	Urinary incontinence						Bowel incontinence					
	Yes (n=15)		No (n=25)		statistic	p	Yes (n=11)		No (n=29)		statistic	p
	Mean	SD	Mean	SD			Mean	SD	Mean	SD		
HoNOS-LD total	13.87	11.44	5.80	14.48	-1.837	.074	15.00	13.18	6.48	13.58	-1.785	.082
GAF	22.67	15.73	7.76	19.84	-2.476*	.018	24.45	17.84	9.14	18.84	-2.328*	.025
CGI	1.67	1.50	.72	1.67	-1.802	.080	1.91	1.64	.76	1.57	-2.042*	.048
CANDID-R unmet needs	3.93	3.75	2.36	4.41	-1.154	.256	2.91	3.67	2.97	4.44	.038	.970
CANDID-R met needs	3.27	3.58	2.92	4.03	.274	.785	2.82	3.25	3.14	4.07	-.233	.817

* significant at the p< .05 level
** significant at the p< .01 level
*** significant at the p< .001 level

Since several of the socio-clinical variables at baseline are significantly related to longitudinal outcome the null hypothesis is rejected.

4.11 Examining measures of psychopathology and socio-clinical variables as independent predictors of longitudinal outcome.

Null hypothesis eleven:
Dimensional measures of psychopathology, and socio-clinical variables are not independently associated with the longitudinal outcome of mental disorders.

Linear regression is used to examine which baseline variables predict longitudinal outcome (dependant variables in the linear regression). As for the previous analyses, separate multiple linear regression analyses are carried out using the psychopathology dimensional factor scores, dimensional symptom counts and the three overall measures of psychopathology. All regression analyses are adjusted for the baseline score on the specific measure of outcome.

4.11.1 Independent predictors of longitudinal outcome measured with the HoNOS-LD total score

Different dimension factor scores, and symptom counts are significant predictors of longitudinal outcome on the HoNOS-LD in tables 4.85 and 4.86. Only the behaviour-affective factor score at baseline is an independent predictor, whilst the depressive and organic symptom counts predict longitudinal outcome on the HoNOS-LD. The other independent predictors of outcome across the two regression analyses is the level of intellectual disabilities.

Table 4.85: Multivariate associations of dimension factor scores and socio-clinical variables with longitudinal change in HoNOS-LD scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension factor score‡	.018*		Not retained in the model				
Behaviour-affective dimension factor score‡	.001**		13.898	6.255	.292	.033*	
Living circumstances	023*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.003**	Mild- moderate	14.990	6.002	.439	.018*	.546
		Mild-severe	15.342	5.478	.486	.008**	
		Mild- profound	18.733	5.374	.671	.001**	
Hearing impairment	.018*		Not retained in the model				
Urinary incontinence	.074		Not retained in the model				
Bowel incontinence	.082		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level
‡ the square root transformed variable is used in the analyses

Table 4.86: Multivariate associations of dimension symptom counts and socio-clinical variables with longitudinal change in HoNOS-LD scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension symptom count	.009**		1.633	.737	.297	.034*	
Organic dimension symptom count	.097		-3.727	1.279	-.382	.006**	
Behaviour-affective dimension symptom count	.004**		Not retained in the model				
Living circumstances	.023*	Independent- family carer	Not retained in the model				
		Independent- paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.003**	Mild- moderate	17.731	5.588	.519	.003**	.601
		Mild-severe	19.513	5.424	.618	.001**	
		Mild- profound	18.854	5.187	.676	.001**	
Hearing impairment	.018*		Not retained in the model				
Urinary incontinence	.074		Not retained in the model				
Bowel incontinence	.082		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

All three overall measures of psychopathology were retained as independent predictors of outcome in the regression models. The results are shown in table 4.87-4.89 for the linear regression analysis with the total dimension factor score, total dimension symptom count and the EFS PPS-LD symptom count- 41, respectively.

Table 4.87: Multivariate associations of total dimension factor score and socio-clinical variables with longitudinal change in HoNOS-LD scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension factor score	.008**		3.210	.858	.427	.001**	.546
Living circumstances	.023*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.003**	Mild- moderate	20.119	5.843	.589	.002**	
		Mild-severe	18.762	5.545	.594	.002**	
		Mild- profound	24.124	5.058	.864	.000***	
Hearing impairment	.018*		Not retained in the model				
Urinary incontinence	.074		Not retained in the model				
Bowel incontinence	.082		Not retained in the model				

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

Table 4.88: Multivariate associations of total dimension symptom count and socio-clinical variables with longitudinal change in HoNOS-LD scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension symptom count	.004**		2.445	.435	.395	.001**	.614
Living circumstances	.023*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.003**	Mild- moderate	17.438	5.164	.510	.001**	
		Mild-severe	16.551	4.886	.524	.002**	
		Mild- profound	16.723	4.914	.599	.002***	
Hearing impairment	.018*		Not retained in the model				
Urinary incontinence	.074		Not retained in the model				
Bowel incontinence	.082		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.89: Multivariate associations of EFS PPS-LD symptom count- 41 and socio-clinical variables with longitudinal change in HoNOS-LD scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
EFS PPS-LD symptom count- 41	.002**		1.472	.401	.426	.001**	
Living circumstances	.023*	Independent- family carer	Not retained in the model				
		Independent- paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.003**	Mild- moderate	16.773	4.664	.521	.002**	
		Mild-severe	17.175	4.905	.584	.002**	.541
		Mild- profound	21.849	5.375	.873	.000***	
Hearing impairment	.018*		Not retained in the model				
Urinary incontinence	.074		Not retained in the model				
Bowel incontinence	.082		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

4.11.2 Independent predictors of longitudinal outcome measured with the GAF

There is only one difference between the variables from the bivariate analysis included in the HoNOS-LD and GAF multivariate analyses- the organic dimension symptom count was not associated with the GAF. The independent predictors of longitudinal outcome on the GAF are, therefore, similar to those for the HoNOS-LD.

In the regression models that include the depressive and behaviour-affective factor scores (table 4.90) and symptom counts (table 4.91) level of intellectual disabilities and hearing impairment were retained as independent predictors of longitudinal outcome on the GAF. However, whilst both dimensions are retained for the model using factor scores, only the depression symptom count is a significant predictor of outcome in the model shown in table 4.91.

Similar to the findings for the HoNOS-LD in the previous section, all three overall measures of psychopathology were independent, significant predictors of longitudinal outcome on the GAF. The models for the overall measures of psychopathology were very similar. For each regression model, in addition to the overall measure of psychopathology, level of intellectual disabilities and hearing impairment are significant predictors of outcome, and the regression models account for 67.2-69.6% of the overall variance. The details of the regression models for all three overall measures of psychopathology are shown in table 4.92-4.94.

Table 4.90: Multivariate associations of dimension factor scores and socio-clinical variables with longitudinal change in GAF scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension factor score‡	.003**		23.201	7.057	.342	.002**	.646
Behaviour-affective dimension factor score‡	.005**		16.438	7.522	.244	.036*	
Living circumstances	.024*	Independent-family carer	Not retained in the model				
		Independent paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	18.860	8.247	.390	.029*	
		Mild-severe	18.400	7.470	.412	.019*	
		Mild- profound	18.470	7.691	.467	.022*	
Hearing impairment	.000***		-28.252	6.226	-.483	.000***	
Urinary incontinence	.018*		Not retained in the model				
Bowel incontinence	.025*		Not retained in the model				

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level
‡ the square root transformed variable is used in the analyses

Table 4.91: Multivariate associations of dimension symptom counts and socio-clinical variables with longitudinal change in GAF scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension symptom count	.000***		3.404	.800	.437	.000***	.633
Behaviour-affective dimension symptom count	.022*		Not retained in the model				
Living circumstances	.024*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	22.585	7.472	.467	.005**	
		Mild-severe	19.630	7.120	.439	.009**	
		Mild- profound	21.808	6.848	.552	.003**	
Hearing impairment	.000***		-28.089	6.033	-.480	.000***	
Urinary incontinence	.018*		Not retained in the model				
Bowel incontinence	.025*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.92: Multivariate associations of total dimension factor score and socio-clinical variables with longitudinal change in GAF scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension factor score	.000***		5.289	1.026	.496	.000***	
Living circumstances	.024*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	14.097	8.094	.291	.041*	.696
		Mild-severe	15.883	7.111	.355	.032*	
		Mild- profound	21.318	6.444	.539	.002**	
Hearing impairment	.000***		-30.514	5.526	-.521	.000***	
Urinary incontinence	.018*		Not retained in the model				
Bowel incontinence	.025*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.93: Multivariate associations of total dimension symptom count and socio-clinical variables with longitudinal change in GAF scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension symptom count	.000***		2.375	.527	.459	.000***	
Living circumstances	.024*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	17.698	7.252	.366	.020*	.672
		Mild-severe	16.318	6.900	.319	.037*	
		Mild- profound	22.898	5.963	.554	.001**	
Hearing impairment	.000***		-29.493	5.856	-.504	.000***	
Urinary incontinence	.018*		Not retained in the model				
Bowel incontinence	.025*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.94: Multivariate associations of EFA PPS-LD symptom count- 41 and socio-clinical variables with longitudinal change in GAF scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
EFS PPS-LD symptom count- 41	.000***		2.317	.495	.474	.000***	
Living circumstances	.024*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	16.594	7.209	.343	.027*	
		Mild-severe	17.558	7.967	.390	.012*	.681
		Mild- profound	21.933	5.922	.531	.001**	
Hearing impairment	.000***		-29.286	5.778	-.500	.000***	
Urinary incontinence	.018*		Not retained in the model				
Bowel incontinence	.025*		Not retained in the model				

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

4.11.3 Independent predictors of longitudinal outcome measured with the CGI

In comparison to the HoNOS-LD and GAF, gender and epilepsy are added to the variables included in the analyses looking at the variables that are independent predictors of longitudinal outcome on the CGI. Epilepsy is retained across all the regression models but otherwise the variables at baseline that independently predict longitudinal outcome on the CGI are similar to those for the GAF.

Tables 4.95 and 4.96 show the results of the linear regression analyses that include the depression and behaviour-affective dimension factor scores and symptom counts. Similar to findings for the GAF, both dimension factor scores, but only the depressive dimension symptom count, are significant independent predictors of outcome on the CGI. In addition to epilepsy, level of intellectual disabilities and hearing impairment are also significant predictors of outcome on the CGI.

In contrast to the results for the HoNOS-LD and GAF linear regression analyses that included the three overall measures of psychopathology, the results are slightly different across the three final regression models with the CGI as the dependant variable. The common findings across the three models in tables 4.97-4.99 are:

- all three overall measures of psychopathology are significant independent predictors of outcome on the CGI
- only the mild-profound dummy variables for level of intellectual disabilities are retained
- hearing impairment is retained across all three models
- there are differences across the models in the results for the epilepsy variable.

Table 4.95: Multivariate associations of dimension factor scores and socio-clinical variables with longitudinal change in CGI scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension factor score‡	.007**		2.136	.615	.373	.001**	
Behaviour-affective dimension factor score‡	.004**		1.695	.614	.298	.009**	
Gender	.097		Not retained in the model				
Living circumstances	.013*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	1.262	.696	.309	.079	.655
		Mild-severe	1.478	.614	.392	.022*	
		Mild- profound	1.746	.628	.523	.009**	
Epilepsy	.048*	No- well controlled	1.084	.449	.265	.022*	
		No- poor control	-1.139	.587	-.209	.041*	
Hearing impairment	.005**		-1.638	.532	-.331	.004**	
Urinary incontinence	.080		Not retained in the model				
Bowel incontinence	.048*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level
‡ the square root transformed variable is used in the analyses

Table 4.96: Multivariate associations of dimension symptom counts and socio-clinical variables with longitudinal change in CGI scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension symptom count	.001**		.279	.071	.425	.000***	
Behaviour-affective dimension symptom count	.020*		Not retained in the model				
Gender	.097		Not retained in the model				
Living circumstances	.013*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	1.591	.637	.389	.018*	.683
		Mild-severe	1.597	.590	.423	.011*	
		Mild- profound	2.053	.563	.616	.001**	
Epilepsy	.048*	No- well controlled	.910	.444	.223	.048*	
		No- poor control	-1.057	.565	-.194	.046**	
Hearing impairment	.005**		-1.780	.553	-.360	.003**	
Urinary incontinence	.080		Not retained in the model				
Bowel incontinence	.048*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.97: Multivariate associations of total dimension factor score and socio-clinical variables with longitudinal change in CGI scores

Bivariate associations (p<.1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension factor score	.004**		.454	.088	.505	.000***	.681
Gender	.097		Not retained in the model				
Living circumstances	.013*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	1.025	.344	.307	.005**	
Epilepsy	.048*	No- well controlled	1.427	.416	.349	.002**	
		No- poor control	Not retained in the model				
Hearing impairment	.005**		-1.474	.497	-.298	.005**	
Urinary incontinence	.080		Not retained in the model				
Bowel incontinence	.048*		Not retained in the model				

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

Table 4.98: Multivariate associations of total dimension symptom count and socio-clinical variables with longitudinal change in CGI scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Total dimension symptom count	.001**		.194	.045	.445	.000	.694
Gender	.097		Not retained in the model				
Living circumstances	.013*	Independent- family carer	Not retained in the model				
		Independent- paid carer	Not retained in the model.				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	.817	.345	.245	.024*	
Epilepsy	.048*	No- well controlled	1.276	.427	.312	.005**	
		No- poor control	-1.180	.568	-.217	.045*	
Hearing impairment	.005**		-1.569	.503	-.318	.004**	
Urinary incontinence	.080		Not retained in the model				
Bowel incontinence	.048*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

Table 4.99: Multivariate associations of EFA PPS-LD symptom count- 41 and socio-clinical variables with longitudinal change in CGI scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
EFA PPS-LD symptom count- 41	.001**		.175	.042	.423	.000***	.687
Gender	.097		Not retained in the model				
Living circumstances	.013*	Independent- family carer	Not retained in the model				
		Independent- paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	Not retained in the model				
		Mild-severe	Not retained in the model				
		Mild- profound	.797	.350	.239	.029	
Epilepsy	.048*	No- well controlled	1.073	.425	.263	.017	
		No- poor control	-1.152	.563	-.212	.049	
Hearing impairment	.005**		-1.649	.507	-.334	.003	
Urinary incontinence	.080		Not retained in the model				
Bowel incontinence	.048*		Not retained in the model				

* significant at the p< .05 level
** significant at the p< .01 level
**** significant at the p< .001 level

4.11.4 Independent predictors of longitudinal outcome measured with CANDID-R unmet needs

In the bivariate analyses, of the individual dimensional measures of psychopathology only the symptom count for the depressive dimension was found to be significantly correlated with the change in the CANDID-R unmet needs. However, it was not an independent predictor of outcome in the linear regression analyses in table 4.100.

In fact, this was also the case for the three overall measures of psychopathology. Therefore, the only significant predictor of outcome on the CANDID-R unmet needs is level of intellectual disabilities, with the results in table 4.100 consistent across the analyses using the overall measures of psychopathology.

Table 4.100: Multivariate associations of dimension symptom counts and socio-clinical variables with longitudinal change in CANDID-R unmet needs

Bivariate associations (p< .1)		**Multivariate associations**					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Depressive dimension symptom count	.060		Not retained in the model				.368
Categorical measure of intellectual disabilities	.012*	Mild- moderate	6.500	1.874	.628	.001**	
		Mild-severe	7.100	1.792	.742	.000***	
		Mild- profound	7.188	1.661	.850	.000***	

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

There were no variables associated with the CANDID-R met needs in the bivariate analyses. Therefore, it is concluded that there are no significant predictors of longitudinal outcome on the CANDID-R met needs.

However, the overall findings were that baseline measures of psychopathology and socio-clinical variables that predict longitudinal outcome. Therefore, the null hypothesis is rejected.

4.12 Comparing the predictive validity of categorical and dimensional measures of psychopathology

Null hypothesis twelve:
There are no significant differences in the associations of dimensional and categorical models of psychopathology with the longitudinal outcome of mental disorders.

The regression models examining dimensional models of psychopathology, and socio-clinical variables as predictors of longitudinal outcome were presented in section 4.11 above. Measures representing dimensional models of psychopathology were significant, independent predictors of longitudinal outcome measured with the HoNOS-LD (tables 4.85 and 4.86), GAF (tables 4.90 and 4.91) and CGI (4.95 and 4.96). To examine null hypothesis eleven, these models for dimensional models of psychopathology were compared to models using a categorical model of psychopathology (individual meets criteria for a DC-LD diagnosis of mental disorder) and models including both dimensional and categorical models. The socio-clinical variables with bivariate associations to the HoNOS-LD, GAF and CGI were also included in the linear regression analyses, to allow direct comparison between the models.

4.12.1 Examining categorical diagnosis of mental disorder as a predictor of longitudinal outcome

Twenty six individuals (65%) in sample 3 met the criteria for a DC-LD categorical diagnosis at baseline, shown in table 3.4. The binary variable was included in the linear regression analyses with longitudinal outcome on HoNOS-LD, GAF and CGI as the dependent variables.

The categorical model of psychopathology was not retained in the regression model for HoNOS-LD. However, the final models for GAF and CGI are shown in tables 4.101 and 4.102.

Table 4.101: Multivariate associations of categorical DC-LD diagnosis and socio-clinical variables with longitudinal change in GAF scores

Bivariate associations (p< .1)		**Multivariate associations**					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Categorical diagnosis of mental disorder on DC-LD (Y/N)	N/A		10.518	5.515	.259	.045*	
Living circumstances	.024*	Independent-family carer	Not retained in the model				
		Independent-paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	30.107	7.493	.622	.000***	.586
		Mild-severe	33.997	8.058	.760	.000***	
		Mild- profound	31.950	6.509	.809	.000***	
Hearing impairment	.000***		-36.181	6.893	-.618	.000***	
Urinary incontinence	.018*		Not retained in the model				
Bowel incontinence	.025*		Not retained in the model				

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

Table 4.102: Multivariate associations of categorical DC-LD diagnosis and socio-clinical variables with longitudinal change in CGI scores

Bivariate associations (p< .1)		Multivariate associations					
Variable	**p**	**Dummy variable**	**B**	***SE* B**	**β**	**p**	**R^2**
Categorical diagnosis of mental disorder on DC-LD (Y/N)	N/A		.879	.477	.257	.044	.565
Gender	.097		Not retained in the model				
Living circumstances	.013*	Independent- family carer	Not retained in the model				
		Independent- paid carer	Not retained in the model				
Categorical measure of intellectual disabilities	.018*	Mild- moderate	2.605	.648	.638	.000***	
		Mild-severe	2.937	.697	.778	.000***	
		Mild- profound	2.890	.563	.867	.000***	
Epilepsy	.048*	No- well controlled	Not retained in the model				
		No- poor control	Not retained in the model				
Hearing impairment	.005**		-2.732	.596	-.553	.000***	
Urinary incontinence	.080		Not retained in the model				
Bowel incontinence	.048*		Not retained in the model				

* significant at the p< 0.05 level
** significant at the p< 0.01 level
**** significant at the p< 0.001 level

The variable representing the categorical model of psychopathology was retained as a significant, independent predictor of outcome on the GAF and CGI. Comparing the standardised coefficients (β) across models, for longitudinal outcome on the GAF the depressive dimension factor score (β= .342) and symptom count (β= .437) are stronger predictors of outcome than the categorical model of psychopathology (β= .259), which is a stronger predictor than the behavioural affective dimension symptom score (β=.244). Similarly for longitudinal outcome on the CGI the depressive dimension factor score (β= .282) and symptom count (β= .437) are stronger predictors of outcome than the categorical model of psychopathology (β= .257), which is a stronger predictor than the behavioural affective dimension symptom score (β=.238).

The final regression models using the dimensional model of psychopathology explain a greater proportion of the variance in longitudinal outcome on the GAF and CGI than the models using the categorical model of psychopathology.

4.12.2 Examining whether categorical and dimensional models of psychopathology are co-predictors of longitudinal outcome

To examine if the categorical and dimensional models of psychopathology have complimentary effects on predicting outcome, a final set of linear regression models were examined including both sets of variables, and run separately for dimension factor scores and dimensions symptom counts. However, the variable representing the categorical of psychopathology was not retained as significant in the final models for the longitudinal outcome on the HoNOS-LD, GAF and CGI, which were therefore unchanged from those reported in section 4.11 for the dimensional models.

Therefore, the evidence suggests that dimensional models of psychopathology are better predictors of longitudinal outcome than categorical models, and are considered to have better predictive validity. Null hypothesis twelve is rejected.

4.13 Summary of results

Prior to discussing the findings and implications in detail in Chapter 5, the results relevant to the twelve null hypotheses are summarised.

Null hypothesis one: Rejected

There are no stable, identifiable dimensions of psychopathology experienced by adults with intellectual disabilities.

Four dimensions were identified, interpreted as representing depressive, organic, behaviour-affective and anxiety dimensions of psychopathology. There were minor changes in the items of psychopathology included in the four dimensions extracted from the original EFA, and separate analyses using two random sub-samples. However, across the separate analyses there was excellent agreement in the loadings of individual items of psychopathology to the four dimensions. Therefore, the stability of the dimensions appears good.

Null hypothesis two: Accepted

There are no significant correlations between the individual dimensions of psychopathology experienced by adults with intellectual disabilities.

Since there were no significant correlations between the four dimensions, they appear to be independent dimensions of psychopathology.

Null hypothesis three: Rejected

There are no significant cross-sectional, bivariate relationships between dimensional measures of psychopathology and socio-clinical variables.

The socio-clinical variables significantly associated with the measures of psychopathology, in the bivariate analyses, are shown in table 4.103 below. Only gender and hearing impairment were not associated with any measure of psychopathology.

Table 4.103: Socio-clinical variables significantly associated with higher levels of psychopathology

		Socio-clinical variables
Dimension factor scores	Depressive	Older age
	Organic	Living with family carers
		More severe level of intellectual disabilities
		Down syndrome
		Does not have visual impairment
	Behaviour-affective	Younger age
		Living with paid carers
		Severe level of intellectual disabilities
	Anxiety	Down syndrome*
		Urinary incontinence
		Younger age
		Severe level of intellectual disabilities
		Does not have pilepsy
		Autism*
		Does not have mobility problems
		Does not have urinary incontinence
		Does not have bowel incontinence
	Total	Moderate intellectual disabilities
		Does not have mobility problems *
Dimension symptom counts	Depressive	Older age
	Organic	Older age
		Autism*
		Down syndrome
	Behaviour-affective	Younger age
		More severe level of intellectual disabilities
		Does not have Down syndrome
	Anxiety	Younger age
		Moderate intellectual disabilities*
		Does not have epilepsy*
		Autism*
		Does not have mobility problems
		Does not have urinary incontinence
		Does not have bowel incontinence
	Total	Moderate intellectual disabilities
		Does not have mobility problems *
EFA PPS-LD symptom count- 41		Moderate intellectual disabilities

* Variables included in the multivariate analyses since they are associated with the specific measure of psychopathology with a significance level less than .1 but greater than .05

Null hypothesis four: Rejected

There are no significant cross-sectional, multivariate relationships between measures of psychopathology and socio-clinical variables.

In table 4.104 the socio-clinical variables retained as independently associated with the measures of psychopathology are shown. The socio-clinical variables retained in the final regression models varies between the dimensional measures of psychopathology. It is evident that there are a greater number of socio-clinical variables associated with the dimensional measures of psychopathology, than with the three overall measures of psychopathology.

Table 4.104: Socio-clinical variables retained as independently associated with measures of psychopathology in the final regression models

		Socio-clinical variables
Dimension factor scores	Depressive	Older age
	Organic	More severe level of intellectual disabilities
	Behaviour-affective	Down syndrome
		Younger age
		More severe level of intellectual disabilities
	Anxiety	Down syndrome
		Younger age
		Moderate intellectual disabilities
		Does not have epilepsy
		Does not have mobility problems
		Does not have bowel incontinence
	Total	Moderate intellectual disabilities
Dimension symptom counts	Depressive	Older age
	Organic	Older age
		Down syndrome
	Behaviour-affective	Younger age
		More severe level of intellectual disabilities
		Down syndrome
	Anxiety	Younger age
		Moderate intellectual disabilities
		Mobility problems
	Total	Moderate intellectual disabilities
EFA PPS-LD symptom count- 41		Level of intellectual disabilities

Null hypothesis five: Rejected

There are no significant cross-sectional, bivariate relationships between dimensional measures of psychopathology and measures of the severity of mental disorders.

Each of the four dimensional factor scores, and symptom counts, were correlated with one or more measure of severity. These correlations are summarised in table 4.105. The only clear difference between the correlations of factor scores and symptom counts for an individual dimension of psychopathology is seen for the organic dimension. All three overall measures of psychopathology were significantly correlated with each of the five measures of severity.

Table 4.105: Summary of the dimensional measures of psychopathology correlated with the measures of severity

Measure of severity	Dimension factor score	Dimension symptom count
HoNOS-LD	Depressive [a]	Depressive
	Behaviour-affective	Organic
	Total	Behaviour-affective
		Total
GAF	Depressive	Depressive
	Organic	Organic
	Behaviour-affective	Behaviour-affective
	Total	Total
CGI	Depressive	Depressive
	Organic	Organic
	Behaviour-affective	Behaviour-affective
	Total	Total
CANDID-R unmet needs	Depressive*	Depressive
	Organic*	Organic
	Behaviour-affective	Behaviour-affective
	Total	Total
CANDID-R met needs	Depressive*	Depressive*
	Anxiety	Organic*
	Total	Anxiety
		Total

[a] higher level of psychopathology is associated with greater severity of mental disorder on all measures

* Variables included in the multivariate analyses since they are associated with the measure of severity with a significance level less than .1 but greater than .05

Null hypothesis six: Rejected

There are no significant bivariate relationships between socio-clinical variables and measures of the severity of mental disorders.

Of the socio-clinical variables included in the analysis, gender, Down syndrome and hearing impairment were not associated with any of the measures of severity. The cross-sectional relationships between the other variables and the measures of severity are shown in table 4.106.

Null hypothesis seven: Rejected

There are no significant multivariate associations between dimensional measures of psychopathology, socio-clinical variables and measures of the severity of mental disorders.

Table 4.107 summarises the dimensional measures of psychopathology and socio-clinical variables independently associated with the measures of severity. The retained socio-clinical variables are identical in both sets of models. However, the dimension factor scores and symptom counts retained vary. The three overall measures of psychopathology were all retained as independently associated with the five measures of outcome. Identical socio-clinical variables were retained to those shown for each of the measures of outcome in table 4.107.

Table 4.106: Socio-clinical variables significantly associated with greater severity of mental disorder

Measure of severity	Socio-clinical variable
HoNOS-LD	Living with a paid carer*
	More severe intellectual disabilities
	Urinary incontinence
	Bowel incontinence
GAF	No significant bivariate associations
CGI	Moderate intellectual disabilities
CANDID-R unmet needs	Younger age
	Living indepedently
	Moderate intellectual disabilities*
	Visual impairment
CANDID-R met needs	Older age*
	Living with a family or paid carer
	More severe intellectual disabilities
	Autism*
	Epilepsy- well controlled seizures
	Visual impairment
	Mobility problems
	Urinary incontinence
	Bowel incontinence

Table 4.107: Measures of psychopathology and socio-clinical variables independently associated with greater severity of mental disorder, apart from met needs

Measure of severity	Models including dimension factor scores and socio-clinical variables	Models including dimension factor scores and socio-clinical variables
HoNOS-LD	Depressive dimension	Depressive dimension
	Behaviour-affective dimension	Organic dimension
	Profound intellectual disabilities	Behaviour-affective dimension
		Profound intellectual disabilities
GAF	Depressive dimension	Depressive dimension
	Organic dimension	Organic dimension
	Behaviour-affective dimension	Behaviour-affective dimension
CGI	Depressive dimension	Depressive dimension
	Organic dimension	Organic dimension
	Behaviour-affective dimension	Behaviour-affective dimension
CANDID-R unmet needs	Younger age	Organic dimension
	Living independently	Behaviour-affective dimension
	More severe intellectual disabilities	Younger age
	Does not have visual impairment	Living independently
		More severe intellectual disabilities
		Does not have visual impairment
CANDID-R met needs	Depressive dimension	Depressive dimension
	Older age	Organic dimension
	Living with family or paid carer	Older age
	Mores severe intellectual disabilities	Living with family or paid carer
	Epilepsy- well controlled seizures	More severe intellectual disabilities
	Visual impairment	Epilepsy- well controlled seizures
	Urinary incontinence	Visual impairment
		Urinary incontinence

Null hypothesis eight: Rejected

There are no significant differences in the associations of dimensional and categorical models of psychopathology with measures of the severity of mental disorders.

The categorical model of psychopathology was only significantly associated with severity measured on the HoNOS-LD. However, when both the dimensional and categorical models of psychopathology were included in the regression analysis the categorical model was not retained. Therefore, it appears that the categorical model does not explain any additional variance, over and above the dimensional model of psychopathology. It is concluded that the dimensional model of psychopathology is more strongly related to measures of the severity of mental disorders.

Null hypothesis nine: Rejected

Dimensional measures of psychopathology are not significantly correlated to the longitudinal outcome of mental disorders.

Only the anxiety dimension of psychopathology was not significantly associated with any measure of outcome. No baseline measure of psychopathology was associated with longitudinal outcome measured on the CANDID-R met needs.

Table 4.108: Summary of the baseline measures of psychopathology correlated with poorer longitudinal outcome

Measure of outcome	Dimension factor score	Dimension symptom count
HoNOS-LD	Depressive	Depressive
	Behaviour-affective	Organic*
	Total	Behaviour-affective
		Total
GAF	Depressive	Depressive
	Behaviour-affective	Behaviour-affective
	Total	Total
CGI	Depressive	Depressive
	Behaviour-affective	Behaviour-affective
	Total	Total
CANDID-R unmet needs	Total	Depressive*
		Total
CANDID-R met needs	None	None

* Variables included in the multivariate analyses since they are associated with the specific measure of psychopathology with a significance level less than .1 but greater than .05

Null hypothesis ten: Rejected

Socio-clinical measures are not significantly associated with the longitudinal outcome of mental disorders.

Only the CANDID-R met needs was not associated with any socio-clinical variable.in table 4.109

Table 4.109: Socio-clinical variables associated with poorer longitudinal outcome

Measure of severity	Socio-clinical variable
HoNOS-LD	Living independently*
	Mild intellectual disabilities
	Hearing impairment
	Does not have urinary incontinence*
	Does not have bowel incontinence*
GAF	Living independently
	Mild intellectual disabilities
	Hearing impairment
	Does not have urinary incontinence
	Does not have bowel incontinence
CGI	Gender*
	Living independently
	Mild intellectual disabilities
	Epilepsy
	Hearing impairment
	Does not have urinary incontinence *
	Does not have bowel incontinence
CANDID-R unmet needs	Mild intellectual disabilities
CANDID-R met needs	None

* Variables included in the multivariate analyses since they are associated with the specific measure of psychopathology with a significance level less than .1 but greater than .05

Null hypothesis eleven: Rejected

Dimensional measures of psychopathology, and socio-clinical variables are not independently associated with the longitudinal outcome of mental disorders.

Varying combinations of measures of psychopathology and socio-clinical variables were retained as significant predictors of outcome on the HoNOS-LD, GAF, CGI and CANDID-R unmet needs, shown in table 4.110.

Table 4.110: Measures of psychopathology and socio-clinical variables independently associated with poorer longitudinal outcome

	Models including dimension factor scores and socio-clinical variables	**Models including dimension factor scores and socio-clinical variables**
HoNOS-LD	Behaviour-affective dimension	Depressive dimension
	Mild intellectual disabilities	Organic dimension
		Mild intellectual disabilities
GAF	Depressive dimension	Depressive dimension
	Behaviour-affective dimension	Mild intellectual disabilities
	Mild intellectual disabilities	Hearing impairment
	Hearing impairment	
CGI	Depressive dimension	Depressive dimension
	Behaviour-affective dimension	Mild intellectual disabilities
	Mild intellectual disabilities	Epilepsy-poorly seizure control
	Epilepsy-poorly seizure control	Hearing impairment
	Hearing impairment	
CANDID-R unmet needs	Level of intellectual disabilities	Level of intellectual disabilities
CANDID-R met needs	No significant associations	No significant associations

Null hypothesis twelve: Rejected

There are no significant differences in the associations of dimensional and categorical models of psychopathology with the longitudinal outcome of mental disorders.

The variable representing the categorical model of psychopathology was retained as a significant, independent predictor of outcome on the GAF and CGI. However, the dimensional model of psychopathology was also associated with the HoNOS-LD and was more strongly associated with the GAF and CGI. When both models were included in a regression analysis the categorical model of psychopathology was not retained in the final model. Therefore, it is concluded that the dimensional model of psychopathology is a better predictor of longitudinal outcome of mental disorders.

Chapter 5 Discussion

This chapter aims to fully consider the findings from chapter 4 in the context of previous research. The first section discusses the principal findings in relation to the 12 research null hypotheses. For the purposes of the discussion the null hypotheses are grouped together into five sections, corresponding to the research aims of the thesis:

- the dimensional model of psychopathology (Null hypotheses one and two)
- the relationships between psychopathology and socio-clinical variables (Null hypotheses three and four)
- psychopathology and the severity of mental disorders (Null hypotheses five to seven)
- psychopathology as a predictor of the longitudinal outcome of mental disorders (Null hypotheses nine to eleven)
- comparing dimensional and categorical models of psychopathology (null hypotheses eight and twelve).

Following on from the discussion of the specific findings in comparison with previous literature, the strengths and limitations of the research carried out to address the hypotheses are considered in the second section. Finally, the implications of the findings for clinical practice and research in the field of mental disorders and intellectual disabilities are discussed.

5.1. The multi-dimensional model of psychopathology

Exploratory factor analysis of the PPS-LD data resulted in a model of psychopathology with four dimensions, labeled as depressive, organic, behavioural affective and anxiety. This multi-dimensional model explains just over 31% of the total variance in the psychopathology data collected using the PPS-LD.

In the studies summarised in table 1.2, the different instruments used to assess psychopathology, the different samples, and even issues relating to the labelling of dimensions affects the comparison with the results in this thesis. For example, the PAS-ADD checklist does not include items of psychopathology related to problem

behaviours, and Kellett *et al.* (2004) included only participants with mild intellectual disabilities. The issue with labelling is illustrated by the dimensions that include items describing affective psychopathology, in studies in table 1.2. These are described using different labels- such as depression, mood, anxiety, and dementia/ anxiety. To add to the problems with labelling, confusingly, two studies using the PAS-ADD checklist included two separate dimensions labelled as depression (Moss *et al.* 1998; Hatton & Taylor 2008). These variations between studies are considered where relevant below, in the comparisons of studies reporting multi-dimensional models of psychopathology.

Compared with the previous studies (table 1.2), the number of dimensions identified and the overall variance explained in the model described in this thesis was placed towards the midpoint. The number of dimensions in the previous studies varies from one (Sturmey *et al.* 1996; Tsiouris *et al.* 2003) to nine (Linaker 1991). These models also vary considerably in the proportion of the overall variance in psychopathology they account for- ranging from 9.4% (Tsiouris *et al.* 2003) to 61.25% (Hatton & Taylor 2008). Whilst accounting for a higher proportion of overall variance could be seen as desirable, it is not the case that a higher overall variance should be accepted at the expense of including additional factors, which are unstable, or un-interpretable.

Compared to other studies in table 1.2, the methods used for the EFA in this thesis more closely followed best practice guidelines (Costello & Osborne 2005). Although this will have reduced the overall number of factors extracted, and therefore the proportion of the overall variance explained, it would have maximised the stability of the final multi-dimensional model of psychopathology. In particular, a case: item ratio less than 5:1 (Matson *et al.* 1984; Linaker 1991; Gustafsson & Sonnander 2005; Watson *et al.* 1988; Sturmey *et al.* 1996; Sturmey *et al.* 2003; Tsiouris *et al.* 2003), the use of eigenvalues to decide the number of factors extracted in models (Matson *et al.* 1984; Linaker, 1991; Balboni *et al.* 2000; Gustafsson & Sonnander 2005; Watson *et al.* 1988; Moss *et al.* 1998; Hatton & Taylor 2008; Hove & Havik 2008; Kellet *et al.* 2004), acceptance of factors with less than three items (Moss *et al.* 1998; Hatton & Taylor 2008; Hove & Havik 2008) and cross-loading of items across factors (Moss *et al.* 1998; Sturmey *et al.*

2005; Sturmey *et al.* 1996; Kellet *et al.* 2004) have a negative effect on the stability of the final multi-dimensional models in studies reported in table 1.2. The methods of EFA used in a study will also have contributed to the difference in the proportion of variance models account for even when they have used the same instrument of assessment. A clear example of this is seen in the differing results from the three studies using the PAS-ADD checklist (Moss *et al.* 1996; Sturmey *et al.* 2005; Hatton & Taylor 2008).

The decisions on which items of psychopathology from the PPS-LD to include in the EFA is relevant to comparisons of the results with those of other studies. Items that occurred at an overall frequency less than 5%, or were dependent on the verbal communication of participants i.e. couldn't be observed by an informant, were excluded from the EFA. This was done to improve the stability and generalisability of the final multi-dimensional model of psychopathology. Whilst this left 41 items of psychopathology for inclusion in the EFA, it had a differential effect on specific forms of psychopathology. For example, most items of affective or problem behaviour psychopathology are included in the EFA but this was not the case for other forms of psychopathology. Studies using the PIMRA (Matson 1984; Linaker 1993; Balboni 2000; Gustafsson & Sonnander 2005), PAS-ADD checklist (Moss *et al.* 1998; Sturmey *et al.* 2005; Hatton & Taylor 2008), RSMB (Sturmey *et al.* 1996) and DASH-II (Sturmey *et al.* 2004) identified psychosis dimensions of psychopathology. The exclusion of items of psychopathology relating to psychosis meant that this was not possible in this thesis. Therefore, the multi-dimensional model described here cannot be considered as representing all forms of psychopathology experienced by adults with intellectual disabilities. Rather, it is a model of commonly experienced psychopathology that can be identified, and reported, across the full range of abilities.

Despite the differences between studies, the four dimensions are similar to dimensions reported in previous studies (table 1.2). Furthermore, equivalents to the depressive, organic, behaviour-affective and anxiety dimensions are included in the nine dimensions identified across studies using different instruments to assess psychopathology, listed in table 1.3. However, there are no previous studies that have reported a final model with

an identical combination of these four dimensions. Each of the four dimensions included in the final model, and aspects of the overall model, are discussed below.

5.1.1 The depressive dimension of psychopathology

In the EFA reported in section 4.1, the depressive dimension was extracted first- with nine items of psychopathology, representing the greatest proportion of the overall variance of the four dimensions (9.8%). A depressive dimension, or equivalent, was identified in seven previous studies using the informant version of the PIMRA (Matson *et al.* 1984; Watson *et al.* 1988), PAS-ADD checklist (Moss *et al.* 1996; Sturmey *et al.* 2005; Hatton & Taylor 2008), MOSES (Sturmey *et al.* 2003), CBCPID (Tsiouris *et al.* 2003) and BSI (Kellet *et al.* 2004) instruments of assessment, Furthermore, of the seven studies that identified a depressive dimension it was extracted as the first factor, explaining the highest variance, in five of the studies (Moss *et al.* 1996; Sturmey *et al.* 2005; Hatton & Taylor 2008; Tsiouris *et al.* 2003; Kellet *et al.* 2004). Therefore, a depressive dimension of psychopathology is consistently identified across studies with adults with intellectual disabilities as participants, and accounts for a significant proportion of the psychopathology. This finding is in keeping with studies diagnosing mental disorders using categorical diagnostic classification systems. For example, a large-scale, population based study found that, after problem behaviours, DC-LD depressive disorder had the highest point prevalence (4.6%) of any mental disorder (Cooper *et al.* 2007c).

Since a depressive dimension is identified within the majority of multi-dimensional models of psychopathology, it is relevant to consider possible reasons why it was not reported in a minority of studies in table 1.2. It is seen from the results of the study by Hove and Havik (20008) that depressive psychopathology is located within a dimension labelled as severe psychopathology. As well as depressive psychopathology, this dimension also includes psychopathology described as dementia, mania and psychosis. On closer inspection of the methodology used in the EFA, the items used in the analysis are the scores from the 18 checklists, rather than the 260 individual items of psychopathology. Thus, the results of this study do not present an empirically defined,

multi-dimensional model of psychopathology. Rather, the model describes which checklists of psychopathology correlate with one another. However, this study based the checklists on diagnostic criteria for specific categorical diagnoses in DC-LD- in turn derived form the ICD and DSM categorical classification systems. Therefore, rather than describing higher order dimensions of psychopathology (Achenbach & Edelbrock 1978; Cantwell 1996; Slade & Watson 2006; Slade 2007) the results describe the associations of DC-LD categories. This is maybe a reflection of the poor discriminant validity described for categorical diagnoses (section 1.4.2, Brown *et al.* 2001; Kessler *et al.* 2005). Studying a multi-dimensional model of psychopathology could be achieved by using the data on the 260 individual items of psychopathology in the EFA (Hove and Havik, 2008). However, since the study by Hove & Havik (2008) is not a true EFA of individual items of psychopathology it will not be used further in the comparison of results.

Of the five studies that extracted a multi-dimensional model of psychopathology from the informant version of the PIMRA, only two identified a depressive dimension (Matson *et al.* 1984; Watson *et al.* 1988). Since these five studies have used the same items of psychopathology, and a similar methodology for the EFA, it is not clear why the depressive dimension was not identified across all the studies. For example, the items that loaded to the affective dimensions in the studies by Matson *et al.* (1984) and Watson *et al.* (1988) are not extracted in any of the dimensions in the study by Linaker (1991), are distributed across the anxiety, adjustment and psychosomatic dimensions in Balboni *et al.* (2000) and across the psychosis and anxiety dimensions of Gustafson & Sonnander (2003). All these studies have used methods of EFA that reduce the reliability and stability of the results. One additional potential explanation for the variations between studies using the PIMRA is that there is a problem with the 56 items of psychopathology. The PIMRA items of psychopathology are said to be based on criteria within DSM -III, organised into eight sub-scales (Matson *et al.* 1984):

- schizophrenic disorders
- affective disorders
- psychosexual disorders

- adjustment disorders
- anxiety disorders
- somatoform disorders
- personality disorders
- inappropriate mental adjustment.

It appears from the description of the questions included in the PIMRA that some items are similar to those in the PPS-LD depressive dimension (Matson *et al.* 1984). Therefore, the variation across studies is not due to an absence of relevant items. However, within the PIMRA items there are some confusing questions, which seem to lack relevance to the assessment of psychopathology. For example, "Do you wish you were a tree instead of a man/ woman?....When things go bad for you do you feel OK?.... Is it bad to be sick?". It could be that the inclusion of incongruous items leads to variation in the response to questions on psychopathology across studies- especially when it is being translated for use in different countries (Linaker 1991; Balboni *et al.* 2000; Gustafson & Sonnander 2005). This question over the PIMRA items highlights the influence that the items included in any EFA can have on the results.

Of the items of psychopathology that loaded significantly to the depressive dimension in this thesis, all nine are included in the DC-LD criteria for depressive episode, seven are included within the ICD-10 criteria for depressive episode and eight in the DSM-IV-TR criteria for the categorical diagnosis of a major depressive disorder. The two items that are included in DC-LD but not ICD-10 criteria are "tearfulness" and "reduction of verbal communication"- which is also the item not included in DSM-IV criteria. Interestingly, the DM-ID notes that "has decreased or stopped talking" may be reported by informants, and should be considered as indicative of the DSM-IV-TR diagnostic criterion, *psychomotor agitation or retardation*. The depressive dimension is therefore most similar to the DC-LD depressive disorder category.

Several instruments for assessment of psychopathology used in the EFA studies in table 1.2 do not include items similar to "tearfulness" or "reduction in verbal communication"

(PIMRA, PAS-ADD checklist, DASH-II, BSI). Of those that do, the equivalent items to "tearfulness" and "reduction in verbal communication" did not load to the depression dimension extracted from the MOSES (Sturmey *et al.* 2003) or CBCPID (Tsiouris *et al.* 2003). Therefore, although this thesis provides some support for including these two additional criteria for depressive disorder in DC-LD, further work investigating the relevance of these items to the classification of depressive psychopathology is required.

As well as the items of psychopathology extracted as part of the depressive dimension, it is useful to consider items that did not load to this dimension in the EFA. In DC-LD and DM-ID, irritable mood can be used as an alternative to depressed mood, as a key criterion that should be present. Therefore, it is of interest that "increased irritability" is not part of the depressive dimension from the PPS-LD data. Instead "increased irritability" is one of the items that load significantly to the behaviour-affective dimension. The irritability item loaded to similar mixed dimensions, comprising mood and problem behaviour items of psychopathology, in the studies using the RSMB (Sturmey *et al.* 1996), MOSES assessment instrument (Sturmey *et al.* 2003), DASH II (Sturmey *et al.* 2004) and BSI (Kellet *et al.* 2004). However, the results in studies using the PAS-ADD checklist varied considerably. In one study the irritability item loaded to the depressive dimension (Moss *et al.* 1998), in another it did not load to any of the three interpretable dimensions- including one labelled mood (Sturmey *et al.* 2005), and formed a second depressive dimension with one other item "attempts suicide/ talks about suicide" in the most recently published study (Hatton & Taylor 2008). Finally, the irritability item did not load to the depressive dimension from the CBCPID (Tsiouris *et al.* 2003). Therefore, in only one study does the irritability item load significantly to a coherent depressive dimension. There is stronger evidence, from the PPS-LD model in this thesis, and studies using four other assessment instruments (Sturmey *et al.* 1996; Sturmey *et al.* 2003; Sturmey *et al.* 2004; Kellet *et al.* 2004), for irritability forming part of a behaviour-affective dimension of psychopathology.

Reduced concentration is also included in the diagnostic criteria for depressive episodes in DC-LD, ICD-10 and DSM-IV-TR. Similar to "increased irritability", the PPS-LD

item “reduced concentration” loaded significantly to the behaviour-affective dimension rather than the depressive dimension of psychopathology. However, unlike “increased irritability”, there is less evidence from other studies to support the finding that “reduced concentration” loads to the behaviour-affective dimension. Instead, “reduced concentration” loads to different dimensions across studies in table 1.2- including depressive dimensions (PAS-ADD checklist- Sturmey *et al.* 2005; MOSES-Sturmey *et al.* 2003), a restlessness dimension (PAS-ADD checklist- Moss *et al.* 1998) and cognitive impairment/ organic dimensions (BSI- Kellet *et al.* 2004; PAS-ADD checklist- Hatton & Taylor 2008). Some of these differences could have been influenced by the different sample or methodologies in the studies- a view that is supported by there being different findings across the three studies using the PAS-ADD checklist (Moss *et al.* 1998; Sturmey *et al.* 2005; Hatton & Taylor 2008). Alternatively, the variation across studies may suggest that psychopathology that relates to concentration is experienced across several different types of disorder. This is in keeping with the inclusion of items relating to concentration in diagnostic criteria for depressive disorders, manic episodes, generalised anxiety disorder, and ADHD in categorical diagnostic classification systems. Therefore, the relevance of the “reduced concentration” item of psychopathology to depressive, or other diagnostic, categories require further examination.

The other items that were expected to be extracted as part of the depressive dimension are those items from the PPS-LD that relate to sleep problems. However, in the multi-dimensional model reported here, none of the four items on sleep problems included in the EFA loaded to the depressive dimension. This isn’t too dissimilar to the findings from other studies. Of the seven studies that reported a depressive dimension in table 1.3, any form of sleep problem only loaded significantly to the depressive dimension in the study that used the CBCPID (Tsiouris *et al.* 2003). In the studies using the PAS-ADD checklist, two reported a specific sleep problem dimension (Moss *et al.* 1998; Hatton & Taylor, 2008), and the other extracted sleep problems in the restlessness dimension (Sturmey *et al.* 2005). Sleep problems were extracted as an item in the somatisation dimension of the BSI (Kellet *et al.* 2004) and did not load significantly to any dimension in studies using the PIMRA (Matson *et al.* 1984) and MOSES (Sturmey *et al.* 2003).

Although none of the four sleep problem items from the PPS-LD loaded significantly to the depressive dimension, initial insomnia was included in the anxiety dimension.

This discussion of the depressive dimension raises a question of why certain items of psychopathology, often considered to be part of depressive psychopathology, load significantly to the behaviour-affective, and anxiety dimensions.

5.1.2 The behaviour-affective dimension of psychopathology

Eight items of psychopathology from the PPS-LD loaded significantly to the behaviour-affective dimension of psychopathology. Four items relate to problem behaviours and four are commonly described affective symptoms- together accounting for 7.46% of the overall variance in the psychopathology. It is relevant to consider the fact that both affective and problem behaviour psychopathology load significantly to this dimension, with a view to developing an understanding of the relationship between problem behaviours and other forms of psychopathology. One point of interest is that this dimension does not easily map onto any one diagnostic category in DC-LD, DM-ID, ICD-10 or DSM-IV-TR. In fact, as discussed in section 5.1.1, the behaviour-affective dimension includes items of psychopathology that are often included in the diagnostic criteria for several different disorders.

Four of the studies summarised in table 1.2 explicitly identify dimensions of psychopathology related to problem behaviours- using the PIMRA (Linaker 1991), RSMB (Sturmey *et al.* 1996), DASH II (Sturmey *et al.* 2004) and BSI (Kellet *et al.* 2004). Of these, on inspection of the items of psychopathology that loaded to these dimensions, three are a mixture of problem behaviour and affective items of psychopathology (Sturmey *et al.* 1996; Sturmey *et al.* 2004; Kellet *et al.* 2004). Although not labelled as such, the irritability/ depression dimension extracted from the MOSES data (Sturmey *et al.* 2003) is also a mixed behaviour-affective dimension that includes items on oppositional problem behaviours, physical aggression and verbal aggression. The relative consistency of a behaviour-affective dimension across studies suggests that this may be a valid dimension of psychopathology experienced by adults

with intellectual disabilities. Similarly, DC-LD (Royal College of Psychiatrists 2001) and DM-ID (Fletcher *et al.* 2007) both recognize that affective disorders presenting with depressive and manic episodes may both be associated with an increase in problem behaviours in adults with intellectual disabilities. However, only the DC-LD criteria for a depressive episode lists an increase in problem behaviours as a specific item within the diagnostic criteria.

The relationships between affective and problem behaviour psychopathology have been considered in previous studies. One relevant area is research on problem behaviours as potential depressive equivalents in adults with intellectual disabilities and depressive disorders. The studies have used categorical diagnostic classification systems with equivocal findings. Studies are split between those that have found a link between affective psychopathology and problem behaviours (Lowry & Sovner 1992; Charlot *et al.* 1993; Marston *et al.* 1997; Moss *et al.* 2000; Cain *et al.* 2003; Kishore *et al.* 2005; Tyrer *et al.* 2006; Hurley 2008) and those that do not (Holden & Gitlesen 2003; Tsiouris *et al.* 2003; Rojahn *et al.* 2004). The findings reported here, and in the four studies in table 1.2 that identified an equivalent behaviour-affective dimension (Sturmey *et al.* 1996; Sturmey *et al.* 2003; Sturmey *et al.* 2004; Kellet *et al.* 2004) suggest that there is a link between affective psychopathology and problem behaviours. However, the findings suggest that this link may be distinct from depressive psychopathology.

One explanation to examine is that the link between affective psychopathology and problem behaviours is explained by psychopathology related to mania/ hypomania. If this is the case then the behaviour-affective dimension from the PPS-LD would be better viewed as a mania/ hypomania dimension. This explanation is supported by the finding from several studies, using categorical diagnostic classification systems, that reported increased problem behaviours in individuals meeting diagnostic criteria for hypomania/ mania compared to depressive disorders (Cain *et al.* 2003; Holden & Gitlesen 2004; Hurley 2008). Furthermore, the items of psychopathology relevant to irritability (Sturmey *et al.* 1996; Sturmey *et al.* 2003; Sturmey *et al.* 2004; Kellet *et al.* 2004) and impaired concentration (Sturmey *et al.* 1996) that were extracted within the behaviour-

affective dimension, in this and other studies, are common to the diagnostic criteria for depressive episode and manic episode in DC-LD and DM-ID.

To examine this further, it is useful to consider the results in more detail. One point to note is that several items of psychopathology from the PPS-LD of potential relevance to a mania/ hypomania dimension were excluded from the EFA. The items expansive mood, reckless irresponsible mood and social disinhibition were excluded as they were reported by less than 5% of participants. A low base rate of these items of psychopathology is in keeping with reported low incidence and prevalence rates of hypomania/ mania (Smiley *et al.* 2007; Cooper *et al.* 2007c). Although other relevant items from the PPS-LD were included, without the full range of items, a mania/ hypomania dimension is less likely to be extracted from any EFA.

In considering whether the behaviour-affective dimension is better considered as a mania/ hypomania dimension, the results from the EFA that extracted five dimensions of psychopathology are important. This five-dimension model was rejected because of cross-loading of items between the anxiety and fifth dimensions. The fifth dimension included five items of psychopathology- increased verbal communication, increased energy levels, initial insomnia greater than one hour, mid-insomnia greater than one hour, early morning wakening greater than one hour. Although not entirely coherent, the fifth dimension was recognised as a possible mania/ hypomania dimension. However, it can be seen that no items from the behaviour-affective dimension in the four factor solution moved to this fifth dimension. Rather, the items of psychopathology that loaded to the fifth dimension were previously included in the anxiety dimension in the four factor solution. If the behaviour-affective dimension is more accurately considered a mania/ hypomania dimension, at least some items of psychopathology would have loaded significantly to the fifth dimension. This suggests that the link between affective psychopathology and problem behaviours in the PPS-LD is not due to mania/ hypomania.

Two of the assessment instruments used in the studies that reported an equivalent to the behaviour-affective dimensions include items of psychopathology related to mania/hypomania, such as euphoric/ elevated mood and over activity (RSMB- Sturmey *et al.* 1996; DASH-II- Sturmey *et al.* 2004). In neither of these studies do these items of psychopathology load significantly to the equivalent of the behaviour-affective dimension. The absence of items relevant to mania/ hypomania in the studies reporting behaviour-affective dimension using the MOSES (Sturmey *et al.* 2003) and BSI (Kellett *et al.* 2004) preclude the results from clarifying this issue. A lack of relevant items of psychopathology also explains why from all the studies in table 1.2 only two, both using the PAS-ADD checklist, report a specific mania/ hypomania dimension of psychopathology (Moss *et al.* 1998; Hatton & Taylor 2008). However, since the PAS-ADD checklist does not have items on problem behaviours these two studies do not provide any additional data relevant to this issue.

To summarise, results from studies using categorical diagnostic classification systems are equivocal on whether problem behaviours and depressive psychopathology are associated Although there are fewer studies using categorical models of mania/ hypomania, the evidence more consistently reports a specific association between a diagnosis of mania/ hypomania and problems behaviours. However, the studies using dimensional models of psychopathology, suggest the link between affective psychopathology and problem behaviours, may be distinct from depressive or mania/ hypomania psychopathology. Since this issue cuts across the multi-dimensional model of psychopathology it is discussed further in section 5.1.5

5.1.3 The anxiety dimension of psychopathology

Anxiety was the final dimension of psychopathology extracted from the PPS-LD data. Ten items of psychopathology loaded to the dimension, which explained 5.49% of the overall variance in the psychopathology. Similar anxiety dimensions were identified using the PIMRA (Matson *et al.* 1984; Linaker 1991; Balboni *et al.* 2000; Gustafsson & Sonnander 2005; Watson *et al.* 1988), PAS-ADD checklist (Moss *et al.* 1998; Hatton & Taylor 2008), DASH-II (Sturmey *et al.* 2004), and the BSI (Kellett *et al.* 2004).

However, the DASH-II dimension is distinct since, of the seven items that load to the dementia/ anxiety dimension four are related to cognitive impairment, and the three anxiety items are *visibly sweats with certain objects/ situations, trembles/ shakes for no obvious reason* and *extremely happy/ cheerful for no reason.*

Examining the PPS-LD anxiety dimension in more detail, the items labeled *generalized anxiety* and *agoraphobia* stand out from the others that loaded significantly to the dimension. Firstly, whilst the other items describe individual changes in behaviour or mood, these two items are more accurately thought of as combinations of items of psychopathology. In the PPS-LD, the item of psychopathology labeled *generalized anxiety* includes prompts for the characteristic free-floating anxiety and fear, autonomic arousal symptoms, and symptoms of tension. Similarly, the *agoraphobia* item of psychopathology incorporates prompts on characteristic symptoms that are triggered by identifiable situations and are associated with avoidance. Thus, both these items in the PPS-LD are composite measures, requiring several items of psychopathology to be present before they can be rated positively. For the purposes of using EFA to identify a multi-dimensional model of psychopathology, it would be preferable for each of the items of psychopathology within the composite items to be rated individually. These additional items could then be included in the EFA, and may add to our understanding of anxiety psychopathology experienced by adults with intellectual disabilities.

One reason why it is preferable to include individual items of psychopathology is that anxiety dimensions from intellectual disabilities studies appear different to results from studies with participants who do not have intellectual disabilities. Many studies that include anxiety related psychopathology identify two distinct dimensions (Watson 2005), labeled with various terms to represent a general distress dimension (often including depressive psychopathology and free floating symptoms, restlessness, tension) and an anxious, fear dimension (including avoidance, panic, phobic and obsessional symptoms). In contrast, the multi-dimensional model of psychopathology identified from the PPS-LD, and other assessment instruments in table 1.2, generally report a single dimension that includes both generalized and fear/ phobic items of psychopathology

(Matson *et al.* 1984; Linaker 1991; Balboni *et al.* 2000; Gustafsson & Sonnander 2005; Watson *et al.* 1988; Moss *et al.* 1998; Sturmey *et al.* 2004; Kellett *et al.* 2004). Although one study reported separate anxiety and avoidant/ anxious dimensions (Linaker 1991), both dimensions are made up of general anxiety psychopathology with no items relating to phobic behaviours, panic or avoidance.

It may be that individuals with intellectual disabilities experience, and report, anxiety psychopathology differently from individuals who do not have intellectual disabilities. However, similar to the PPS-LD, none of the assessment instruments used in the previous studies included a comprehensive range of items relevant to all forms of anxiety psychopathology. This may explain why the results are different from the studies involving participants who do not have intellectual disabilities. Future studies with the PPS-LD, or other assessment instruments, should consider including additional, or more specific, items relevant to anxiety psychopathology.

It is interesting to note that the items *increased appetite* and *weight gain* from the PPS-LD load significantly to the anxiety dimension. Of the other assessment instruments in table 1.2, only the PAS-ADD checklist asks about either of these items of psychopathology; *increased appetite* loads to the anxiety dimension in one study (Moss *et al.* 1998) and the hypomania dimension in another (Hatton & Taylor 2008). This apparent association between anxiety psychopathology and increased appetite and weight gain would benefit from further study. However, this finding is relevant to the significantly increased prevalence of obesity in children (Emerson 2009) and adults (Melville *et al.* 2007; Bhaumik *et al.* 2008; Melville *et al.* 2008) with intellectual disabilities.

An association between anxiety and weight gain (Stice 2002; Torres & Nowson 2007), and anxiety and obesity (Jorm *et al.* 2003; Scott *et al.* 2008) has been described in individuals who do not have intellectual disabilities. However, no intellectual disabilities studies to date have reported an association between anxiety and weight gain, or obesity. There is a general lack of understanding of the determinants of obesity in individuals

with intellectual disabilities, and few studies have examined the relationships with psychopathology (Melville *et al.* 2007). However, two recent population based studies found no significant, independent associations between obesity (defined as a body mass index greater than 30) and a diagnosis of a mental disorder (Melville *et al.* 2008) or problem behaviours (Melville *et al.* 2008; Bhaumik *et al.* 2008). The loading of *increased appetite* and *weight gain* to the anxiety dimension in this study, suggests that there is value in examining the relationships between psychopathology, weight gain and dimensional models of psychopathology in adults with intellectual disabilities.

5.1.4 The organic dimension of psychopathology

The six items of psychopathology that were extracted in the organic dimension accounted for 8.7% of the total variance in the psychopathology. All six items that were extracted are included as relevant items of psychopathology within DC-LD diagnostic criteria for dementia. The criteria in ICD-10 and DSM-IV-TR are somewhat different in that rather than listing specific items of psychopathology, broader descriptions of psychopathology associated with neurological impairment are used. These include memory impairment, aphasia (language disturbance), apraxia (impaired ability to carry our motor activities), agnosia (failure to recognize objects) and disturbance in executive functioning (i.e. planning, organizing, sequencing and abstracting). Despite these differences between the categorical diagnostic classification systems, overall the items included in the organic dimension of psychopathology are in keeping with commonly reported phenomena reported as part of organic disorders, such as dementia.

It is worth noting that several items of psychopathology that are often considered indicative of organic disorders were excluded from the EFA as they were reported in less than 5% of cases:

- mixing up day and night
- loss of literary skills
- loss of financial skills
- word finding difficulties.

It is likely that the items on literary and financial skills, and word finding difficulties are identified infrequently because many of the participants with intellectual disabilities have low baseline levels of abilities relevant to these items. Therefore, it is difficult for informants and clinicians to detect change in these domains of functioning. The reason why the item on "mixing up day and night" is reported infrequently is less clear. Perhaps this is explained by the fact that the majority of participants receive support from carers. Prompts from carers about time of day, and routines around waking and sleep, may be strong enough to counter-act any change in this area of functioning due to organic disorders.

From a statistical point of view there are reasons to exclude from EFA items of psychopathology that occur infrequently, as the low variance has a negative impact on the stability and reliability of the final model (Hair *et al.* 1998a). By reducing the number of relevant items included in the EFA, inevitably the number of potential items that can be extracted is reduced. However, this does not reduce the potential face validity of the dimension, since these items are occurring at low frequencies in the total sample.

Of previous studies, three identified similar dimensions to the organic dimension reported here (DASH-II- Sturmey *et al.* 2004; BSI-Kellett *et al.* 2004; PAS-ADD checklist- Hatton & Taylor 2008). The PIMRA (Matson *et al.* 1984), RSMB (Sturmey *et al.* 1996) and CBCPID (Tsiouris *et al.* 2003) assessment instruments do not include items of psychopathology relevant to change in memory and other cognitive functioning, explaining why no equivalent to the organic dimension were reported. Since the MOSES is designed for use with older adults, the absence of an organic dimension from the final model is noteworthy (Sturmey *et al.* 2003). The authors describe a self-help dimension accounting for 20.6% of the overall variance that includes items of psychopathology relating to change in dressing, bathing, grooming, incontinence & toileting, and an item relating to problems with awareness of time. It is surprising that only one of the items rating change in cognitive functioning loaded significantly to this dimension. On the basis of the self-help dimension, the authors suggest the MOSES would be useful for the diagnosis of dementia and one study has shown that the MOSES differentiates between

individuals with intellectual disabilities and Alzheimer's type dementia (Dalton *et al.* 2002). However, since memory impairment is central to current concepts of dementia the absence of the item rating memory impairment from the self-help dimension suggests the MOSES requires further study before being used routinely in clinical or research settings.

A coherent organic dimension is consistently extracted when assessment instruments include relevant items of psychopathology. Therefore, it is necessary to include the organic dimension within comprehensive methods of assessment and management of mental disorders experienced by adults with intellectual disabilities.

5.1.5 General issues of relevance to the multi-dimensional model of psychopathology

The prior discussion of the individual dimensions extracted within the PPS-LD multi-dimensional model of psychopathology identified several issues relevant to the overall model.

The finding that the four dimensions of psychopathology were not significantly correlated, suggests that there are no higher order internalising and externalising dimensions. Rather, the finding of three independent dimensions including affective items of psychopathology- depressive, behaviour-affective and anxiety suggests a different model. Importantly, certain items of psychopathology (irritability and impaired concentration), included in the criteria for a diagnosis of depressive disorders in categorical diagnostic classification systems, are more strongly associated with the behaviour-affective dimensions in this and other studies. Finally, the consistent identification of a behaviour-affective dimension, distinct from depressive or mania/ hypomania psychopathology, may help to clarify the relationship between affective psychopathology and problem behaviours, and will also be discussed.

Although, there were no significant correlations between the four dimensions, or cross-loading of items to more than one dimension there may be useful links between the

dimensions that suggest areas of study to examine solutions to the poor validity of categorical models of psychopathology. For example, conceptualising a broader dimensional model of psychopathology that cuts across the boundaries of diagnostic categories may provide an understanding of the significant comorbidity between anxiety and depressive disorders.

Of the four dimensions extracted in the EFA, the organic dimension appears to be qualitatively distinct from the other three dimensions, labelled depressive, behaviour-affective and anxiety. The depressive, behaviour-affective and anxiety dimensions all include items of psychopathology that can be conceptualised as affective and behavioural. However, the organic dimension is made up of items of psychopathology linked to cognitive functioning and change in daily living skills. Therefore, the discussion of the broader aspects of a multi-dimensional model of psychopathology will be limited to consideration of the depressive, behaviour-affective and anxiety dimensions.

The majority of items of psychopathology in the depressive, behaviour-affective and anxiety dimensions are related to affects or behaviours. This suggests that there may be value in examining an affective-behaviour model of psychopathology. The research literature recognises a close relationship between affects and behaviour. Although there is no single accepted conceptualisation of affects, the influence of affects on behaviour is central to the definition, and function of affects (Mauss *et al.* 2005). Therefore, the term *affective model of psychopathology* will be used to consider a global model of psychopathology based on the affective and behavioural items of psychopathology in the depressive, behaviour-affective and anxiety dimensions.

As stated in section 4.1, items of psychopathology on the PPS-LD were only rated positively if there was a clear change from an individual's baseline functioning. Therefore, affective change, or stability, can be viewed as an overarching aspect of the three affective dimensions of psychopathology extracted from the PPS-LD data; in turn affective stability is encapsulated within the construct of affect regulation within the research literature.

The study of affect regulation has been heavily influenced by work in the fields of developmental psychology and psychopathology. It is clear from the literature is that the term affect regulation is used to refer to a complex and diverse range of processes which are central to affective and psychological functioning (Gross & Thompson 2007). Given this complexity, it is perhaps not surprising that there does not seem to a single accepted definition of what is meant by affect regulation (Cole *et al.* 2004). However, several key aspects of affect regulation are important to mention prior to a discussion of the multi-dimensional model of psychopathology.

Importantly for the consideration of the relevance of affect regulation across the depressive, behaviour-affective and anxiety dimensions of psychopathology identified in this thesis, affect regulation does not seem to be specific to which affects are being regulated. Rather, affect regulation refers to changes or processes that apply equally across affects, and therefore, potentially, across the three distinct affective dimensions.

Each of the three dimensions includes affective and behavioural items of psychopathology. Within the construct of affect regulation it is recognised that two related phenomena can be identified, and described, as regulating and regulated (Cole *et al.* 2004). Therefore, emotion regulation can be applied to changes in specific affects, as in the case of sadness in the depressive dimensions (affect as regulated), and the effects of changes in affects on behaviour e.g. increased verbal and physical aggression related to changes in irritability/ anger (affect as regulated) .

Finally, affect regulation involves both internal and external processes. For example, one model of affect regulation proposes five families of processes (Gross & Thompson 2007):

- situation selection e.g. avoidance of situations known to provoke negative affect
- situation modification e.g. moving to a quieter area of a busy centre to reduce fear
- attentional deployment e.g. concentrating on the non-aversive aspects of a situation
- cognitive change e.g. using learnt cognitive strategies to reappraise an intense affect

- response modulation e.g. using learnt strategies or drugs to alter affects or associated behaviours.

The finding that affect regulation involves internal and external processes has specific relevance to an affect regulation model of psychopathology experienced by adults with intellectual disabilities. In section 1.3.1, the challenges inherent in the assessment and measurement of psychopathology in adults with intellectual disabilities were described. Similarly, only a minority of adults with intellectual disabilities will have the level of verbal communication and cognitive abilities necessary to the study of internal processes involved in affect regulation. This is particularly relevant to the cognitive change family in the model above. On the other hand, the other four families of processes include readily observable processes or behaviours, which could be either directly observed or reported by informants. Furthermore, the importance of situational and environmental elements to affect regulation suggests that appropriate support from others, or environmental modifications may impact on psychopathology.

To summarise, the construct of affect regulation:

- appears to apply across dimensions of psychopathology
- incorporates affective and behavioural items of psychopathology
- can be studied using self and proxy report, or direct observation
- potentially offers opportunities to develop novel interventions.

This suggests that affect regulation is an area of research that could offer insights into psychopathology experienced by adults with intellectual disabilities. Since the construct of affect regulation has emerged from the disciplines of developmental psychology and psychopathology (Cicchetti *et al.* 1995), it is surprising that relatively few studies have involved individuals with intellectual disabilities. For example, the ability to regulate affect has been shown to impact on the development of problem behaviours and difficulties with interpersonal relationships in typically developing children (Eisenberg *et al.* 2001; Spinrad *et al.* 2006) and children with developmental delay (Crnic *et al.* 2004). However, affect regulation does not seemed to have been examined in relationship to

psychopathology experienced by adults with intellectual disabilities. Given the relevance of affect regulation to the findings in this thesis and the potential applicability of the construct across the boundaries of categorical diagnostic classification systems suggests that further research is merited.

Affective arousal or activation is another construct of relevance to the depressive, behaviour-affective and anxiety dimensions of psychopathology. Arousal and valence were proposed as the two key dimensions underlying the circumplex model of affect (Russell 1980) and subsequently incorporated into integrated models of affective states (Posner et al, 2005). Neurobiological research has begun to report evidence to support proposed distinct neural circuitry underlying the dimensions of affective arousal and valence (Gerber *et al.* 2008; Posner *et al.* 2009).

There are items of psychopathology in each of the depressive, behaviour-affective and anxiety dimensions that can be interpreted as changes in affective arousal:

- depressive dimension (under-arousal)- low mood, social withdrawal, anhedonia, lower energy levels and reduced appetite
- behaviour-affective dimension (over-arousal)- increased mood lability, increased irritability, increased verbal and physical aggression
- anxiety dimension (over-arousal)- generalised anxiety, increased verbal communication, increased energy, initial insomnia, increased appetite.

Therefore, affective arousal appears to be a construct that appears to be relevant to psychopathology commonly experienced by adults with intellectual disabilities. Despite models recognising the relevance of affective arousal to psychopathology (Bradley *et al.* 2000), compared to affect regulation, overall, there is less evidence on the relationship between affective arousal and psychopathology. Part of the reason for this may be that arousal has been incorporated into the broader model of affect regulation (Fox & Calkins, 2003: Schore 2005), or the focus of arousal research has been on psychophysiology and autonomic arousal (Brown, Chorpita & Barlow 1998). Regardless, the evidence available suggests that the construct of affective arousal should be considered for further study of

psychopathology. For example, a putative model examining the relationships between attachment, affective arousal and problem behaviours experienced by individuals with intellectual disabilities has been proposed (Janssen *et al.* 2002).

Alongside arousal, valence was the second dimension of affect proposed by Russell (1980), conceptualised as comprising positive and negative affect. An established tripartite model of depression and anxiety psychopathology (Clark & Watson 1991) emerged from further study of the valence of affect. The description of three affective dimensions of psychopathology linked by in this thesis, and one other study in table 1.2 (Kellett *et al.* 2004), is very similar to this tripartite model. Using EFA, and other multivariate statistical methods of analysis, this tripartite model has been shown, to explain the relationship between depressive, anxiety and other affective psychopathology (Clark & Watson 1991). However, the tripartite model has seldom been examined in relation to psychopathology experienced by adults with intellectual disabilities.

This tripartite model emerged from a broader model that proposes that there are two independent dimensions of affect, termed negative affect and positive affect. The negative affect dimension consists of psychopathology reflecting unpleasant affective states, associated with distress- such as sadness, fear, and disgust (Watson & Tellegen 1985; Clark & Watson 1991; Watson *et al.* 1995). The positive affect dimension includes states such as happiness, engagement and energy (Clark & Watson 1991; Watson *et al.* 1995). Rather than being two opposite ends of a single dimension, studies have shown that these two dimensions are relatively independent (Watson *et al.* 1988; Clark & Watson 1988). Initial studies of the two dimensional model of affect in individuals with mood and anxiety disorders suggested that a characteristic distribution could be identified with three dimensions of psychopathology, called the tripartite model. The three dimensions of psychopathology in the tripartite model are:

- a depressive dimension- comprising increased scores on the negative affect dimension and low scores on the positive affect dimension
- an anxiety dimension- with high scores on the dimensions of negative affect and positive affect (representing hyperarousal)

- a general distress dimension- that includes items of psychopathology common to various emotionally distressed states, including irritability, impaired concentration and restlessness (Watson *et al.* 1995).

The tripartite model has been shown to be a valid model of affective psychopathology in children and adolescents (Joiner & Lonigan 2000; Chorpita & Daleiden 2002; Cannon & Weems 2006) and adults (Watson *et al.* 1995; Brown *et al.* 1998; Beck *et al.* 2003; Cook *et al.* 2004). In fact the level of evidence is such that some authors have called for the tripartite model to be incorporated into DSM-V (Watson 2005). However, the intellectual disabilities studies on psychopathology are clearly not at this level.

Although the study by *Kellett et al.* (2004) identified three dimensions of affective psychopathology the authors did not consider the results against the tripartite model of depression and anxiety psychopathology. One study used EFA to examine the dimensional structure of psychopathology assessed with the Beck Depression Inventory-II (BDI-II) and Beck Anxiety Inventory (BAI; Lindsay & Skene 2007). The authors concluded that a two dimensional structure- representing depression and anxiety- best fitted the data. This result contrasts with EFA of data from the BDI-II and BAI in college students (Joiner 1996) which found that the data best fitted a tripartite model; perhaps suggesting that there is a difference in psychopathology identified by these assessment instruments when used with adults with intellectual disabilities. No other intellectual disabilities studies examining the tripartite model of depression and anxiety psychopathology were identified.

The results of the EFA using PPS-LD data appears to be a reasonable fit for the tripartite model of depression and anxiety psychopathology. Characteristic affective items of psychopathology described in the tripartite model (Clark & Watson 1991), are included in the depressive (low mood, anhedonia, reduced energy), anxiety (hyperarousal-increased energy, increased verbal communication, initial insomnia) and general distress (irritability, impaired concentration) dimensions. As in the tripartite model (Watson *et al.* 1995), the three dimensions are not correlated and can thus be considered relatively

independent. Despite the possible relevance of the tripartite model of depression and anxiety psychopathology, this finding needs further study. Nonetheless, since problem behaviour psychopathology was included in the tripartite model described here, and in the three affective dimensions described by Kellett *et al.* (2004), perhaps the tripartite model can further our understanding on the relationship between problem behaviours and affective psychopathology.

As described in section 5.1.3, research that has used categorical models of psychopathology has produced inconsistent evidence on whether there is an association between depressive psychopathology and problem behaviours. The PPS-LD multi-dimensional model of psychopathology could be interpreted as suggesting that problem behaviours are associated with the general distress dimension of a tripartite model, rather than a depressive dimension. This has not been reported previously for adults with intellectual disabilities, and the relationship between the tripartite model and conduct problems in children and adolescents, or antisocial behaviours in adults, does not appear to have been studied previously. Thus, further work is needed to examine whether problem behaviours experienced by adults with intellectual disabilities are associated with the general distress dimension of a tripartite model.

To achieve this, studies would collect data on a broad range of psychopathology, with a particular focus on including items relevant to affective and problem behaviour psychopathology. Although the PPS-LD includes items relevant to problem behaviours, these are limited to physical and verbal aggression, self-injurious behaviour and sexually-inappropriate behaviours. The assessment process could include structured instruments in addition to the PPS-LD. For example, structured assessments relevant to DC-LD criteria for problem behaviours have been devised for use in epidemiological studies (Jones *et al.* 2008; Hove & Havik 2009). Regardless of which instruments are used the key issue is to include the items of psychopathology relating to problem behaviours and other mental disorders in a single EFA.

The exclusion of items of psychopathology from the EFA will have impacted on the final multi-dimensional model of psychopathology identified from the PPS-LD. Essentially, the items of psychopathology included in the EFA are those which can be observed and reported by an informant, in circumstances where self-report psychopathology is not available. Most often an individual with intellectual disabilities is unable to self-report because the cognitive and communication demands for an item, or assessment instrument, are out with that person's level of abilities. Rather than excluding items of psychopathology from the EFA another strategy is to only include participants with mild intellectual disabilities (Kellet *et al.* 2004). Whilst, this potentially increases the number of items of psychopathology included in, and, therefore, extracted from the EFA, the final result cannot be considered generalisable across the range of abilities of adults with intellectual disabilities. Excluding items from the EFA, and including only a sub-sample of participants, both have advantages and disadvantages depending on the research questions being examined. Problem behaviours are more prevalent in individuals with more severe intellectual disabilities (Jones *et al.* 2008). Therefore, if future studies are going to examine further the relationship between affective psychopathology and problem behaviours, it would be preferable to include individuals across the full range of abilities. Hence, it is likely that the strategy used in this thesis will be used- resulting in inclusion of only those items of psychopathology that can either be self-reported, or reported by an appropriate informant.

From the original 90 PPS-LD items of psychopathology, 25 were not included based on a base rate of less than 5%, or on the basis that the required cognitive and verbal communication abilities for an item was not achieved across the entire sample. Items of psychopathology can be reported infrequently for several different reasons. Certain items of psychopathology are rarely reported within any clinical population or research sample. For example, items of psychotic psychopathology, such as made affect or delusional perception are reported at frequencies less than 5% in many studies (Andreasen & Flaum 1994; Nordgaard *et al.* 2008). The rate that items of psychopathology are reported also differs across cultures and ethnic minority groups (Ndetei & Vadher 1984; Kulhara & Chakrabarti 2001). Base rates of items of

psychopathology will also be affected by the cognitive and communication abilities of individuals with intellectual disabilities. Items that are dependent on individual self-report and verbal communication will inevitably be less likely to be identified in studies involving adults with intellectual disabilities as participants. This effect acts to increase the number of items of psychopathology with low base rates in adults with intellectual disabilities.

In conclusion, the multi-dimensional model of psychopathology from the PPS-LD raises issues relevant to future research on psychopathology and the clinical management of mental disorders experienced by adults with intellectual disabilities.

5.2 The multi-dimensional model of psychopathology and socio-clinical variables

Relatively few studies in the field of intellectual disabilities have examined the associations of socio-clinical variables with psychopathology. Therefore, there is a limited understanding of potential risk factors for psychopathology and mental disorders-compared to the evidence on risk for children, adolescents and adults who do not have intellectual disabilities. Although longitudinal, prospective studies are the gold standard research methodology to identify risk factors, more often putative risk factors are identified from cross-sectional studies.

In this study, several socio-clinical variables were found to be independently associated with the multi-dimensional model of psychopathology. Since no previous studies examining the associations of socio-clinical variables with empirically derived multi-dimensional models of psychopathology were identified in section 1.7, the results will be compared with population studies based on categorical models of psychopathology (table 1.4).

Prior to comparing these results to previous studies there is an issue relevant to one study in table 1.4 to clarify. It is difficult to compare the results of this study with the study of Taylor *et al.* (2004). Female gender and younger age was found to be associated with

above threshold scores on the affective/ neurotic subscale on the PAS-ADD checklist (Taylor *et al.* 2004). However, the affective/ neurotic sub-scale lacks specificity, as it includes items of psychopathology that are relevant to the depressive, behaviour-affective and anxiety dimensions. Therefore, rather than comparing the results of all three dimensions to this study it is excluded from the discussion.

The socio-clinical variables were included in the analyses in this thesis because they were associated with psychopathology in the previous population-based studies identified. Several of these variables were not independently associated with any of the dimensional, or overall, measures of psychopathology- including gender, a diagnosis of autism, sensory impairments and urinary incontinence. Despite the negative finding, a discussion of gender is included below. The reason for this is gender was consistently shown to be associated with psychopathology across studies summarised in table 1.4, and additional evidence from other fields of research highlight the potential value of gender research in psychopathology.

To explore whether the dimensional model can be used to derive overall measures of psychopathology, three overall measures were included in the analyses. All three overall measures were only independently associated with level of intellectual disabilities in the multivariate analyses examining measures of psychopathology and socio-clinical variables. In contrast, the dimensional measures of psychopathology were associated with a greater number, and varying, socio-clinical variables (table 4.103). Similar findings were found in the multivariate analyses that used the measures of severity and longitudinal outcome as the dependent variables. Therefore, it is concluded that there is little value in creating overall measures of psychopathology by adding together the individual factor scores, or dimension counts, from the dimensional model of psychopathology. The use of the individual dimensions provides results more likely to inform an understanding of the relationships between psychopathology, socio-clinical variables and measures of severity and outcome.

In the studies summarised in table 1.4, the evidence for the associations of autism, sensory impairments and urinary incontinence with psychopathology is less convincing. Therefore, these variables are discussed in section 5.2.5 on categorical socio-clinical variables.

5.2.1 Gender and psychopathology

Gender was not associated with any of the four dimensions of psychopathology, the overall multi-dimensional model of psychopathology or the overall measure of psychopathology that was independent of the dimensional model (EFA PPS-LD symptom count- 41). This contrasts with the findings from studies using categorical diagnostic classification systems in table 1.4. Women were more likely to be diagnosed with any mental disorder (Cooper *et al.* 2007a; Hassiotis *et al.* 2008), depressive disorders (Cooper *et al.* 2007c) and problem behaviours (Jones *et al.* 2008).

One possible explanation for the contrasting finding with these studies is the different samples used. The studies in table 1.4 used populations based samples. However, the sample used to examine the associations between the PPS-LD multi-dimensional model of psychopathology and socio-clinical variables was a clinical sample, comprising referrals to the Glasgow UCEDD over a defined time period. Therefore, participants included in the sample used in this study will have complained of, or been recognised by informants or professionals to be experiencing, problems suggestive of mental disorders. It would be expected that the UCEDD sample would be biased towards the inclusion of individuals with more severe psychopathology, in comparison to a population- based sample. Since this effect is likely to be similar for both genders in the sample it could act to mask any actual differences in the distribution of psychopathology against gender.

An alternative explanation is that there is a gender bias that impacts on categorical diagnostic classification systems differentially from multi-dimensional models of psychopathology (Hartung & Widiger 1998). Ideally, diagnostic criteria should be gender neutral but this is difficult to achieve for disorders which present differently in females and males. Of relevance here is the suggestion that depressive disorders present

differently, with existing diagnostic criteria more closely describing psychopathology experienced by females (Kockler & Heun 2002). For example, studies show that women are more likely to report somatic depressive psychopathology such as appetite or sleep disturbance (Silverstein 1999). Any such gender bias has been shown to have been introduced into assessment instruments derived from diagnostic criteria (Cole *et al.* 2000). Although this effect is unlikely to explain the differences in the findings between this study and the population based studies in table 1.4, it highlights the potential relevance of gender to psychopathology research.

Research on the effects of gender bias upon the identification and management of psychopathology has largely involved participants who do not have intellectual disabilities. Studies have focussed on conduct problems (Hartung *et al.* 2006) and psychopathology relevant to attention, concentration and overactivity in children (Waschbusch & King 2006), and affective psychopathology (Piccinelli & Wilkinson 2000) in adults. Several different influences have been identified including measurement bias i.e. assessment instruments include items that are more commonly reported by either men or women (Stommel *et al.* 1993); observer bias, i.e. informants or clinicians being more likely to report or rate positively psychopathology in males (Ohan & Visser 2009) and sampling bias, particularly within clinical samples (Hartung & Widiger 1998). Although very little research has examined the potential influence of gender bias on psychopathology experienced by individuals with intellectual disabilities, all of these influences of gender bias are potentially relevant. Of particular interest would be the influence of gender bias on informant reporting of psychopathology. For example, within the developing literature on staff attributions and problem behaviours no studies have examined whether staff make different attributions depending on gender (Willner & Smith 2008).

It has been proposed that examining the relationship between gender and psychopathology can potentially contribute to an understanding of the pathophysiology of mental disorders (Rutter *et al.* 2003). Therefore, research on gender in relation to the

prevalence, presentation and assessment of psychopathology should be considered as a relevant area of study in the field of intellectual disabilities.

5.2.2 Age and psychopathology

In this study, younger age was associated with higher scores on the behaviour-affective and anxiety dimensions, and older age was associated with higher scores on the depressive dimension.

One of the population-based studies in table 1.4 reported an association between younger age and problem behaviours (Hove & Havik 2010) but the other study that examined it found there was no independent relationship between age and problem behaviours (Jones *et al.* 2008). Although both these studies are based on the DC-LD criteria for problem behaviours, the study methodologies differed in how psychopathology was rated. The study by Jones *et al.* (2008) gathered data on problem behaviours using checklists derived for the DC-LD criteria and used the DC-LD categorical criteria to diagnose problem behaviours as being present. Hove & Havik (2010) also used checklists based on DC-LD criteria to gather the data on problem behaviours. However, the analysis was carried out using a derived overall problem behaviour score, rather than a categorical diagnosis of a problem behaviour. Therefore, the continuous measure of Hove & Havik (2010) is closer to the dimensional model of psychopathology used in this thesis. This may explain the similar results from these two studies, which contrast to the study using the categorical model of psychopathology (Jones *et al.* 2008).

The use of dimensional and categorical models of psychopathology may also explain the different results on the relationship between age and the depressive dimension, and a categorical diagnosis of depressive disorder (Cooper *et al.* 2007c). However, the study using the scores from the DC-LD checklists as a continuous measure also did not find a significant association between age and the score from the DC-LD depression checklist (Hove & Havik 2010).

Population based samples in the studies using categorical diagnostic classification systems (Cooper *et al.* 2007c; Jones *et al.* 2008) have important advantages over the study described here. In particular, population-based samples are more representative and less likely to influence the findings through sampling bias. This could explain the different results examining the associations of psychopathology with age. For example, health professionals may be less likely to refer older people with problem behaviours for assessment, assuming that the psychopathology is long-standing, or an integral feature of ageing, and unlikely to respond to available management options. Despite this possibility, the agreement in the findings for problem behaviours with Hove and Havik (2010) raises the possibility that there are advantages to the use of dimensional, or continuous, models of psychopathology in research.

However, looking beyond the limited intellectual disabilities research, there is no consistent pattern in the relationship between age and depressive psychopathology (Jorm 2000; Stordal *et al.* 2003). Therefore, the different results could be attributable to challenges inherent to research examining the relationship between age and psychopathology. Certainly, data from longitudinal studies would help to clarify any changes in the risk of depressive psychopathology with age (Jorm 2000) and would also contribute to an understanding of developmental models of psychopathology (Rutter & Sroufe 2000; Hudziak *et al.* 2007) relevant to intellectual disabilities. For example, age has been proposed as a key factor to study in relation to developing valid models of the development of anti-social problem behaviours (Lahey *et al.* 1999).

5.2.3 Level of intellectual disabilities and psychopathology

A significant, independent association was found between level of intellectual disabilities and the organic, behavioural-affective and anxiety dimensions of psychopathology. Level of intellectual disabilities was also associated with all three of the overall measures of psychopathology. In all models the relationship was a direct relationship such that as the severity of intellectual disabilities increased the scores on the organic, behavioural-affective and anxiety dimensions, and the overall measures,

increased. However, none of the relationships were consistent across the range of abilities, suggesting that the relationships are non-linear.

Only for the behaviour-affective dimension factor scores were the three dummy variables representing the full range of intellectual disabilities retained in the final regression model. This suggests that this is the dimension which has the most coherent relationship with intellectual disabilities. If there was a linear relationship we would expect the value of β to gradually increase, or decrease, across the mild-moderate, mild-severe and mild-profound dummy variables. However, the standardised coefficients (β) in table 4.25 show that, even controlling for potential confounding effects of the other socio-clinical variables, the relationship is not linear. The effect is even greater for the behaviour-affective symptom count where the mild-severe variable drops out of the final model. It is difficult to be certain of the reasons for this non-linear relationship between level of intellectual disabilities and the dimensions of psychopathology from the PPS-LD. Of the models that retain level of intellectual disabilities, the mild-moderate variable is retained as the only dummy variable for the anxiety dimension factor scores and symptom counts, and for all three overall measures of psychopathology. However, it is the mild-severe dummy variable that is retained as significant in the regression model for the organic dimension factor score. Therefore, there does not appear to be a consistent pattern of association between level of intellectual disabilities and psychopathology across the dimensions of psychopathology.

The linearity of the relationship between level of intellectual disabilities and psychopathology was examined in the study by Hove & Havik (2010). Similar to the findings reported here, a non-linear relationship between level of intellectual disabilities and the measures of organic, problem behaviour, anxiety, depressive and obsessional psychopathology was reported. However, a linear relationship was reported for psychosis psychopathology, with a linear decrease in psychopathology as the severity of intellectual disabilities increased (Hove & Havik 2010).

At a general level, these findings highlight the complexity of understanding the influences on psychopathology experienced by individuals with intellectual disabilities. Although multivariate statistics were used to control for the effects of relevant variables (Hove & Havik 2010), it could be that there are confounding effects from other variables that could explain the non-linear relationships. For example, bias from the methods used to assess psychopathology could have differential effects across the range of intellectual disabilities. An example of such a bias is similar to that described for diagnostic overshadowing. The study by Hove and Havik (2010) used informant ratings of psychopathology across the entire sample. Perhaps participating in an assessment relevant to mental disorders, informants attribute changes in mood, or behaviour for individuals with profound intellectual disabilities to a person's intellectual disabilities, rather than reporting the changes as indicative of psychopathology. Alternatively, the items of psychopathology included in assessment instruments may not be appropriate for use across the full range of intellectual disabilities.

Similar to this study, a direct relationship between severity of intellectual disabilities and problem behaviour (Jones *et al.* 2008; Hove & Havik 2010) and overall psychopathology (Cooper & Bailey 2001; Cooper *et al.* 2007a; Bailey 2007; Hove & Havik 2010) was reported in more than one population-based study. It is of note that this finding is consistent across studies using dimensional, continuous (Hove & Havik 2010) and categorical models of psychopathology (Jones *et al.* 2008; Cooper & Bailey 2001; Cooper *et al.* 2007a; Bailey 2007. Problem behaviour is included in the overall measure of psychopathology in several (Cooper *et al.* 2007a; Bailey 2007; Hove & Havik 2010), but not all studies (Cooper & Bailey 2001). This and the direct relationship between severity of intellectual disabilities and anxiety reported here and one other study (Hove & Havik 2010) suggest the association is not entirely due to psychopathology related to problem behaviours.

No association between level of intellectual disabilities and depressive psychopathology was found in this thesis, or the other two studies summarised in table 1.4 that examined this (Cooper *et al.* 2007c; Hove & Havik 2010). Within the context of the tripartite

model of affective psychopathology suggested by the results of the EFA, it is interesting to discuss the possible relevance of the different relationships between severity of intellectual disabilities and depressive, behaviour-affective and anxiety psychopathology.

Level of intellectual disabilities and age are both considered of relevance to developmental models of psychopathology used in intellectual disabilities (Dosen 2007)- younger age and more severe intellectual disabilities considered as lower developmental levels of functioning. In this study, higher levels on the behaviour-affective and anxiety dimension were associated with younger age and increasing severity of intellectual disabilities. Therefore, there is a strong suggestion that behaviour-affective and anxiety psychopathology are associated with a lower developmental level of functioning. Although higher levels on the depressive dimension correlated with older age, there was no association with severity of intellectual disabilities. The findings on the association between depressive psychopathology and older age are inconsistent in section 5.2.2. Taken with the more consistent lack of association between depressive psychopathology and level of intellectual disabilities (Cooper *et al.* 2007c; Hove & Havik 2010), a tentative conclusion is that depressive psychopathology is not associated with developmental level of functioning.

Independent depressive, behaviour-affective and anxiety dimensions, in keeping with the tripartite model of depression and anxiety psychopathology, were described in this thesis and one other multi-dimensional model of psychopathology in table 1.4 (Kellet *et al.* 2004). Given that these dimensions are distinct and have different associations with variables relevant to development, further study of developmental aspects of the tripartite model should be considered. For example, of relevance to understanding pathophysiology studies have described phenotypic and genetic associations with the tripartite model in middle childhood (Hallett *et al.* 2009).

5.2.4 Down syndrome and psychopathology

Individuals with Down syndrome were found to have higher scores on the organic dimension, and lower scores on the behaviour-affective dimension of psychopathology.

These results are in agreement with one study, summarised in table 1.4, using categorical model of psychopathology for DC-LD problem behaviours (Jones *et al.* 2008), and the study using the continuous measures of organic psychopathology derived from the DC-LD (Hove & Havik 2010).

Down syndrome is known to be associated with a higher risk of dementia. Considerable research has been done to examine the nature of the association in the hope that it will further our understanding of dementia and Alzheimer's disease more broadly. In contrast to the increased risk of dementia- and other disorders, including congenital heart disease, autoimmune disorders and haematological malignancies- individuals with Down syndrome are thought to be protected against other disorders, including solid tumours (Hasle *et al.* 2000) and hypertension (McIntyre *et al.* 1999). It is relevant to examine the reasons these disorders are less frequently experienced by individuals with Down syndrome. Problem behaviours are known to have a significant negative impact on the quality of life of individuals with intellectual disabilities, some of whom have Down syndrome (Beadle-Brown *et al.* 2009), their families and carers (Jenkins *et al.* 1997; Hastings 2002). Therefore, research on problem behaviours should be seen as a priority and could examine further the findings that individuals with Down syndrome are at lower risk of psychopathology related to problem behaviours. It is possible that identifying protective factors could inform prevention and intervention strategies for individuals with Down syndrome, and other persons. Understanding the factors protecting individuals with Down syndrome against the development of problem behaviours could also have relevance for broader models of aggression (Loeber & Hay 1997; Eley *et al.* 2003).

5.2.5 Other categorical socio-clinical variables and psychopathology

Participants with epilepsy, mobility problems and bowel incontinence were found to have lower scores on the anxiety dimension of psychopathology. This seems counterintuitive, as it might be expected that individuals with additional health needs would be at greater risk of anxiety, or other forms of psychopathology (Deb *et al.* 2001). However, other population based studies in table 1.4 also found that individuals with

similar health problems, to those included in the analyses have lower levels of psychopathology.

Individuals with mobility problems were less likely to be diagnosed with any mental disorder (Cooper *et al.* 2007a), persons with epilepsy were at lower risk of psychosis (Cooper *et al.* 2007b) and anxiety (Hove & Havik 2010), and having a hearing impairment was associated with a lower risk of an affective disorder (Cooper *et al.* 2007c). However, it is noted that the more expected direction of association was also reported- visual impairment was directly associated with psychosis (Cooper et al; 2007b) and problem behaviours (Jones *et al.* 2008); urinary incontinence was associated with being diagnosed with any mental ill-health (Cooper *et al.* 2007a) and problem behaviours (Jones *et al.* 2008).

Even in the context of similar findings from other studies, it is not easy to explain why individuals with epilepsy, mobility problems and incontinence would have lower levels of anxiety psychopathology. One possibility is that the management of a specific health problem has an impact on psychopathology. For example anti-epileptic drugs are known to have a positive effect on affective psychopathology (Muzina *et al.* 2005) and have been suggested to have a role in the management of anxiety (Mula *et al.* 2007). It could also be that individuals with additional health needs are supported by family or paid carers in a way that reduces the risk of experiencing anxiety. Although entirely speculative, if carers tend to support individuals with complex health problems in their own home this would reduce an individual's risk of exposure to anxiety provoking triggers.

These additional health needs occur with increased frequency in persons with more severe intellectual disabilities. Therefore, informant report is more likely to form the basis of any assessment of psychopathology in individuals with these needs. Perhaps the reduced levels of anxiety are an artifact related to informant reporting of psychopathology in individuals with more severe intellectual disabilities. This is unlikely as we would expect reduced anxiety to be reported universally across all the health needs

included in the analyses. Nonetheless, this does raise the issue of the reliability of the assessment of psychopathology, using self-report and informant/ proxy report across the full range of intellectual disabilities (Bramston & Fogarty 2000; Ross & Oliver 2003).

Compared to most other socio-clinical variables, there have been more studies published specifically examining the relationship between epilepsy and psychopathology. However, no studies using an empirically defined dimensional model of psychopathology were identified. Most studies used a categorical model to compare psychopathology in individuals with epilepsy against individuals who do not have epilepsy. Although one study reported an increased risk in individuals who do not have epilepsy (Deb & Hunter 1991), studies have tended to report no between group differences in the risk of psychopathology (Espie *et al.* 1989; Gillies *et al.* 1989; Deb & Hunter 1991; Matson *et al.* 1999; Chung & Cassidy 2001). However, analyses including more detailed seizure- related data suggest that greater seizure intensity and frequency (Gillies, Espie & Montgomery, 1989; Espie *et al.* 2003) and treatment-resistance of seizures (Espie, Pashley *et al.* 1987) are associated with an increased risk of psychopathology. A meta-analysis of psychopathology in children with epilepsy highlights the potential value of using a dimensional model of psychopathology in future studies (Rodenburg *et al.* 2005). Children with epilepsy had higher scores on internalising and externalising dimensions of psychopathology, than controls (studies involving participants with severe intellectual disabilities were excluded from the analysis).

Autism was not associated with psychopathology in this study. This disagrees with the finding of increased levels of anxiety psychopathology reported by Hove & Havik (2010). However, another population based study found no difference in the prevalence and incidence of mental disorders, or problem behaviours, between adults with autism and intellectual disabilities and controls with intellectual disabilities, matched for gender, age, level of intellectual disabilities and Down syndrome (Melville *et al.* 2008). These conflicting results suggest further research in this area is required.

5.2.6 Key issues on risk factors for mental disorders in intellectual disabilities

This exploratory study of the relationships between a dimensional model of psychopathology identified several findings of interest:

1. multi-dimensional models of psychopathology offer a useful adjunct to the use of categorical diagnostic classification systems in studying risk factors
2. studying the complex relationships between psychopathology and socio-clinical variables can potentially elucidate the causes and pathophysiology of mental disorders.
3. examining the associations between psychopathology and gender, age, level of intellectual disabilities and behavioural phenotypes are of particular relevance.
4. psychopathology research in intellectual disabilities should aim to have a broader relevance to the understanding of the pathophysiology of mental disorders.

5.3 Psychopathology, socio-clinical variables and the severity of mental disorders

Section 4.7 examined the independent relationships between the multi-dimensional model of psychopathology, socio-clinical variables and measures of the severity of mental disorders. This offers an insight into the contribution that psychopathology makes to impairment and need associated with mental disorders. Socio-clinical variables were included in the analyses as potential confounders but also to identify if any are independently associated with the severity of mental disorders.

The depressive, organic and behaviour-affective dimensions of psychopathology were independently associated, in varying combinations, with all of the measures of the severity of mental disorders. However, the anxiety dimension was not correlated with any measure of severity. Since the association of socio-clinical variables with the measures of severity of disorder did not show any particular pattern, these are discussed individually below.

It is important to discuss the relevance of the CANDID-R met needs as a measure of severity of mental disorders. Met needs is reported as standard in studies using the CAN

or CANDID. The original CAN is most often used in epidemiological studies or needs assessment in relation to a specific clinical service, or population. Met needs are relevant to these types of study, as they give an indication of what level of needs a service should be resourced to address. Thus, they can be helpful to strategic planning and delivery of clinical services. However, the total number of met needs is less useful as a measure of severity of disorder. A higher score is a reflection of the degree to which services are meeting an individual's needs, whilst a lower score reflects that an individual has fewer needs that services are currently meeting. Since neither of these circumstances provide any relevant issue relevant to severity, the CANDID-R met needs will not be discussed here.

The individual measures of severity were found to have different associations with the psychopathology and socio-clinical measures. This finding suggests that the measures of severity assess distinct aspects of the severity of mental disorders. Thus, they can be considered to be complementary and useful to include within a battery of measures of severity. Not unexpectedly, the results for the two overall measures of severity, the GAF and CGI were similar. These were both included because of the limited evidence on their use, and concerns that the GAF may not be reliable in intellectual disabilities (Hurley 2001; Shedlack *et al.* 2005; Hurley *et al.* 2007). However, the results for the HoNOS-LD, the two global measures and the CANDID-R unmet need are quite distinct. These are examined in detail below, after first considering some relevant findings for the multi-dimensional model of psychopathology.

5.3.1 The multi-dimensional model of psychopathology and severity of mental disorders

Greater levels of psychopathology on the depressive dimension were associated with increased severity measured with the HoNOS-LD, GAF and CGI. The GAF and CGI are global measures, with an explicit focus on psychopathology. Therefore, the association with HoNOS-LD could be considered of greater significance as it suggests that depressive psychopathology has an impact on broader aspects of the severity of mental disorders, such as physical health, interpersonal functioning, self-care, and occupation

and activities. Two previous studies (table 1.5) examined the relationship between depressive psychopathology and the severity of mental disorders (Lunsky & Benson 2001; Endermann & Zimmermann 2009). However, only the study including participants with mild intellectual disabilities (Lunsky & Benson 2001) found a significant association between higher depressive psychopathology and greater severity, measured as a lower quality of life. These results suggest that effective management of depressive psychopathology could have a significant positive impact on the lives of individuals with intellectual disabilities.

Examining the CANDID-R and HoNOS-LD in table 3.6 it is seen that there is considerable overlap in the items included in the two measures. Therefore, since depressive psychopathology was associated with severity measured on the HoNOS-LD, an association with unmet needs on the CANDID-R might have been expected. Although the scoring system across the CANDID-R and HoNOS-LD are different, if this explained why depressive psychopathology was not significantly related to unmet need, the association with organic and behaviour-affective psychopathology to both measures of severity would not have been found. Therefore, it is not clear why depressive psychopathology was associated with all the measures of severity apart from the level of unmet need on the CANDID-R.

The organic and behaviour-affective dimensions of psychopathology, within the multi-dimensional model, were significantly associated with all four measures of disease severity. None of the studies summarised in table 1.5 examined the relationship between organic psychopathology and disease severity. Therefore, the impact on severity highlights the importance of including items relevant to organic psychopathology in research studies - which was also only done in a minority of the previous studies of multi-dimensional models of psychopathology in the table 1.2. Combined with the increased prevalence of dementia in adults with intellectual disabilities (Strydom *et al.* 2007), the strong relationship with severity of mental disorders, suggests that organic psychopathology should be a priority for research and clinical services (Janicki & Dalton 2000).

An association of the behaviour-affective dimension with severity of mental disorder offers some validation of the novel dimension, hypothesized to fit within a tripartite model of depression and anxiety psychopathology (Clark & Watson 1991). Since this dimension is correlated with all measures of severity, it appears to be of potential significance to the lives of adults with intellectual disabilities. Some support for this is provided by the previous study that reported an association of problem behaviours with severity of mental disorders (Beadle-Brown *et al.* 2009).

Given the link to severity, one area of relevance to consider is how comorbid affective and problem behaviour psychopathology could be effectively managed. There is some evidence on the separate assessment and management of affective psychopathology (Masi *et al.* 1997; McCabe *et al.* 2006) and problem behaviours (Tyrer *et al.* 2009; Harvey *et al.* 2009) experienced by individuals with intellectual disabilities. However, research on the co-morbidity of the two forms of psychopathology is more limited-largely focused on examining problem behaviours as equivalent criteria for the diagnosis of depressive disorders (Lowry & Sovner 1992; Charlot *et al.* 1993; Marston *et al.* 1997; Moss *et al.* 2000; Holden & Gitlesen 2003; Tsiouris *et al.* 2003; Cain *et al.* 2003; Rojahn *et al.* 2004; Kishore *et al.* 2005; Tyrer *et al.* 2006; Hurley 2008). Interestingly, research is beginning to consider the effectiveness of interventions based on the tripartite model (Barlow *et al.* 2004; Diefenbach & Goethe 2006). If the model is confirmed as valid in future studies it may offer novel treatment strategies for problem behaviours.

One previous study reported a correlation between neuroticism (as a proxy measure of anxiety) and severity of mental disorders (Endermann & Zimmermann 2009). However, the anxiety dimension of psychopathology was not significantly correlated with any measure of severity in this thesis. Given that the other dimensions are correlated to severity, it is not clear why the findings for the anxiety dimension are quite different. One possibility is that the measures of severity are not sensitive to the impact of anxiety psychopathology. However, the GAF and CGI are designed to be used across any form of mental disorder and the items included in the HoNOS-LD and CANDID-R, shown in

table 3.4, would appear to be relevant. That said, only 8% of participants in the HoNOS-LD pilot study had an ICD-10 neurotic disorder and there were no participants with neurotic/ anxiety disorders in the CANDID-R pilot study. Therefore, the psychometric properties of these measures when used by individuals with anxiety psychopathology would benefit from clarification.

5.3.2 Socio-clinical variables associated with the severity of mental disorders

The only socio-clinical variable independently associated across more than one measure of the severity of mental disorders was the level of intellectual disabilities. This finding is consistent with the previously described direct relationship between severity of intellectual disabilities and severity of mental disorder, rated as lower quality of life (Beadle-Brown *et al.* 2009). Compared to the mild intellectual disabilities reference category - moderate, severe and profound intellectual disabilities were associated with higher levels of unmet needs on the CANDID-R, and profound intellectual disabilities was associated with greater severity on the HoNOS-LD. Since the findings reported here are independent of the impact of psychopathology, and other variables, it suggests that either:

- the impact of psychopathology increases as the severity of intellectual disabilities increases
- interventions and services provided to individuals with mental disorders are less effective with increasing severity of intellectual disabilities.

One explanation that could account for both of these effects is the challenge inherent in identifying psychopathology as the level of intellectual disabilities of individuals' increases. Verbal communication and methods of self-report are central to the reliable identification and assessment of psychopathology. As the severity of intellectual disabilities increases, the level of functioning in the verbal communication domain is reduced. As a consequence, the assessment of psychopathology is increasingly dependent on informant report and observation. However, informants have been found to be less likely to identify psychopathology, and recognise the need for treatment, in adults with more severe intellectual disabilities (Edelstein & Glenwick 2001). Furthermore, it

has been found that there is poor agreement in the items of psychopathology reported by individuals with intellectual disabilities and informants (Moss *et al.* 1996). Therefore, this dependence on informant report has been recognised as a potential barrier to the recognition of psychopathology (Ruddick 2005) and other health problems (NHS Health Scotland 2004). These issues surrounding informant report could therefore lead to the delayed identification and assessment of psychopathology in persons with more severe intellectual disabilities.

Intellectual disabilities research on the impact of the delayed presentation of psychopathology is limited. However, such delayed presentation has been shown to be associated with increased severity of mental disorders in children (Keller *et al.* 1992) and adults who do not have intellectual disabilities (Coryell *et al.* 1995; Scully *et al.* 1997). Potential solutions to improve informant recognition and report of psychopathology are proactive screening for psychopathology (Cooper *et al.* 2006; Baxter *et al.* 2006), training programs for carers (Costello *et al.* 2006; Woodwards & Halls 2009) and the use of reliable and valid informant-report measures of psychopathology (Cuthill *et al.* 2003).

Despite this possible effect associated with informant report of psychopathology, the positive impact of support from carers is supported by the lower level of unmet needs, and higher met needs, for individuals living with family or paid carers- compared to individuals living independent of support. This was not examined in previous studies (Lunsky & Benson 2001; Beadle-Brown *et al.* 2009; Endermann & Zimmermann 2009). However, the key role that carers have in supporting the health and social needs of adults with intellectual disabilities is widely recognised (McGrother *et al.* 1996; McConkey *et al.* 2006).

Younger age was found to be independently associated with severity of mental disorders, indicated by higher levels of unmet needs. Once again, none of the previous studies examining correlates with severity included age in the analysis (Lunsky & Benson 2001; Beadle-Brown *et al.* 2009; Endermann & Zimmermann 2009). Although younger age was found to be associated with higher levels of psychopathology in the behaviour-

affective and anxiety dimensions, the association of younger age with severity is independent of the effects of psychopathology. It is not certain why this might be but one possibility could be that younger individuals are more likely to be presenting to services for the first time, or are at an earlier stage of contact with services. Therefore, unmet needs which have been addressed through previous, or longer, contact with services in older people have not yet been addressed for younger people.

Generally, researchers have highlighted the health needs of older people with intellectual disabilities (Janicki *et al.* 1999; Evenhuis *et al.* 2000; Janicki *et al.* 2002). Perhaps the finding reported here serves as a reminder that mental disorders starting in childhood and adolescence can continue to have an impact into adulthood in individuals with intellectual disabilities (Maughan *et al.* 1999; Beadle-Brown *et al.* 2008). Furthermore, the transition period into adulthood is recognised as a period of increased risk for the development of mental disorders (NHS Health Scotland 2004).

5.3.3. Key issues on psychopathology, socio-clinical and severity of mental disorders

1. the multi-dimensional model of psychopathology is related to severity of mental disorders measured with a battery of measures that include the impact of psychopathology on physical health, interpersonal functioning, self-care and occupation and activities.
2. increased severity of intellectual disabilities is associated with greater severity of mental disorders, even after controlling for the effects of psychopathology and other potential confounding variables.

5.4 Psychopathology as a predictor of the longitudinal outcome of mental disorders

A key criticism of the prevailing categorical model of psychopathology is that it lacks predictive validity; that is to say, categorical models of psychopathology are poorly correlated with longitudinal outcome and thus provide little information on an individual's prognosis. Therefore, the examination of psychopathology and longitudinal

outcome is an important aspect of understanding psychopathology experienced by persons with intellectual disabilities.

5.4.1 Psychopathology and longitudinal outcome

The finding that the depressive and behaviour-affective dimensions of psychopathology are related to positive longitudinal outcome is similar to some previously published studies (tables 1.6 and 1.7). Follow up studies of adults with intellectual disabilities have reported that problem behaviours (van Minnen *et al.* 1997) and affective/ neurotic psychopathology (Spiller *et al.* 2007) are correlated to outcome. Only one previous study found an association between childhood psychopathology and outcome in adulthood (McCarthy 2008). These three studies used only a single measure of outcome (van Minnen *et al.* 1997; Spiller *et al.* 2007; McCarthy 2008). The one study that included a battery of measures of outcome, including the GAF used in this thesis, did not find any significant correlation between psychopathology and outcome (Xenitidis *et al.* 2004).

The organic dimension symptom count was negatively correlated with the change in the HoNOS-LD over time. This is in keeping with the progressive nature of most types of dementia. Although there is some suggested efficacy of cognitive-enhancers in adults with Down syndrome (Lott *et al.* 2002; Prasher *et al.* 2002) this research is at an early stage and there is less evidence on the use of cognitive enhancers in adults with intellectual disabilities not associated with Down syndrome. Furthermore, with the four-five year follow-up, it would be expected that progression of the dementia would have occurred even if an individual had received cognitive enhancers. The limited evidence base on non-pharmacological management of organic psychopathology experienced by individuals with intellectual disabilities has also been recognized (Courtenay *et al.* 2010).

Of equal relevance is the finding that the anxiety dimension of psychopathology was not related to longitudinal outcome. Since there was no significant change in this dimension over time (table 4.70), this could be attributed to the lack of effectiveness of interventions and services on this dimension of psychopathology. Although adults with

intellectual disabilities experience high rates of anxiety psychopathology, there is little evidence on the effectiveness of pharmacological and psychosocial interventions (Dagnan & Jahoda 2006; Davis *et al.* 2008) for anxiety psychopathology.

Give the strong association between psychopathology and longitudinal outcome, research on the assessment and management of psychopathology should be a priority. Based on these findings, developing effective interventions and services and may improve outcomes and quality of life of adults with intellectual disabilities and mental disorders.

5.4.2 Level of intellectual disabilities and the longitudinal outcome of mental disorders

Independent of psychopathology and the effects of other variables, outcome is better for individuals with moderate, severe and profound intellectual disabilities compared to persons with mild intellectual disabilities. This contrasts with findings from one study (van Minnen *et al.* 1997) that reported poorer outcomes for individuals with lower levels of social competence, whilst another found no significant association between intellectual disabilities and outcome (Spiller *et al.* 2007). The use of social competence as a proxy measure of level of intellectual disabilities, and a composite measure of psychopathology as the sole measure of outcome could partly explain the different finding from the study by van Minnen *et al.* (1997). Clearly, in light of limited evidence on the influence of level of intellectual disabilities on the outcome of mental disorders, further research would be desirable.

Although living circumstances were not independently associated with outcome, it could be that the improved outcome for adults with more severe intellectual disabilities is related to support arrangements. Since individuals with more severe intellectual disabilities will receive increased support from carers, this could influence outcomes. For example, perhaps individuals living with support from family or paid carers have improved compliance with pharmacological and psychosocial interventions for mental

disorders. This again highlights the positive impact that carers can maybe have on the outcome of mental disorders.

5.4.3 Other socio-clinical variables associated with outcome

The finding that individuals with poorly controlled seizures have poorer outcomes highlights the relevance of epilepsy to the management of mental disorders in individuals with intellectual disabilities. This is in keeping with the finding that individuals with intellectual disabilities and poorly controlled seizures are more likely to report psychopathology (Espie *et al.* 2003; Ring *et al.* 2007). Previous studies have rarely examined the influence of epilepsy on the outcomes of mental disorders experienced by adults with intellectual disabilities. However, potential barriers to the effective management of mental disorders (Barry *et al.* 2008) and the interaction between seizures and the efficacy of interventions (Kanner 2004) have been recognized in non-intellectual disabilities research. The poorer outcome of individuals with psychopathology and seizures supports the suggested need for specialist intellectual disabilities services for individuals with comorbid mental disorders and epilepsy (McGrother *et al.* 2006; Fitzgerald & Ring 2009).

Individuals with hearing impairment were found to have poorer outcomes on the GAF and CGI. It is difficult to understand why this would be the case. Hearing impairment was included in the analysis on the basis that a previous study showed that individuals with intellectual disabilities and a hearing impairment were less likely to be diagnosed with an affective disorder (Cooper *et al.* 2007c). More generally, individuals with hearing impairments are described as being at increased risk of mental disorders (Carvill 2008). The poorer outcome for individuals with hearing impairment can perhaps be needs to be understoodin the context of the complex physical and mental health needs of adults with intellectual disabilities.

5.4.4 Key issues on psychopathology, socio-clinical variables and the outcome of mental disorders

1. the multi-dimensional model of psychopathology is useful to developing an understanding of the longitudinal outcome of mental disorders
2. further research is required to examine if the efficacy of interventions and services for individuals with mental disorders varies with level of intellectual disabilities
3. the complex physical health needs of adults with intellectual disabilities could impact on the longitudinal outcome of mental disorders.

5.5 Comparisons of dimensional and categorical models of psychopathology

The categorical model of psychopathology was independently associated with severity of mental disorder on the HoNOS-LD, and longitudinal outcome on the GAF and CGI. However, the multi-dimensional model of psychopathology was associated with all four measures of severity, and longitudinal outcome on the HoNOS-LD, GAF and CGI. Further, the categorical model was no longer associated with any measure of severity or longitudinal outcome, when both models of psychopathology were included in the regression analysis. Therefore, the categorical model does not provide any additional contribution to the variance in measures of severity & outcome, over and above the dimensional model of psychopathology. It is concluded that the multi-dimension model is a better representation of psychopathology when considering the severity, and longitudinal outcome, of mental disorders. This finding strongly suggests that dimensional models of psychopathology are of relevance to future research on psychopathology experienced by individuals with intellectual disabilities, and may be of value to the strategic planning and provision of clinical services.

No intellectual disabilities studies have compared dimensional and categorical models of psychopathology. Although one study of psychosis found that dimensional and categorical models of psychopathology were equally relevant to predicting longitudinal outcome (Dikeos *et al.* 1996), the finding that the multi-dimensional model is more strongly associated with severity of disorder (van Os *et al.* 1999a; Prisciandro & Roberts 2009) and outcome (van Os *et al.* 1996; van Os *et al.* 1999b) is in keeping with most studies examining dimensions of psychosis. The potential relevance of the finding that dimensional models of psychopathology are more closely associated with severity, and outcome, of mental disorders is worth considering.

This thesis used similar methods to the general research comparing the association of dimensional and categorical models with severity and outcome of psychosis (van Os *et al.* 1996; van Os *et al.* 1999b; van Os *et al.* 1999a Dikeos *et al.* 2006) and affective disorders (Prisciandro & Roberts 2009). It has been suggested that the methodology

examines the predictive validity of different models of psychopathology (Prisciandro & Roberts 2009). However, before accepting that there there is a need to consider some aspects of the methodology.

The strength of dimensional models of psychopathology over categorical models has been attributed to the retention of greater information describing the person to person variability in psychopathology (Kraemer 2007). Examining the requirements for a good classification system for mental disorders in section 1.2.1, this suggests that a dimensional model has better face validity than a categorical model of psychopathology. The improved face validity of dimensional models is also supported by the findings that psychopathology has a continuous rather than bimodal distribution (section 1.5.1), which is better represented by a dimensional model of psychopathology. The retention of greater information relevant to the psychopathology an individual is experiencing within the dimensional model, which can be used to derive continuous measures, is also recognised to improve the sensitivity to change, compared to a categorical model of psychopathology (Hemingway *et al.* 1997; Haslam 2003). It could be that the improved face validity and sensitivity of a dimensional model of psychopathology, at least in part, explains the stronger relationships with severity and longitudinal outcome, compared to a categorical model. However, the research is at an early stage and further work examining the advantages and disadvantages of both models of psychopathology is required.

The severity of an individual's mental disorder is closely tied to decisions by clinician's about need for treatment. This is a complex process, which at some level will always involve clinicians making a categorical decision (Pickles & Angold 2003). However, the validity of using categorical models of psychopathology within the decision making process has been questioned. Decisions on the need for treatment of mental disorders are, at least in part, influenced by whether the psychopathology an individual is experiencing meets the criteria for a disorder, defined within a categorical diagnostic classification system (Kraemer *et al.* 2004). Certain systems of health care operate a policy where the costs for treatment will only be met by health insurance in

circumstances where the diagnostic criteria are met. In these circumstances categorical models of psychopathology act as barriers to care for some individuals. Clinical decision making processes based on a categorical model of psychopathology, run the risk of viewing all individuals who meet the diagnostic criteria as identical (Widiger & Samuel 2005) and excluding individuals from care who have significant impairments and would benefit from treatment (Angst *et al.* 1997; Wagner *et al.* 2000; Cuijpers *et al.* 2004; Chuan *et al.* 2008). Overall, this represents a loss of relevant data to inform the decision making process. The multi-dimensional model of psychopathology was more closely related to severity than the DC-LD categorical model in this thesis, and previous studies of psychosis (van Os *et al.* 1999a). This suggests that incorporating dimensional models into assessments could have advantages for clinical decision-making processes based on the severity of mental disorders.

In this thesis, the multi-dimensional model of psychopathology was also more strongly associated with the outcome of mental disorders than the categorical model. This suggests that dimensional models may hold advantages in monitoring response to treatment in clinical services and intervention studies, and understanding change in psychopathology in longitudinal studies. Of course, continuous measures of psychopathology are often used as outcome measures in intervention studies. Instruments have been developed for the assessment of depressive (Cuthill *et al.* 2003), anxiety (Mindham & Espie 2003; Charlot *et al.* 2007) and problem behaviour (Rojahn *et al.* 2009) psychopathology in adults with intellectual disabilities. Examining multi-dimensional models of psychopathology derived through EFA, and other multivariate methods, can help to ensure the validity of these measures. For example, further work examining the relationship between affective and problem behaviour psychopathology could lead to the development of new assessment instruments.

What is likely to be more challenging is the incorporation of dimensional models of psychopathology into routine clinical practice. Even with robust instruments to assess and monitor dimensions of psychopathology, changing clinical practice to routinely monitor psychopathology or outcomes has been shown to be problematic. The reasons

for this are likely to be complex but one possibility is that the categorical model of psychopathology already meets the needs of clinicians (Kendell & Jablensky 2003; Mellsop *et al.* 2007; Bell *et al.* 2008).

In fact, although multi-dimensional models appear to be more closely related to severity and outcome of mental disorders, there is no suggestion that they should replace categorical models of psychopathology. As described in section 1.4.1, categorical models have several strengths- particularly when used in clinical practice. Rather, current proposals explore means by which dimensional and categorical models can be used side-by-side, to complement one another (Achenbach *et al.* 2005; Kraemer 2007). This will capture the strengths of both approaches to understanding psychopathology and hopefully take forward the study and management of mental disorders. It will be interesting to see if dimensional models of psychopathology are incorporated into ICD-11 and DSM-V, due for publication in the near future.

5.6 Strengths and limitations

This study followed best practice guidelines on EFA to identify a multi-dimensional model of psychopathology experienced by adults with intellectual disabilities. A review highlighted the methodological weaknesses in studies that use EFA in the field of developmental disabilities (Norris & Lecavalier 2010). The EFA reported in this thesis meets the criteria set out in the review paper and current best-practice guidelines (Costello & Osborne 2005). None of the previous studies, summarised in table 1.2, that describe a dimensional model of psychopathology meet these criteria, with specific methodological limitations related to sample size and a case: item ratio of less than 5:1 (Tabachnik & Fidell 2001; Matson *et al.* 1984; Linaker 1991; Gustafsson & Sonnander 2005; Watson *et al.* 1988; Sturmey *et al.* 1996; Sturmey *et al.* 2003; Tsiouris *et al.* 2003), the sole use of eigenvalues to decide the number of factors extracted in models (Matson *et al.* 1984; Linaker 1991; Balboni *et al.* 2000; Gustafsson & Sonnander 2005; Watson *et al.* 1988; Moss *et al.* 1998; Hatton & Taylor 2008; Hove & Havik 2008; Kellet *et al.* 2004), acceptance of factors with less than three items loading significantly (Moss *et al.* 1998; Hatton & Taylor 2008; Hove & Havik 2008) and cross-loading of

items across factors (Moss *et al.* 1998; Sturmey *et al.* 2005; Sturmey *et al.* 1996; Kellet *et al.* 2004).

A further strength of the EFA described here is the use of a method of factor analysis appropriate to the analysis of categorical data (Wood *et al.* 2003). Most psychopathology assessment instruments collect data that is categorical, usually either ordinal or binary in nature. Common factor and principal components analysis are designed for use with continuous variables (Linting *et al.* 2007). Comparative analyses have shown that the use of these methods with categorical data produces models with poor reliability and stability, compared to non-linear methods of analysis (Woods 2002). In this EFA, a specific form of non-linear analysis better suited to the binary PPS-LD data was used. The method of analysis used is based on inter-item tetrachoric correlations (du Toit 2003), carried out with TESTFACT software. As is common in published psychopathology research, all the studies in table 1.2 use the principal components method to analyse categorical data. Clearly, further studies of intellectual disabilities of psychopathology using appropriate and reliable multivariate methods of analysis are required.

The use of an appropriate method to assess psychopathology in this study will have impacted positively on the data used for the EFA. PPS-LD is a psychopathology assessment instrument specifically developed for use with adults with intellectual disabilities. Inclusion of items of psychopathology from the SCAN, with additional items relevant to mental disorders experienced by persons with intellectual disabilities, ensured appropriate psychopathology was included in the analysis. Although items related to psychosis and mania/ hypomania were not included in the analysis, the results represent a broad, multi-dimensional model of commonly experienced psychopathology. Previously described multi-dimensional models are limited by the range of items of psychopathology included in the assessment instruments, e.g. the PAS-ADD checklist (Moss *et al.* 1998; Sturmey *et al.* 2004; Hatton & Taylor, 2008) or the CBCPID (Tsiouris *et al.* 2003). The inclusion of an extensive range of items of psychopathology also makes it more likely that the reported model of psychopathology is potentially valid.

Despite the comprehensive nature of the PPS-LD, as discussed in section 5.1, there are items of psychopathology of potential relevance to the behaviour-affective and anxiety dimensions that could not be included in the EFA. To improve the coverage of items of psychopathology in the PPS-LD for future studies, consideration should be given to extending the items assessing problem behaviours, and separating out items on free-floating anxiety, autonomic overarousal and avoidance that are currently incorporated in composite items.

Although the use of the PPS-LD can be considered a strength of this thesis, it is relevant to consider the strengths and limitations of other available instruments.

At the start of the period of study relevant to this thesis, the only comprehensive instrument for the assessment of psychopathology in adults with intellectual disabilities that was available was the PAS-ADD (Moss *et. al* 1993). The PAS-ADD is a semi-structured interview schedule based on the Psychiatric Assessment Schedule (PAS: Gask 1988). Since the items of psychopathology in the PAS were included in order to be able to diagnoses depression, generalised anxiety, dysythymia, panic disorder and agoraphobia, additional items for the assessment of psychopathology relevant to psychoses and autism were included in the PAS-ADD.

The researchers who developed the PAS-ADD found it to be a reliable and valid instrument for the assessment of psychopathology in adults with intellectual disabilities (Moss *et al.* 1993; Moss *et al.* 1997). Furthermore, the semi-structured format of the PAS-ADD interview included several innovations designed to maximise its utility in the identification of psychopathology experienced by adults with intellectual disabilities. These innovations included parallel participant and informant interviews and the use of an anchor event to improve recall.

Despite these strengths, certain limitations in the range of items of psychopathology included in the PAS-ADD limited its suitability for use in the EFA to examine the

dimensional structure of psychopathology experienced by adults with intellectual disabilities. In particular, the PAS-ADD does not include items of psychopathology relevant to problem behaviour and obsessional psychopathology. Since problem behaviours are the most commonly experienced form of psychopathology experienced by adults with intellectual disabilities the absence of these in the PAS-ADD was considered to limit its use to examine research hypothesis one, in this thesis.

As the PPS-LD includes a broader range of items of psychopathology than the PAS-ADD, and crucially includes items relevant to problem behaviours it was used in this thesis. Another instrument for the assessment of a broad range of psychopathology in adults with intellectual disabilities has been published since the start of the work described in this thesis- the Developmental Behaviour Checklist for Adults (DBC-A; Mohr *et al.* 2005). The DBC-A was developed from an established checklist of psychopathology for completion by carers of children with intellectual disabilities called the DBC (Einfeld & Tonge, 1992). To decide on the items of psychopathology for inclusion in the DBC-A, the items of psychopathology described in the clinical notes of six hundred and five adults with intellectual disabilities seen at a specialist centre in Victoria, Australia were compared against the 94 items of psychopathology included in the DBC. Twelve items of psychopathology were added to those in the DBC. The resultant 106 items of psychopathology in the DBC-A were reported to have satisfactory inter-rater reliability, and concurrent validity compared to the PAS-ADD.

Since the development of the DBC-A was informed by a "bottom up process" that examined psychopathology recorded in a large sample of case notes it is likely that it assesses a comprehensive range of psychopathology However, the researchers that developed the DBC-A note that the clinical assessments were unstructured and are thus dependant on the training and clinical practice of professionals working in the specialist centre (Mohr *et al.* 2005). Nonetheless, like the PPS-LD, the DBC-A includes items of psychopathology commonly experienced by adults with intellectual disabilities that are not included in generic psychopathology assessments e.g. problem behaviours. Therefore, the breadth and relevance of items of psychopathology in the DBC-A suggest it may be

suitable for use in an EFA to examine the dimensional structure of psychopathology experienced by adults with intellectual disabilities.

A second checklist of psychopathology published recently is the P-AID (Hove & Havik 2008) used in the EFA described in table 1.2. The P-AID comprises 260 items of psychopathology based on diagnostic criteria in DC-LD (Royal College of Psychiatrists 2001), including problem behaviours. Although the 260 items of psychopathology are organised into 18 separate checklists that correspond to DC-LD categorical diagnoses, as described in section 5.1.1, use of the 260 items of psychopathology in an EFA could be done to examine the dimensional structure of psychopathology.

The PPS-LD (Cooper 1997), DBC-A (Mohr *et al.* 2005) and P-AID (Hove & Havik 2008) all include a comprehensive range of psychopathology relevant to mental disorders experienced by adults with intellectual disabilities, and use a similar checklist format to rate items of psychopathology. Therefore, future research should consider comparing the multi-dimensional model of psychopathology extracted from the three instruments.

Since the items of psychopathology included in the EFA can be identified by self and informant report, the model is applicable to individuals across the range of mild-profound intellectual disabilities. Although the model from the BSI (Kellett *et al.* 2004) is similar, the design of the assessment instrument and the sample used mean the results are not generalisable beyond individuals with mild intellectual disabilities. Adults with intellectual disabilities are heterogeneous across many variables, and using inclusion criteria to define samples more tightly could be advantageous for some types of psychopathology research. For example, studies of psychosis psychopathology could limit the samples to individuals with mild intellectual disabilities. However, one aspect of the thesis was comparing a dimensional model of psychopathology to the categorical models in diagnostic classification systems. Since systems such as DC-LD and DM-ID are designed for use across mild-profound intellectual disabilities it was necessary to include participants across a similar range of abilities. The use of a sample that includes individuals with severe-profound intellectual disabilities meant that psychopathology

relevant to problem behaviours was more likely to be included in the EFA. This contributed to finding a potentially important model to explain the relationship of problem behaviours to other commonly experienced psychopathology. Finally, a broad sample makes the findings more likely to be of relevance to professionals working in the field of intellectual disabilities and clinical services.

All the psychopathology assessments were done by psychiatrists trained by the intellectual disabilities psychiatrist who originally developed the PPS-LD (Cooper 1997). This ensures the consistent use of the PPS-LD. The collection of psychopathology data was done in the context of the standardised UCEDD clinical assessment. Since this includes a full clinical history and examination, consideration is given to changes attributable to physical health problems or side-effects of medication and avoids falsely rating long-standing traits as psychopathology associated with a mental disorder. This standardised process will, therefore, have improved the reliability of the psychopathology data used in the EFA.

Further to the use of the PPS-LD, the use of standardised methods to assess level of intellectual disabilities and outcome is a further strength of this study. Level of intellectual disabilities was assessed by psychiatrists trained in the use of the Vineland's adaptive behaviour scales (Sparrow *et al.* 1984). The Vineland's adaptive behaviour scales have been endorsed for use in the assessment of functioning by the World Health Organisation (World Health Organisation 1994) and the Royal College of Psychiatrists (2001). Furthermore, they were used in the process to examine the standardization of the Weschler Adult Intelligence Scale-Third Edition (Weschler 1997), which is commonly used to measure IQ. A field trial to test the psychometric properties of the Vineland's adaptive behavior scales and derive population norms for adults with intellectual disabilities living in institutional and community settings was used as part of the process to develop the Vineland's adaptive behavior scales (Sparrow *et al.* 1984). This established the Vineland's as reliable and valid for the assessment of level of functioning in adults with intellectual disabilities. Despite these strengths, some specific weaknesses of the Vineland's scales when compared to other measures of ability have been

highlighted (Beail 2003). The version of the Vineland's used in this thesis has been replaced by an updated version which addresses criticisms that the previous version, piloted in 1984, was outdated. To complete the Vineland's adaptive behaviour scales a trained interviewer administers the scale with an informant who knows the person with intellectual disabilities, covering a broad range of functioning. It has been suggested that more direct assessments of an individual's functioning would improve the reliability and validity of the Vineland's adaptive behaviour scales (Beail 2003). Whilst this is the case, and more comprehensive batteries of assessments are available, these require considerable more time and resource. One advantage of the Vineland's adaptive behaviour scales is that a trained interviewer can complete it in 20-30 minutes. It is therefore useful as a standardised way to assess level of functioning in circumstances where a more comprehensive battery of assessments is not feasible, such as large-scale research studies, or in busy clinical services.

This study uses four measures of outcome designed to be complementary and provide a battery of assessments relevant of mental disorders experienced by adults with intellectual disabilities. HoNOS-LD (Roy *et al.* 2002) and the CANDID-R (Xenitidis *et al.* 2000) were developed specifically for use with adults with intellectual disabilities. Although they have only been used in a limited number of published research studies, both include items of relevance to the lives of adults with intellectual disabilities and have been shown to be reliable, valid and sensitive to change. In keeping with recommendations on the use of different forms of outcome measures, the HoNOS-LD and CANDID-R are designed to measure different aspects of outcome. HoNOS-LD, like the generic HoNOS, aims to measure a person's health and social functioning, against a theoretical "optimal functional autonomy" (Wing *et al.* 1998). The CANDID-R measures need across the 25 domains (Xenitidis *et al.* 2000). A strength of these two measures is that they cover a broad range of domains that could be impacted upon by psychopathology associated with mental disorders. Thus they avoid the criticism aimed at other measures of outcome that they are limited in scope and place too much emphasis on measuring symptoms.

Two global outcome measures were also used. The GAF and CGI are the two most commonly used global measures in psychopathology research. Since they were not developed for specific use in intellectual disabilities, and the psychometric properties have not been studied it was decided to use both measures. Researchers have raised concerns that GAF scores in intellectual disabilities may be scored down due to the influence of a person's intellectual disabilities on functioning. However, in contrast to previous studies (Oliver *et al.* 2003; Shedlack *et al.* 2005; Hall *et al.* 2006) this study used the recommended modified scoring method (Hurley 2001) which rates the GAF purely on the impact of psychopathology.

Although this thesis used several measures of outcome, there are some available forms of outcome measure that were not used. In a review of different measures of outcome used in non-intellectual disabilities mental disorder research seven relevant categories of outcome measure were identified (Slade 2002):

- well-being e.g. quality of life
- cognition/ emotion- symptom or psychopathology
- behavior- psychopathology and functioning
- physical health
- interpersonal functioning- social functioning and relationships
- society- carer burden, employment and welfare benefits
- services- service use, satisfaction with services and health economics.

Despite certain gaps, overall the measures of outcome used in this thesis provide an assessment relevant to the majority of these categories of outcome. The HoNOS-LD and CANDID-R include items of relevance to cognition/ emotion, behavior, physical health, interpersonal functioning and society. The battery of measures of outcome could have been made more comprehensive by the inclusion of a measure relevant to the categories of well-being and services. Quality of life research is well established in intellectual disabilities research, and several specific quality of life measures have been developed and validated for use. Therefore, future studies would benefit from inclusion of a measure of well-being; for example using the QoLQ (Schalock & Keith 1993) or LSS

(Harner & Heal 1993), used in two of the studies summarised in table 1.5. No measures of service use or satisfaction with services have been developed for use in the field of intellectual disabilities. The use of generic instruments in studies with adults with intellectual disabilities as participants could be considered following research to establish the utility, reliability and validity of such measures.

Perhaps the most significant limitation in the study is the low rate of participation in the follow up research interviews. Of 150 individuals assessed in the UCEDD clinical services 40 (26.7%) consented to participate in the interviews. However, since there were no significant differences in the socio-clinical characteristics of sample 2 and sample 3 the follow up sample is representative. What is less certain is whether a latent difference between participants in sample 2 and individuals who chose not to participate could have biased the results. For example, if individuals were more likely to take part in the follow-up interviews if there had been an improvement from baseline in the psychopathology they experience this could introduce a systematic bias to the findings. Alternatively, individuals may be more likely to participate if they are still using specialist intellectual disabilities services which could mean they continue to experience significant levels of psychopathology. Although it is difficult to be certain of the influence of the attrition rate on the findings, perhaps of greater relevance is giving consideration as to how to improve recruitment rates in future follow up studies.

One methodological change that may improve follow-up would be to reduce the duration of time between interviews. For example, in a recent two-year incidence study of mental disorders the follow-up rate was 70% (Smiley *et al.* 2007). Even if the aim of the study is to follow up participants over a longer period, perhaps contacting participants more frequently would help to improve retention. Serial follow-up research interviews would also give valuable detail on changes in psychopathology over time, and could address the research questions, discussed in section 5.2, about the relationship between psychopathology and age, and developmental aspects of the proposed tripartite model.

5.7 Implications for clinical practice

The findings in this thesis raise several issues of relevance to clinical practice, and the delivery of services, for individuals with intellectual disabilities and mental disorders. Identification of a mixed behaviour-affective dimension in the EFA highlights the importance of comprehensive assessments of psychopathology, whenever an individual presents to services. From this thesis, and other epidemiological studies, it appears that as severity of intellectual disabilities increases the risk and severity of psychopathology also increases. This suggests that mental health promotion interventions should be targeted at individuals with more severe intellectual disabilities. Finally, the follow-up study emphasizes the potential usefulness of incorporating outcome measures into routine clinical practice.

In clinical services, individuals presenting with problem behaviours are often referred to psychologists and psychiatrists see individuals with other forms of psychopathology. This model of service provision could encourage an unhelpful focus on a restricted range of psychopathology when assessing individuals at the time of presentation. The finding that affective and problem behaviour items of psychopathology loaded significantly to a single dimension reinforces the need to assess the full range of psychopathology, regardless of the primary presenting complaint. To achieve this, structured assessments of psychopathology should be used in clinical practice.

The prevention of mental disorders, and mental health promotion, have received increasing attention in national mental health strategies and clinical guidelines. Resources have been provided to educational and clinical interventions to support children and young people to develop resilience, and parenting interventions to improve outcomes for at risk children. Since individuals with more severe intellectual disabilities appear to be at greater risk of mental disorders, consideration should be given to how best to reduce the risk. Some aspects of generic resilience models may be of use. However, it is likely that prevention and mental health promotion interventions for persons with intellectual disabilities will have a broader focus beyond an individual. A

social model of disability would suggest that interventions with parents and families, schools and communities should be considered as well as work with individuals.

Although routine monitoring of outcome in clinical practice is often advocated, it is seldom achieved. Several different outcome measures were used in this study, all of which are appropriate for use in clinical settings. It is unlikely that clinicians would move from not using any measure, to using four. Therefore, it is more realistic to invite clinicians to incorporate one measure of outcome into clinical practice. Although concerns over the use of the GAF in intellectual disabilities have been raised, the revised scoring method (Hurley 2001) described in DM-ID appeared to produce similar results to the other outcomes- including the HoNOS-LD and CANDID-R designed for use in intellectual disabilities. Therefore, since the GAF is linked to the DM-ID, appears to be valid, likely to be familiar to clinicians and takes the minimum time to complete- it may be appropriate to introduce first. Of course, the GAF is limited in scope compared to other measures and it would be hoped that clinicians may use other measures once the value of using the GAF routinely is recognized. Since the GAF is a continuous measure of outcome, its use alongside the prevailing categorical models of psychopathology may be the first step towards incorporating dimensional models in routine clinical practice.

5.8 Future research

This thesis described the first multi-dimensional model of psychopathology experienced by adults with intellectual disabilities; derived using data collected using the PPS-LD. The value of intellectual disabilities psychopathology research has been demonstrated and suggests possible directions of future research. One obvious stream of future research is to further examine the reliability and stability of the dimensional model of psychopathology. Given that problem behaviours have a negative impact on the lives of persons with intellectual disabilities, the finding that problem behaviours was extracted within a behaviour-affective dimension of psychopathology merits further study. Finally, a common theme running throughout the thesis is the challenge of reliably identifying psychopathology experienced by persons with intellectual disabilities. Thus, returning to

a basic level of research to improve methods of self, and informant, report of psychopathology should be considered.

Possible methods to study the reliability and validity of the multi-dimensional model of psychopathology are repeating the EFA described here using a different sample, and the use of confirmatory factor analysis. The only two psychopathology assessment instruments for which more than one EFA has been published are the PIMRA (Matson *et al.* 1984) and the PAS-ADD checklist (Moss *et al.* 1998; Sturmey *et al.* 2004; Hatton & Taylor 2008). Inclusion of items of psychopathology in the PIMRA of questionable validity, the limited range of items in the PAS-ADD checklist and the broader limitations of the methods of EFA used in these studies have been described previously. Therefore, replicating any multi-dimensional model of psychopathology would add significantly to the evidence-base. If possible, using a larger population-based sample, or a random sub-sample of such a sample would maximize the reliability and validity of the multi-dimensional model.

Confirmatory factor analysis (CFA) can be used to examine whether a multi-dimensional model of psychopathology derived using EFA is verified in a separate sample. Although none of the models from previous intellectual disabilities studies have been tested with CFA, it has been used previously to verify the dimensional model of psychopathology in psychosis (Dollfus & Everitt 1998), ADHD in children (Gomez *et al.* 2003) and autism (Frazier *et al.* 2008). Various different methods can be used for CFA but most commonly structural equation modeling is used. Thus the methods of CFA are quite separate from those used in EFA, which might partly explain why few EFA studies in intellectual disabilities have lead on to research with CFA. Either through replicating the EFA or using CFA, examining further the PPS-LD could develop the understanding of the relationship between a putative tripartite model of depression and anxiety psychopathology and problem behaviours.

Another future study of value to understanding the multi-dimensional model of psychopathology would improve the coverage of items of psychopathology included in

the analysis. In particular, including additional items of psychopathology relevant to the presentation of anxiety, and inclusion of problem behaviours in addition to physical and verbal aggression, and self-injurious behaviour in PPS-LD could be considered. As well as potentially improving the validity of any resultant model, this could potentially reveal additional dimensions of psychopathology or higher order dimensions.

Examining the existing research literature, it appears that the relationship between problem behaviours and other forms of psychopathology is of interest to researchers and clinicians alike. This thesis has shown that EFA offers one method to examine this area in more detail. One hypothesis that arises is that problem behaviours are associated with a general distress dimension, within a tripartite model of depression and anxiety psychopathology. As well as future research involving EFA and CFA, methodologies to examine this area could include:

- longitudinal studies involving detailed and frequent assessments of affective psychopathology in individuals with clinically significant problem behaviours. This would inform an understanding of the relationship in time between changes in affect and behaviour
- follow up studies of individuals receiving interventions for the management of disorders presenting with mixed affective psychopathology and problem behaviours. If these two forms of psychopathology are part of a single dimension, and possibly share an underlying pathophysiology, it would be predicted that effective interventions would lead to improvements in both.

Such studies offer an opportunity for close working between intellectual disabilities psychiatrists and psychologists. Both professions have important, and complementary, contributions to make to the study of psychopathology. Bringing together the distinct areas of expertise could potentially lead to new models and management approaches for problem behaviours and other psychopathology.

The inclusion of affective items of psychopathology across the depressive, behaviour-affective and anxiety dimensions suggests examining the relevance of global affective

models of psychopathology. Findings from this thesis support studying models of affect regulation, affective arousal and valence models of affect in relation to psychopathology experienced by persons with intellectual disabilities.

A potential use for dimensional models of psychopathology is in the study of the pathophysiology of mental disorders. Genetic and neurobiological research has already evidenced the relevance of dimensions of psychopathology and endophenotypes to pathophysiology. In the field of intellectual disabilities, this is most likely to be of value in behavioural phenotype research. The use of categorical models of psychopathology has produced potentially important findings in understanding psychopathology experienced by individuals with Prader-Willi syndrome (Soni *et al.* 2008) and Williams syndrome (Einfeld *et al.* 1997; Dodd *et al.* 2009). However, the insights offered by moving beyond categorical models of autism spectrum disorders in individuals with fragile X syndrome (Kaufmann *et al.* 2004; Hagerman 2006), is a useful example of the potential offered by the study of dimensions and endophenotypes. The sample sizes required for EFA may be larger than those in many published behaviour phenotype studies. However, initiative to promote collaboration between researchers working on phenotype, such as the European Prader- Willi syndrome Clinical Research Database (Holland *et al.* 2009), offer an opportunity to examine the relevance of dimensional models of psychopathology to behaviour phenotypes.

5.9 Conclusions

The findings presented in this thesis highlight the value of research on psychopathology experienced by individual with intellectual disabilities. Psychopathology research in the field of intellectual disabilities is at an earlier stage compared to the evidence from studies involving children, adolescents and adults who do not have intellectual disabilities. However, research using categorical and dimensional models of psychopathology can further our understanding of mental disorders experienced by individuals with intellectual disabilities.

Categorical models of psychopathology are integral to existing classification systems for mental disorders. With the improved utility and reliability of categorical diagnostic classification systems it is likely that they will continue to be used for clinical and research purposes. The findings of this thesis suggest that the use of multivariate statistical methods to identify dimensional models of psychopathology can contribute to research examining the validity of categorical diagnostic classification systems. For example, the validity of including "tearfulness" and "reduced verbal communication" in the DC-LD criteria for a depressive episode is supported by item loadings to the depressive dimensions. However, since "increased irritability" did not load to the depressive dimension. Therefore, including *irritable mood* as an alternative to *depressed mood* in the DC-LD criteria for a depressive episode needs further study and validation.

One potential advantage of dimensional models of psychopathology compared to categorical models is improved validity. The results of this thesis are in agreement with previous research suggesting that dimensional models of psychopathology have stronger associations with the severity and outcome of mental disorders, and therefore greater predictive validity. Further research is needed to examine the validity of both categorical models, which are central to diagnostic classification systems, and dimensional models. However, perhaps exploring ways to combine the utility and reliability of categorical models with the advantages for validity of dimensional models offers an opportunity to develop classification systems.

On the basis of the increased prevalence and negative impact on the lives of adults with intellectual disabilities, psychopathology associated with problem behaviors is a priority area for research. This study highlights the relevance of examining problem behaviours within broader models of psychopathology. The findings in this thesis support new research hypotheses on psychopathology experienced by adults with intellectual disabilities. A dimensional model with similarities to the tripartite model of depression and anxiety psychopathology was defined by the exploratory factor analysis. Items representing problem behaviour psychopathology were extracted within the dimension similar to the general distress, rather than the depressive, dimension of the tripartite

model. Few intellectual disabilities studies have studied the relevance of the tripartite model of depression and affective psychopathology. Therefore, further research is required to examine hypotheses that:

- affective psychopathology experienced by adults with intellectual disabilities is best represented by a tripartite model of depressive, anxiety and general distress dimensions.
- problem behaviours are associated with a general distress dimension of psychopathology.

Psychopathology research offers opportunities to develop an understanding of mental disorders experienced by adults with intellectual disabilities. There are advantages to considering novel models, methods and hypotheses alongside those derived from the prevailing categorical model of psychopathology.

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Appendix I Information sheets

SOCIO-CLINICAL OUTCOMES OF PSYCHIATRIC DISORDERS

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a research study. The information sheet tells you about the study. Please read the information sheet, or ask someone to read it with you. This information sheet is for you to keep. It is also available on a tape.

You can talk to your family and friends about the study. Ask them what they think about it.

What will the research study find out?

This research study will find out how mental health problems affect people with learning disabilities.

Why do you want me to take part?

We would like to invite you to take part because you used the Learning Disabilities Psychiatry Service. Your name was given to us by the psychiatrist you met with to talk about your mental health. We would like to speak to people who used the Learning Disabilities Psychiatry Service four to five years ago.

What will the study involve?

A researcher will contact you and ask to visit you. You do not have to meet the researcher. Please let us know if you do not want to see the researcher.

You can ask the researcher questions about the study. The researcher will invite you to decide if you want to take part in the research study. If you say yes, you will be asked to sign a form. You can keep a copy of the consent form.

If you take part, the researcher will arrange to meet you, at a place that is suitable for you. The meeting will last about one hour. If this seems too long for you, you can choose to have two shorter meetings instead.

The researcher will ask you questions about:

- ✓ The things you do in your life, and yourself
- ✓ Any symptoms of mental ill-health you still have
- ✓ The problems caused by mental ill-health

We would like to speak to someone who knows you well like a relative, or carer. We would also like to look at your Learning Disabilities Psychiatry casenotes. This will provide us with information about the time when you first started using the Learning Disabilities Psychiatry Service.

If you have a mental illness which is not being treated we will discuss this. We will offer to arrange an appointment with a psychiatrist from the health service. Your GP could be involved in getting you help for your mental illness.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this if you wish to complain about any aspect of the way you have been treated during the course of this study, the normal National Health Service complaints mechanism will be available to you.

Has ethical approval been granted for this study?

This study has been granted ethical approval by the MREC for Scotland, Committee A, and the local research ethics committee for the Primary Care Division of NHS Greater Glasgow.

Will taking part in the study help me?

If you decide to take part, it won't benefit you now. It may help people with learning disabilities in the future. This study will also help people who plan services.

What will happen if I decide not to take part in the study?

You do not have to take part in this research study. It is OK to say no. If you don't want to take part, this will not affect the care and support you receive.

What if I change my mind and do not want to take part during the study?

You can change your mind about taking part, or stop, at any time. You do not have to give a reason. If you change your mind this will not affect the care and support you receive.

Where would the interviews take place?

If it is OK with you, the researcher will arrange to see you at your home. If you want the researcher can arrange to see you somewhere else.

What will happen to the information the researcher collects?

All the information about you is kept safe. It will be treated with strict confidence. It will be kept secret. They will not tell anyone your name. The information will be kept very safely on a computer. The Data Protection Act will be followed at all times.

What will happen to the results of the study?

When the research study is finished, the research team will write to you about the research findings. They will also write reports about the research. Your name will not be used in the reports. No one will be able to tell from the reports if you took part in the research.

Who is organising the research?

This study is organised by the Learning Disabilities Research Group, at the University of Glasgow.

How can I find out more about the study?

You can ask the researcher questions about the study. The name and telephone number of the researcher are shown below. The names of the members of the research team are below. You can contact them at any time to ask questions.

If you would like to take part please complete the reply slip below. After two weeks we will phone to ask if you would like to take part.

Thank you for taking the time to read this information sheet.

Researcher

Dr Craig Melville
Section of Psychological Medicine, Division of Community Based Sciences, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH.
Telephone: 0141 211 0693

Research Team

Professor Sally-Ann Cooper, Professor of Learning Disabilities, University of Glasgow.
Telephone: 0141 211 0690

Dr. Andrew Jahoda, Senior Lecturer in Learning Disabilities,
University of Glasgow.
Telephone: 0141 211 0693

……

Name ……

Address …….

……..

……..

Telephone Number ……..

I would like to find out more about the study Yes ☐

No ☐

Please return this form to:

Dr Craig Melville
Section of Psychological Medicine
University of Glasgow
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
GLASGOW
G12 0XH

UNIVERSITY of GLASGOW

SOCIO-CLINICAL OUTCOMES OF PSYCHIATRIC DISORDERS

RELATIVE, WELFARE GUARDIAN INFORMATION SHEET

We would like to invite the person with learning disabilities whom you support to take part in a research study. We do not think that this person has the capacity to consent to participate in research. However, under the provisions of the Adults with Incapacity (Scotland) Act you are able to provide consent. Before you make your decision about whether to give consent for them to participate in this study, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with the person with learning disabilities whom you support, and others if you wish. Ask us if there is anything that is not clear or if you would like more information. Please keep this information sheet, which is also available on cassette tape. Thank you for reading this information sheet.

What will the research study find out?

This research study wants to examine the impact and outcomes of mental ill-health on adults with learning disabilities. We would like to find out if the person you support still experiences symptoms of mental ill-health, and learn about any changes, or problems that have come about as a consequence of the mental ill-health they have experienced. No one has ever looked carefully at this before. If we know how mental ill-health affects people with learning disabilities, this will help us to plan the services that might be needed. The study will not be of immediate benefit for the person you support, or you, but it may help people with learning disabilities in the future.

Why do you want the person I support to take part?

The person with learning disabilities whom you support has been invited to take part in the study as he/she has used the Learning Disabilities Psychiatry Service. We were given the name of the person with learning disabilities you support by the psychiatrist, who helped the person you support with their mental ill-health. We would like to speak to as many people as possible, who were assessed by the Learning Disabilities Psychiatry Service between January 2000 and August 2002. We are interested to find out what has happened in the life of the person you support since that time. In addition, we want to look at whether their mental ill-health has improved, and the impact that it has had on their life.

What will the study involve?

The study involves a researcher meeting with the person with learning disabilities whom you support, and a carer where appropriate. This meeting will take approximately one hour. However, if this seems too long, the meeting can be divided into two or more shorter meetings. At this meeting, the researcher will ask questions about the life of person with learning disabilities whom you support, including things they enjoy doing, questions about health and the support they receive, and questions about symptoms of mental ill-health that they still experience.

We would also like to examine the learning disabilities psychiatric casenotes belonging to the person with learning disabilities whom you support. This will provide us with information about the time when the person you support first started using the service, and the way in which they have used the service since then. You will be asked separately to decide whether to give consent to the researcher examining the casenotes of the person with learning disabilities whom you support.

If the information we gather suggests that the person you support has a mental illness which is not being managed we will discuss this with you. The GP of the person you support may be able to help with the problem. We will offer to arrange for an assessment to be carried out by a psychiatrist working for the Glasgow Learning Disability Partnership.

If the person you support is harmed by taking part in this research project, there are no special compensation arrangements. If the person you support is harmed due to someone's negligence, then he/she may have grounds for a legal action but he/she may have to pay for it. Regardless of this if the person you support wishes to complain about any aspect of the way he/she has been treated during the course of this study, the normal National Health Service complaints mechanism will be available to him/her.

Will taking part in the study help me, or the person I support?

If you decide to take part, there will be no direct benefits for you, or the person you support. However, the information we gather from the study may help the people who plan services for people with learning disabilities who experience mental ill-health to provide better services in the future.

What will happen if I decide to give consent to the person I support participating in the study?

If you decide to give consent for the participation of the person you support in this research study, you will be asked to sign a written consent form. You will be given a copy of the consent form to keep. The researcher will then arrange to meet with the person with learning disabilities, and a carer where appropriate.

What will happen if I decide not to give consent to the person I support participating in the study?

You do not have to give consent for the participation of the person you support in this research study. It is OK to say 'no'. If you decide you do not want the person you support to take part in the study this will not affect the care that they receive from the psychiatrist, or from anybody else who provides care or support to that person.

What if I change my mind about the person I support taking part during the study?

You can change your mind about the person you support taking part, at any time. You do not have to give a reason for changing your mind. If you change your mind this will not affect the care the person you support receives from the psychiatrist, or anyone else who provides care to that person.

Where would the interview take place?

The researcher will arrange to meet with the person with learning disabilities at a place that is convenient for them. You may like to help the person with learning disabilities choose where they want to meet the researcher. The researcher could meet the person at the home. If this is not suitable, the researcher will arrange to meet with the person with learning disabilities somewhere that is suitable for them.

What will happen to the information the research team collect?

The research team will keep all the information you provide in strict confidence. No one outside of the research team will have access to the information you provide. The information will be kept very safely on a computer database. The Data Protection Act will be adhered to at all times.

Who is organising and funding the research?

This research study is organised by members of the Learning Disability Research Group at the University of Glasgow. The study was funded by the Baily Thomas Charitable Trust.

Has ethical approval been granted for this study?

This study has been granted ethical approval by the MREC for Scotland Committee A and the local Research Ethics Committee for the Primary Care Division of NHS Greater Glasgow.

What will happen to the results of the study?

We will post out information about the findings of this research study to everyone who takes part, after the study is finished. Findings of this study will also be given to managers of learning disabilities health and social work services. The research findings will be written into reports which will be published. It will not be possible to identify any of the individuals who take part in the study from the reports, as all the information will be anonymised, with information from many individuals grouped together.

How can I find out more about this study?

If you would like to discuss any aspect of this study, or wish to ask any questions please ask the researcher, or contact any of the research team, at any stage of the study.

Thank you for taking the time to read this information sheet.

Researcher

Dr Craig Melville
Section of Psychological Medicine,
Division of Community Based Sciences,
Academic Centre, Gartnavel Royal Hospital,
1055 Great Western Road, Glasgow, G12 0XH.
Tel. 0141 211 3878

Research Team

Sally-Ann Cooper, Professor of Learning Disabilities,
University of Glasgow. Tel. 0141 211 0690

Andrew Jahoda, Senior Lecturer in Learning Disabilities,
University of Glasgow. Tel. 0141 211 3878

SOCIO-CLINICAL OUTCOMES OF PSYCHIATRIC DISORDERS

UNIVERSITY of GLASGOW

CARER INFORMATION SHEET

We would like to invite the person with learning disabilities whom you support to take part in a research study. Please keep this information sheet, which is also available on CD. Before you decide it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What will the research study find out?

This research study wants to examine the impact and outcomes of mental ill-health on adults with learning disabilities. We would like to find out if the person you support still experiences symptoms of mental ill-health, and learn about any changes, or problems that have come about as a consequence of the mental ill-health they have experienced. No one has ever looked carefully at this before. If we know how mental ill-health affects people with learning disabilities, this will help us to plan the services that might be needed. The study will not be of immediate benefit for the person you support, or you, but it may help people with learning disabilities in the future.

Why do you want the person I support to take part?

The person with learning disabilities whom you support has been invited to take part in the study as he/she has used the Learning Disabilities Psychiatry Service. We were given the name of the person with learning disabilities you support by the psychiatrist, who helped the person you support with their mental ill-health. We would like to speak to as many people as possible, who were assessed previously by the Learning Disabilities Psychiatry Service. We are interested to find out what has happened in the life of the person you support since that time. In addition, we want to look at whether their mental ill-health has improved, and the impact that it has had on their life.

What will the study involve?

If the person you support wants to find out more, a researcher will contact them to arrange a time to meet. This meeting would be to discuss the study, and answer any questions about the study. If the person you support does not wish to meet the researcher, please let us know.

The researcher will explain the study to the person you support, and answer any questions. If the person you support chooses to take part in the research project there will be a consent form to sign. He/she will be given a copy of the consent form to keep. The person you support does not have to take part in the project it is OK to say 'no' and this will not affect the care that the person you support receives from the Learning Disabilities Psychiatry Service. Some people with learning disabilities are unable to consent to participation in research. If this is the case, under the procedures of the Adults with Incapacity (Scotland) Act a relative, or welfare guardian will be asked to consider providing consent to participation.

If the person you support chooses to take part in the study, the researcher would like to meet for about one hour. If this seems too long, you can choose to have two or more shorter meetings. At this meeting, the researcher would like to ask questions about aspects of the life of the person you support, including things they enjoy doing, questions about their health and the support they receive, and questions about symptoms of mental ill-health that they still experience.

After meeting the person you support, we would like to examine the learning disabilities psychiatric casenotes belonging to the person that you support. This will provide us with information about the time when the person you support first started using the service, and the way in which they have used the service since then.

If the information we gather suggests that the person you support has a mental illness which is not being managed we will discuss this with you. The GP of the person you support may be able to help with the problem. We will offer to arrange for an assessment to be carried out by a psychiatrist working for the Glasgow Learning Disability Partnership.

If the person you support is harmed by taking part in this research project, there are no special compensation arrangements. If the person you support is harmed due to someone's negligence, then he/she may have grounds for a legal action but he/she may have to pay for it. Regardless of this if the person you support wishes to complain about any aspect of the way he/she has been treated during the course of this study, the normal National Health Service complaints mechanism will be available to him/her.

Will taking part in the study help me, or the person I support?

If the person you support decides to take part, there will be no direct benefits for the person you support. However, the information we gather from the study may help the people who plan services for people with learning disabilities who experience mental ill-health to provide better services in the future.

What will happen if the person I support decides not to take part in the study?

The person with learning disabilities whom you support does not have to take part in this research study. It is OK to say 'no'. If he/she decides not to take part in the study this will not affect the care that the person you support receives from the psychiatrist, or from anybody else who provides care or support to that person.

What if the person I support changes his/her mind about taking part during the study?

The person you support can change his/her mind about taking part, or stop, at any time. He/she does not have to give a reason for changing their mind. If he/she changes their mind about taking part in the study this will not affect the care the person you support receives from the psychiatrist, or anyone else who provides care to that person.

Where would the interview take place?

The researcher will arrange to meet with the person with learning disabilities at a place that is convenient for them. He/she can choose where they want to meet with the researcher. The researcher could meet at the home of the person you support. If this is not suitable, the researcher will arrange to meet somewhere that is suitable for the person you support. The person you support will be invited to choose whether they would like a friend, family member or carer to be present during the interview.

What will happen to the information the research team collect?

The research team will keep all the information you provide in strict confidence. No one outside of the research team will have access to the information you provide. The information will be kept very safely on a computer database. The Data Protection Act will be adhered to at all times.

Who is organising the research?

This research study is organised by members of the Learning Disability Research Group at the University of Glasgow.

Has ethical approval been granted for this study?

This study has been granted ethical approval by the MREC for Scotland, Committee A, and the local Research Ethics Committee for the Primary Care Division of NHS Greater Glasgow.

What will happen to the results of the study?

We will post out information about the findings of this research study to everyone who takes part, after the study is finished. Findings of this study will also be given to managers of learning disabilities health and social work services. The research findings will be written into reports which will be published. It will not be possible to identify any of the individuals who take part in the study from the reports, as all the information will be anonymised, with information from many individuals grouped together.

How can I find out more about this study?

If you would like to discuss any aspect of this study, or wish to ask any questions please ask the researcher, or contact any of the research team, at any stage of the study.

Thank you for taking the time to read this information sheet.

Researcher

Dr Craig Melville
Section of Psychological Medicine,
Division of Community Based Sciences,
Academic Centre, Gartnavel Royal Hospital,
1055 Great Western Road, Glasgow, G12 0XH.
Tel. 0141 211 0693

Research Team

Sally-Ann Cooper, Professor of Learning Disabilities,

University of Glasgow. Tel. 0141 211 0690

Andrew Jahoda, Senior Lecturer in Learning Disabilities,

University of Glasgow. Tel. 0141 211 0693

Appendix II Consent forms

SOCIO-CLINICAL OUTCOMES OF PSYCHIATRIC DISORDERS

PARTICIPANT CONSENT FORM

UNIVERSITY of GLASGOW

This form asks if I will take part in a research study.

A researcher will ask me questions about mental ill-health.

The researchers will keep my information confidential (secret) and safe.

Taking part in the research study won't immediately help me.

Please tick the box if you agree with what it says.

I have been given an information sheet about the study.	Yes	☐
I have asked all the questions I want to.	Yes	☐
I have been given enough answers to my questions.	Yes	☐
I know it is OK to say 'No' to taking part in the study. I don't have to take part. I don't have to say why.	Yes	☐
Saying 'No'will not affect my future health care or support in any way. I know I can change my mind and say 'No' later on.	Yes	☐
I know the research team will write about the study results. I know the results will not include my name. No one will be able to identify me from the results.	Yes	☐

Signed

……

.

Name

……

Date

……

Reviewing your casenotes

We would like to look at your Learning Disabilities Psychiatry casenotes. This will provide information about your use of the clinical service. Only members of the research team will have access to your casenotes. This information will be kept confidential (secret) and safe. If you do not want us to look at your casenotes it is OK.

I am happy for you to look at my Learning Disabilities Psychiatry casenotes. Yes ☐

Signed

……..

Name

……

Date

…….

Researcher

Dr Craig Melville

Section of Psychological Medicine,
Division of Community Based Sciences,
Academic Centre, Gartnavel Royal Hospital,
1055 Great Western Road, Glasgow, G12 0XH.
Telephone: 0141 211 0693
Fax: 0141 357 4899

Research Team

Sally-Ann Cooper, Professor of Learning Disabilities,
University of Glasgow. Tel. 0141 211 0690

Andrew Jahoda, Senior Lecturer in Learning Disabilities,
University of Glasgow. Tel. 0141 211 0693

SOCIO-CLINICAL OUTCOMES OF PSYCHIATRIC DISORDERS

RELATIVE, WELFARE GUARDIAN CONSENT FORM

This form asks if I will consent to my relative, or the person I support taking part in a study.

I have been asked to do this as my relative, or the person I support, does not have the capacity to consent to participation in research. I understand that under the provisions of the Adults with Incapacity (Scotland) Act 2000, I can provide consent to the person participating in the research study.

If I provide consent to my relative, or the person I support, participating in the study, a researcher will ask questions about health and the learning disabilities services.

The researchers will keep all the information confidential. Only members of the research team will have access to the information I discuss.

I understand that if I provide consent, participation in the study won't directly help me, or the person with learning disabilities whom I support.

I am completing this form as the nearest relative/welfare guardian. (Delete as appropriate)

My relationship to the participant is ……

As the nearest relative, I confirm that there is no welfare guardian or nearer relative.	Yes	☐
I have been given an information sheet about the study.	Yes	☐
I have asked all the questions I want to.	Yes	☐
I am satisfied that my questions have been thoroughly answered.	Yes	☐
I know it is OK to say 'no' to taking part in the study. I don't have to take part. I don't have to say why.	Yes	☐

If I say 'no', I know it will not affect the future health care, or support, that the person I support receives.	Yes	☐
If I decide to take part in the study, I know I can still change my mind and say 'no' later on.	Yes	☐
I know the research team will write about the study results. However, the results will not include my name, or the name of the person I support. No one will be able to identify me, or the person with learning disabilities I support, from the results.	Yes	☐
I agree to my relative, or the person I support taking part in the research study.	Yes	☐

Reviewing the casenotes of your relative/the person you support

We would like to look at the Learning Disabilities Psychiatry casenotes of your relative/the person you support. This will provide information about his/her use of the clinical service. Only members of the research team will have access to the casenotes. This information will be kept confidential and safe. If you do not want us to look at the casenotes of your relative/the person you support, it is OK.

I am happy for you to look at the Learning Disabilities Psychiatry casenotes of my relative/the person I support.	Yes	☐

Signed

……

Name

……

Date

……

Researcher

Dr Craig Melville
Section of Psychological Medicine,
Division of Community Based Sciences,
Academic Centre, Gartnavel Royal Hospital,
1055 Great Western Road, Glasgow, G12 0XH.
Telephone: 0141 211 0693
Fax: 0141 357 4899

Appendix II Letter of ethical approval

Multi-Centre Research Ethics Committee for Scotland

Secretariat
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9026
Fax 0131 536 9346
www.corec.org.uk

NHS SCOTLAND

Dr C A Melville
Senior Lecturer in Learning Disabilities
Psychiatry
University of Glasgow
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Date: 24 October 2005
Your Ref.:
Our Ref.: 05/MRE00/70

RECEIVED 26 OCT 2005

Enquiries to: Walter Hunter
Extension: 89026
Direct Line: 0131 536 9026
Email: walter.hunter@lhb.scot.nhs.uk

Dear Dr Melville

Study title: **The socio-clinical outcomes of psychiatric disorders experienced by adults with learning disabilities**

REC reference: **05/MRE00/70**

Protocol number: **1**

Thank you for your letter of 16 October 2005, 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 Chair together with the Vice-Chair and Fr M McManus.

Confirmation of ethical opinion

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

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form. Confirmation of approval for other sites listed in the application will be issued as soon as local assessors have confirmed that they have no objection.

Conditions of approval

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

Approved documents

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

Document	Version	Date
Application		29 July 2005
Investigator CV		
Protocol	1	July 2005
Covering Letter		29 July 2005
Letters of invitation to participant	1	July 2005
GP/consultant information sheet	1	July 2005
GP letter	1	July 2005
Participant information sheet	2	16 October 2005
Carer information sheet	2	16 October 2005
Relative, welfare guardian information sheet	2	16 October 2005
Relative, welfare guardian consent form	2	16 October 2005
Participant consent form	2	16 October 2005
Confirmation of indemnity cover		01 April 2005
Authorisation for funding payment		29 July 2005
CV: Sally-Ann Cooper		

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

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

Statement of compliance

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

REC reference number: 05/MRE00/70-Please quote this number on all correspondence

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

Yours sincerely

Professor Kennedy Lees
Chairman
cc: Mr Brian Rae
Greater Glasgow Primary Care R&D Directorate
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH