The Incidence of Mental Ill-Health in Adults with Intellectual Disabilities

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DECLARATION OF AUTHORSHIP

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

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LIST OF ABBREVIATIONS

ABC	The Aberrant Behaviour Checklist
ABI	Additional Behaviour Inventory
AUDIT	Alcohol Use Disorder Identification Test
AJ	Alison Jackson, Research Assistant
CAMDEX	Cambridge examination for Mental Disorders of the Elderly
CI	Confidence Intervals
CIS-R	Clinical Interview Schedule, Revised
DASH-II	Diagnostic Assessment for the Severely Handicapped
DAS	Disability Assessment Schedule
DBC-A	The Developmental Behaviour Checklist for Adults
DBC-P	The Developmental Behaviour Checklist
DC-LD	Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4th edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision
ES	Dr Elita Smiley, Research Psychiatrist
HBS	Handicaps, Behaviours and Skills schedule
ICD-10	International Classification of Diseases, version 10
ICD-10-DCR	International Classification of Diseases – Diagnostic Criteria for Research, version10
IQ	Intelligence Quotient
JF	Janet Finlayson, Research Assistant
LHCC	Local Health Care Co-operatives
MRC	Medical Research Council
OPCRIT	Operational Criteria Checklist for Psychotic Disorders
PAS-ADD	Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist
PIMRA	The Psychopathology Instrument for Mentally Retarded Adults
PPS-LD	Psychiatric Present State–Learning Disabilities
RSMB	The Reiss Screen for Maladaptive Behaviour
SAC	Professor Sally Ann Cooper
SAD-Q	Severity of Alcohol Dependence Questionnaire
SCAN	Schedules for Clinical Assessment in Neuropsychiatry

SCID-II	Structured Clinical Interview for DSM-IV
UCEDD	Glasgow University Centre for Excellence in Developmental Disabilities
WHO	World Health Organisation

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SUMMARY

Introduction

Adults with intellectual disabilities account for a minor proportion of the population, with reported prevalence rates in developed countries in the range of 3-6 per 1000 adults (Beange & Taplin, 1996; McGrother et al, 2002; McConkey et al, 2006) but have very high health needs and thus make up a proportionally larger section of the population with illness. Although it has been demonstrated that adults with intellectual disabilities have a higher prevalence of mental ill-health when compared to that reported for the general population (Bailey, 2008; Hassiotis et al, 2008; Cooper et al, 2007; Cooper & Bailey, 2001; Lund, 1985a; Corbett,1979), and some studies have shown a degree of persistence of behavioural problems and affective symptoms over time (Thompson & Reid, 2002; Collishaw et al, 2003), there is insufficient evidence to answer the question of whether this high prevalence is due to a high level of enduring mental ill-health or a high incidence of mental health, or indeed a combination of the two. To date, three studies (Holland et al, 2000; Zigman et al, 2004; van Schrojenstein Lantman-de Valk et al, 1997) have measured the incidence of dementia and only one study (van Schrojenstein Lantman-de Valk et al, 1997) has attempted to measure the incidence of affective disorder. No study has measured the overall incidence of mental ill-health in this population.

Similarly, although the population based prevalence studies by Deb et al (2001a), Cooper et al (2007) and Bailey (2008) have identified some associations with mental ill-health (female gender, severe intellectual disabilities, past psychiatric history, not living with a family carer, smoking, life events, urinary incontinence and not having immobility), it is unknown whether some of these factors are cause or effect. No study to date has identified any adult risk factors for the onset of all types of mental-ill health in adults with all levels and causes of intellectual disabilities. As a consequence, our current knowledge of the epidemiology of mental ill-health in this population is limited and almost non-existent with regard to incidence and predictive factors of mental ill-health. The aim of this study was to measure the 2 year incidence rate of all types of mental ill-health in a population based sample of adults with

intellectual disabilities with sufficient numbers to allow investigation of possible predictive factors for the onset of mental ill-health and examine the 2 year chronicity of mental-ill health in this population.

Methods

A large scale population based study of the prevalence of mental ill-health in adults with intellectual disabilities living in Glasgow, undertaken during 2002-2003 (Cooper et al, 2007), provided the opportunity to carry out a prospective longitudinal cohort design study, with the prevalence study providing the sample and baseline data. The sample size was 651 with a cohort retention rate of 70%. All participants were assessed using a two stage process (screening then detailed psychiatric assessment of potential cases) at baseline and at the 2 year follow-up interview. A modified version of the PAS-ADD checklist (Moss et al, 1998), with a reduced threshold for caseness to increase sensitivity, plus a problem behaviour checklist, pervasive developmental disorders checklist, and past 2 years mental health needs questionnaire was used to screen for mental ill-health occurring at any point during the two year follow up. All participants with identified episodes of mental ill-health were referred to the Glasgow University Centre for Excellence in Developmental Disabilities for detailed psychiatric assessment using PPS-LD (Cooper, 1997), checklists for problem behaviour, ADHD and pervasive developmental disorders and the Test for Severe Impairment (Albert & Cohen, 1992) (for possible dementia) and consensus diagnosis according to clinician, DC-LD, ICD-10-DCR and DSM-IV–TR criteria. Incidence and recovery rates were calculated. Standardised incident ratios were calculated by comparing the findings with reported rates for the general population. Stepwise binary logistic regression was used to examine factors independently related to the incidence and chronicity of mental ill-health.

Key results

The two year incidence of episodes of mental ill-health in adults with intellectual disabilities according to clinical diagnosis was 16.3%. This incidence rate is similar to the incidence rate of mental disorders in the general population but the type and proportion of individual disorders that accounted for this rate was

different. Approximately 20% of this incidence rate was accounted for by problem behaviour, the incidence of psychosis, bipolar affective disorder and early onset dementia was very much higher than that reported for the general population with standardised incident ratios of 9.93 (95% CI 2.05-29.02), 100.20 (95% CI 12.14-361.96) and 66.67 (95% CI 18.16-170.69) respectively. The incidence of substance misuse and anxiety disorders was lower than that reported for the general population with standardised incident ratios of 0.04 (95% CI 0.00-0.24) and 0.17 (95% CI 0.06-0.37) respectively, although the lowered rate of anxiety disorders might be due to the methodological limitations of this study. Factors found to be predictive of episodes of mental ill-health (excluding problem behaviour, dementia, and delirium) were, in order of decreasing strength of association: not living with a family carer, not having immobility, mental ill-health in the past, more severe intellectual disabilities, abuse/adversity in adulthood, and urinary incontinence.

A high level of chronic mental ill-health was found with a 2 year recovery rate of only 32.5%. Factors identified as associated with the endurance of mental ill-health (excluding problem behaviours) in adults with intellectual disabilities were, in decreasing order of strength of association: problem behaviour, not having Down's syndrome, not having immobility and smoking.

Conclusions

The overall incidence of mental ill-health in adults with intellectual disabilities is similar to that reported for the general population but the type and proportion of disorders accounting for this is different. There is high level of enduring mental ill-health in adults with intellectual disabilities. It appears that the high point prevalence of mental ill-health in adults with intellectual disabilities compared to the general population is accounted for more by a higher level of endurance of mental ill-health than by a higher incidence. The identification of risk factors for the onset of mental ill-health means that hypothesis based studies, leading on to the development of interventions and then randomised controlled trials are now possible.

Chapter 1 INTRODUCTION

MacMahon & Pugh (1970) defined epidemiology as “the study of the distribution and determinants of disease frequency in humans”. Adults with intellectual disabilities account for a minor proportion of the population as a whole but have very high health needs and thus make up a proportionally larger section of the population with illness. It is generally accepted that they are particularly vulnerable to mental ill-health because of a number of bio-psycho-social and developmental reasons, but to date, epidemiological studies measuring rates and risk factors for mental ill-health in this population have produced very different and at times contradictory results. As a consequence, our current knowledge of the epidemiology of mental ill-health in this population is limited and almost non-existent with regard to incidence and predictive factors of mental ill-health.

1.1 Definition of intellectual disabilities

Intellectual disabilities is defined by the World Health Organisation (WHO) (1993) as “a condition of arrested or incomplete development of the mind, which is especially characterised 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”. The American Psychiatric Association (2004) use the term mental retardation in place of intellectual disabilities and define it as “significantly sub average intellectual functioning with concurrent deficits or impairments in present adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health and safety, with onset before 18 years of age”. Both these definitions, and most other used definitions of intellectual disabilities, have three essential criteria: intellectual impairment, impairment of adaptive behaviour and onset during the developmental period. It is generally accepted (World Health Organisation, 1993) that an IQ measurement more than two standard deviations below the norm i.e. <70, is indicative of significantly impaired intellectual functioning, that impairments in adaptive behaviour are best measured within European and north American Cultures using the

Vineland Adaptive Behaviour Scales (Sparrow 1984) and that the developmental period is defined as before 18 years of age.

There are many different causes of intellectual disabilities. These range from genetic disorders such as Down's syndrome and Fragile X to childhood meningitis and encephalitis, poverty and neglect.

Epidemiological studies that have examined the prevalence of intellectual disabilities have reported varying rates, largely due to differing methodology.

1.2 Review of the prevalence of intellectual disabilities

Measuring the prevalence of intellectual disabilities is a challenging task. The country of study, sample population, age range, definition of intellectual disabilities used and the method of case ascertainment can all have a significant impact on the result. Even the most recent studies have produced a wide range of prevalence rates, with the range of results extending from 3.3 (Beange & Taplin, 1996) to 73 (Gustavson, 2005) per 1000.

Studies measuring the prevalence of intellectual disabilities in developing countries report much higher rates than those carried out in developed countries. Gustavson (2005) found a prevalence rate of intellectual disabilities of 73 per 1000 in a birth cohort of 1476 children born in Lahore, Pakistan in 1984-1986. The children were assessed by psychologists and paediatricians at least twice a year until the age of 12 years. Intellectual disabilities was defined as IQ < 70 but the method of assessment was not described. This high prevalence in developing countries is thought not just to be due to socioeconomic factors. Studies in countries with mixed populations have reported rates of intellectual disabilities that vary depending on race even after controlling for maternal education and income (Croen et al 2001). Increased rates of specific genetic disorders, consanguinity, specific infections and specific nutritional differences occurring in developing countries also contribute. A significant proportion of the additional prevalence in the developing world is accounted for by people with mild rather than severe intellectual disabilities. The

use of culturally inappropriate measures of intellectual functioning is also likely to have contributed to the reported higher rates in developing countries.

The definition of intellectual disabilities has caused considerable controversy over the years. Most definitions include significant intellectual impairment plus difficulties with adaptive behaviour with onset of these two conditions before 18 years of age. Many studies measuring the prevalence of intellectual disabilities have used these principles but have used different definitions of significant intellectual impairment and adaptive behaviour impairment. The American Association on Mental Retardation changed their definition of significant intellectual impairment from an IQ of <84 (1 standard deviation below the mean) to an IQ of <70 (2 standard deviations below the mean) in 1973 and as a result comparing prevalence rates from studies undertaken pre 1973 with those since then is very difficult.

Wide ranging methodology has been used to measure the prevalence of intellectual disabilities. These have included case or administrative registries, birth cohort or prospective studies, cross sectional surveys and population based screening or household surveys.

Case or administrative registries tend to report lower prevalence rates than population based screenings mainly because not all people with intellectual disabilities are known to or in receipt of specialist services, although problems with over counting when cases are not removed following death or geographical move can lead to an overestimation of cases. Case or administrative registries that use multiple sources of information to identify cases are more likely to be representative. For example, Van Schrojenstein et al (2006) used data from intellectual disabilities services supplemented by data from general practitioners and estimated a lifespan prevalence rate of intellectual disabilities of 6.4-7.0 per 1000 in Limburg in the Netherlands and in a study with similar methodology conducted in the UK, Allgar et al (2008) reported a lifetime prevalence rate of intellectual disabilities of 6.4 per 1000. However, Arvio et al (2003), found a prevalence of 4.3 per 1000 using only the register of people using medical, rehabilitation, educational or residential services for people with intellectual disabilities in Finland. In Australia, Leonard et al (2003) identified 14.3 per 1000

children born in Western Australia 1983 -1992 as having intellectual disabilities (defined as IQ<70, or a condition associated with intellectual disabilities or clearly documented as having intellectual disabilities) using information from the Disability Service Commission register and educational records and Petterson et al (2005) in an almost identical study reported a prevalence rate of 15.2 per 1000 children born 1983-1996. Croen et al (2001) used the Department of Developmental Services register to identify 5.2 per 1000 children born in California 1987-1994 as having intellectual disabilities (defined as significantly sub average intellectual functioning, existing concurrently with related limitations in at least two adaptive skill areas, manifest before 18 years and the severity established by a physician or psychologist).

The availability of appropriate services can also have a significant effect on administrative prevalence rates. However, in the UK with national provision of specialist services it seems unlikely that this plays a significant factor in UK reported administrative prevalence rates. McGrother et al (2002) reported an administrative prevalence rate of 3.58 per 1000 adults aged 20 years and over with moderate-profound intellectual disabilities living in Leicestershire, Felce (2004) reported that 4.30 per 1000 persons aged over 16 years were known to Welsh local authorities in 2003, and McConkey (2006) reported a total administrative prevalence for Ireland of 6.34 per 1000 adults aged 20 years and over, with the rate falling to 4.14 per 1000 when only those with moderate-profound intellectual disabilities were considered. Beange & Taplin (1996) reported the total administrative prevalence of intellectual disabilities for adults 20-50 years of age living in North Sydney, Australia, as 3.31 per 1000. Of course, variations in underlying population characteristics could explain the variation in these administrative prevalence rates.

Birth cohorts are not susceptible to over counting but problems with retaining the sample over time can lead to biased results. In addition, most birth cohorts have not followed up children past 12 years of age and thus prevalence rates estimated using this methodology have only been reported for children. Heikura et al (2003) followed a cohort of 9,432 children born in Finland 1985-1986 and found a prevalence rate of intellectual disabilities (defined by intelligence quotient less than 70 based on individually administered standardised

psychometric test or developmental assessment on a clinical basis) of 11.23 per 1000. Also, the prevalence of intellectual disabilities varies with age. Lower values for the pre-school group are reported due to many with mild intellectual disabilities not yet being recognised, there is a peak at 10-14 years and then a noticeable fall in adulthood due to the difficulties in identifying people with mild intellectual disabilities who are no longer at school, the increased mortality of people with intellectual disabilities and the fact that intellectual disabilities is not a permanent condition and there are some people who meet the diagnostic criteria in childhood but develop sufficient adaptive behaviour skills to become independent and do not meet the diagnostic criteria in adulthood. As a result, lifespan or adult prevalence rates cannot be reliably compared to prevalence rates for children.

Cross sectional surveys using a screening tool to identify possible cases from a geographically defined area or a random sample of people from a geographically defined area can be very time consuming and costly but generally produce more reliable results, although this very much depends on the reliability and validity of the screening tool used. Noorbala et al (2004) used random cluster sampling to identify a population based sample of 35,104 individuals aged over 15 years in Iran who then underwent assessment by a General Practitioner to identify “evident intellectual disability”. A prevalence rate of 14 per 1000 was reported but there is some doubt about the reliability and validity of the assessment tool used by the General Practitioners and the definition of “evident intellectual disability”. Christianson et al (2002) undertook a population based cross sectional survey of children aged 2-9 years living in rural South Africa using a validated screening tool followed by paediatric/neurodevelopment assessment of the children who screened positive. A prevalence rate of 35.6 per 1000 was found, although this rate included children with borderline intellectual disabilities (defined by intelligence quotient of 71- 80).

National Household surveys depend upon the householder revealing all relevant information and in intellectual disabilities, often because of the stigma attached to this condition, this can lead to an underestimation of prevalence. The National Health Survey in the USA 1994/1995 identified 7.8 per 1000 as

having intellectual disabilities using an operational definition of intellectual disabilities (Larson et al, 2001) and the National Disability, Ageing and Carers Survey in 1998 in Australia identified 12.5 per 1000 as having intellectual disabilities (White et al, 2005) according to ICD10 diagnostic criteria. The difference in these results is partly explained by the fact that the American study did not include people living in nursing homes, psychiatric facilities or congregate care settings of four or more residents but differences in the interview schedule and definition of intellectual disabilities will also have contributed.

The ideal prevalence study would involve a large population based sample undergoing screening with a reliable and valid screening tool for identifying intellectual disabilities followed up by a formal assessment of intellectual functioning and adaptive behaviour using reliable and validated tools for those identified at screening. Unfortunately this has not happened as yet. However, features and reported rates of the most recent prevalence studies are summarised in Tables 1.1-1.3.

From these studies and bearing in mind the limitations already discussed, it seems likely that the total prevalence of adults with intellectual disabilities in developed countries, such as the UK, lies somewhere within the range 3-6 per 1000 adults. A higher prevalence among male children has been noted (Croen et al, 1995) and it is thought that this gender difference increases up to 15 years of age but then the difference decreases substantially. Among people aged 40 years and over there is no consistent gender difference (Wen, 1997). Many studies have consistently found that the prevalence of intellectual disabilities was strongly associated with socioeconomic status (Roeleveld, 1997) with a higher prevalence of intellectual disabilities in people with lower socioeconomic status.

Table 1.1 Recent studies measuring prevalence of intellectual disabilities in children

Author & Publication year	Age Group	Geographical Area	Sample size	Method of case ascertainment	Definition of ID	Prevalence per 1000				
						mild	moderate	severe	profound	total
Eapen, 2006	3 years	United Arab Emirates	694	Population based cross sectional survey – Denver Developmental Screening Test followed by clinical diagnostic interview	presence of functional limitations in two or more adaptive skill areas as determined by clinical assessment					24.4
Gustavson, 2005	6-10 years	Pakistan	1476	Population based 1984 -1986 birth cohort. Paediatric, psychology and social work assessment of all children	IQ<69 – assessment tools used unknown	62	11 combined			73
El-Hazmi, 2003	<18 years	Saudi Arabia	60630	Population based cross sectional survey – specially designed screening questionnaire followed by clinical assessment and psychometric testing	IQ < 70 on Weschler Intelligence Scale for Children or Stanford Binet Intelligence Test	2.6	6.3 combined			8.9
Leonard, 2003	Children <16 years	Australia	240,358	Population based 1983-1992 birth cohort. Cases identified via record linkage of multiple sources	IQ <70 on formal testing, or has condition known to be associated with ID or clearly documented as having ID	10.6 combined		1.4 combined		14.3 (2.3 unspecified level of ID)
Heikura, 2003	11.5 years	Finland	9351	Population based 1985-1986 birth cohort. Cases identified via data collected on all children since birth	IQ <70 on most recently administered standardised psychometric test or developmental assessment (various tests used)	7.5	1.7	0. 75	1.28	11.2
Christianson, 2002	2-9 years	South Africa (rural)	6692	Population based cross sectional survey in 1993-1996. Screening of all households using the Ten Questions Questionnaire followed by paediatric/ neurodevelopmental assessment	GIQ < 80 measured by Griffiths Scale of Developmental Assessment	29.1	6.4 combined			35.6

Author & Publication year	Age Group	Geographical Area	Sample size	Method of case ascertainment	Definition of ID	Prevalence per 1000				
						mild	moderate	severe	profound	total
Bradley, 2002	14-20 years	Canada	225	Population based screening survey in 1994. Cases identified in two stage procedure – identification of children with developmental problems via service registers followed by psychological assessment.	IQ < 75 provided by Weschler Adult Intelligence Scale-Revised or Weschler Intelligence Scale for Children- Revised or Palmer Scale of Mental Tests	3.5	3.6 combined			7.2
Croen, 2001	4-12 years	USA	4590333	Population based birth cohort 1987-1994. Cases identified via Developmental Service Register	Physician or psychologist established diagnosis of significantly sub average intellectual functioning, existing concurrently with related limitations in at least 2 adaptive skill area, manifesting before 18 yrs					5.2
Stromme, 1998	Median age 10.8 years	Norway	30037	Population based birth cohort 1980-1985. Ascertainment via educational and health services for children with ID, followed by psychometric evaluation.	IQ< 70 based on individual administered IQ test, standardised psychometric test or formal developmental assessment (various tests used)	3.5	1.5	0.4	0.8	6.2
Roeleveld, 1997	5-19yrs	Worldwide	2000-652671	Critical review of 43 prevalence studies. Studies with register-based case ascertainment followed by IQ assessment were included for calculation of mod-profound ID rate but only registered case ascertainment studies with additional research or population based surveys including extended psychometric and diagnostic evaluation were included for calculation of mild ID rate.	IQ < 70 – various evaluation methods	29.8	3.8 combined			33.6

Table 1.2 Recent studies measuring prevalence of intellectual disabilities in adults

Author & Publication year	Age Group	Geographical Area	Sample Size	Method of case ascertainment	Definition of ID	Prevalence per 1000				
						mild	moderate	severe	profound	total
McConkey, 2006	>20 years	Ireland	3,961,701	Population based administrative cross sectional survey using the National Intellectual Disability Database for the Republic of Ireland.	Known to have moderate, severe or profound ID according to ICD 10 definition or else in receipt or in need of ID service	2.2	4.14 combined			6.34
Noorbala, 2004	>15 years	Iran	35,014	Population based cross sectional survey using random cluster sampling. Case ascertainment via semi-structured interview by GP.	Evident intellectual disability as assessed by GP					14.0
Felce, 2004	> 16yrs	Wales	2,360,700	Population based administrative cross sectional survey	Known to local authorities as in receipt or in need of ID service					4.3
McGrother, 2002	>20 years	England	2256	Population based, cross sectional administrative prevalence in 1991	Dependency on specialist services among adults with severe or profound adaptive behaviour problems associated with moderate, severe or profound developmental intellectual impairment	NA	3.6 combined			NA
Beange, 1996	20-50 years	Australia	104, 584	Population based administrative (including primary care) cross sectional survey, Identified cases interviewed by a psychologist.	IQ<70 as assessed on psychological testing (various assessments used)	1.12	2.19 combined			3.31

Table 1.3 Recent studies measuring life span prevalence of intellectual disabilities

Author & Publication year	Age Group	Geographical Area	Size of study population	Method	Definition of ID	Prevalence per 1000				
						mild	moderate	severe	profound	total
Allgar et al, 2008	lifespan	UK	218551	Administrative cross sectional survey including primary care	"Significantly reduced ability to understand new and complex information and a reduced capacity to cope independently"					6.4
Van Schrojenstein Lantman-de Valk, 2006	lifespan	Netherlands	1142679	Population based, administrative cross sectional survey including primary care. Case files of identified cases were examined for evidence of ID.	IQ <70-75, manifested before 18 years and with related limitations in two or more skill areas					6.4-7.0
White, 2005	lifespan	Australia	37580	Population based cross sectional Household survey in 1998. All participants had computer assisted interviewed by non-medical household interviewers.	ICD-10 definition of intellectual disability					12.5
Fujiura, 2003	lifespan	USA	202,560	Non-institutionalised population, cross sectional household survey – national Health Interview Survey 1994/1995 – with follow up disability interview for possible cases.	Operational definition - mental retardation reported or in cases of mild intellectual disability, generalised learning difficulty or specific learning disability was associated with activity limitation or need for formal support					12.7
Arvio, 2003	lifespan	Finland	341,227	Population based administrative cross-sectional survey in 1995	IQ<70 and using ID service	3	0.7	0.6 combined		4.3
Larson, 2001	lifespan	USA	202,560	Non-institutionalised population, cross sectional household survey – National Health Interview Survey 1987-1994-– with follow up disability interview for possible cases.	operational definition -mental retardation reported as the primary cause of limitations in basic activities or for seeking services					7.8

1.3 Mental Health problems in people with intellectual disabilities

In the early part of the 20th Century it was believed that people with intellectual disabilities did not have the cognitive capacity to experience mental health problems (Earl, 1961) and that behavioural disturbances were attributable to their intellectual disabilities. However in the past 25 years there has been considerable interest and effort in advancing our knowledge and understanding of mental health problems in people with intellectual disabilities and it is now accepted that they do experience the same mental health problems as people without intellectual disabilities and that they are in fact more vulnerable.

1.4 Problems in the comparison of studies of mental health problems in adults with intellectual disabilities

To date, epidemiological studies examining prevalence, incidence and factors associated with mental ill-health in people with intellectual disabilities have produced very different and at times contradictory results, mainly because of methodological problems.

An accurate measure of mental health problems in adults with intellectual disabilities requires a valid and reliable measurement of both the intellectual disabilities and the mental health problems.

1.4.1 Identification of study populations

The method of population identification used can have a significant effect on the results of studies measuring the prevalence of mental health problems. Identifying populations from case registers or those in receipt of specifically targeted social funding or an intellectual disabilities service has a valid ascertainment rate for people with moderate-profound intellectual disabilities but is less valid for people with mild intellectual disabilities. Adults with mild intellectual disabilities are not always known to intellectual disability services and are more likely to be known if they have additional problems such as mental illness. This leads to a biased sample. Furthermore, there is considerable variation in the methods used to set up and maintain such case

registers and therefore samples taken from different case registers, even within the UK, are not always directly comparable. Samples taken from long-stay hospitals or outpatient clinics are not representative of the population and typically produce much higher prevalence rates of mental health problems. The ideal method of sample selection would be to screen everyone living in a certain area for intellectual disabilities and then to further screen those identified for mental health problems. This would be very time consuming and costly and to date has not been done.

1.4.2 Definition of mental health problems

In studies of mental health problems in people with intellectual disabilities, many researchers have used terms such as mental illness, mental disorder, psychiatric illness, psychiatric disorder, emotional problems and behavioural disorder without detailed definition. Some have excluded personality disorder and behaviour disorder from their results whilst others have included them. This difference in the types of disorder counted can have a considerable effect on the reported prevalence, incidence and associations and makes interpretation and comparison of the studies very difficult.

1.4.3 Defining onset of mental ill-health

Defining the onset of illness is essential to the epidemiological investigation of illness and in particular to the teasing out of whether factors associated with illness are consequences of the pathological process or possible aetiological factors contributing to the development of illness. Onset of illness occurs when the pathological process begins and the sociobiologic dynamics have become abnormal, whereas the aetiological process can be begin well before then and includes the time period when the likelihood of a disease occurring is increased even though the process is still normal.

It is particularly difficult to define onset of mental illness as mental health symptoms are widespread within the population without being part of a mental illness. Differences in the chosen definition of the onset of illness can lead to quite marked variations in measured rates of illness. One definition is when the

individual first notices symptoms. However, this definition is not appropriate for use in adults with severe intellectual disabilities because of their difficulties in both recognising and reporting their symptomatology. Another definition would be when the individual first receives treatment, but again this would be of limited use in the intellectual disabilities population because of the well known difficulties they have in recognising their symptoms and accessing services. The most useful and most widely used definition of onset of illness is when the individuals' symptoms meet defined diagnostic criteria – but this definition excludes that part of the pathological process that occurs prior to the meeting of the diagnostic criteria and may lead to the missing of important risk factors.

1.4.4 Diagnostic criteria & assessment tools for mental ill-health in Intellectual disabilities

Many studies investigating mental ill-health in people with intellectual disabilities have used diagnostic criteria for mental ill-health that have been developed for use in the general population such as ICD-10 (World Health Organization, 1993) or DSM-IV (American Psychiatric Association, 2000). Although these criteria have been demonstrated to have reasonable psychometric properties they are not entirely appropriate for this population. Both ICD-10 and DSM-IV rely on subjective report of symptomatology and as a result many people with intellectual disabilities thought by clinicians to have a specific disorder do not meet ICD-10 or DSM-IV criteria because they are unable to adequately describe their symptomatology. In response to this problem, many researchers have modified these criteria to make them more suitable for people with intellectual disabilities, but frequently these modifications have not been reported making the interpretation and comparison of such studies unreliable. The recently developed Diagnostic Criteria for Adults with Intellectual Disability (DC-LD) published by The Royal College of Psychiatrists (2001) is an attempt to address this issue. The criteria represent a consensus of professional opinion within the UK and Ireland and have very good face validity, but are yet to be evaluated with regard to their psychometric properties.

The identification and correct diagnosis of mental health problems in people with intellectual disabilities is a complex and highly challenging task even for the

most experienced clinicians. Individuals and their carers have difficulty recognising symptomatology and often do not realise the significance of symptomatology because of a lack of understanding of mental health problems in this population.

Several tools have been developed to assist in the identification of mental health problems in people with intellectual disabilities. Comprehensive, carer completed checklists for psychopathology in adults with intellectual disabilities that have been well researched include:

- The Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Matson et al, 1984)
- The Aberrant Behaviour Checklist (ABC) (Aman & Singh, 1985)
- The Diagnostic Assessment for the Severely Handicapped (DASH-II) (Matson et al, 1991)
- The Reiss Screen for Maladaptive Behaviour (RSMB) (Reiss, 1988)
- The Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD Checklist)(Moss et al, 1998)
- The Developmental Behaviour Checklist for Adults (DBC-A) (Mohr et al, 2005)

The PIMRA is designed to measure psychiatric disorder in adults with mild to moderate levels of intellectual disabilities. It is derived from DSM-III and is available in self-report and informant interview format. It consists of 56 items with a forced choice response of yes/no. It has eight sub-scales and measures seven forms of psychopathology (schizophrenia, depression, psychosexual disorders, adjustment disorder, anxiety, somatoform disorders and personality problems) but does not distinguish “in episode” from “remission”. Its psychometric properties are well established although most of the studies were limited by small sample sizes. It gives a diagnosis, the validity of which has been established for schizophrenia (Sweizy et al, 1995) and depression (Senatore et al, 1985).

The ABC was designed for the measurement of treatment effects and common behaviour problems in adults with intellectual disabilities. It consists of 58 items

but these are limited to observable behavioural phenomenon. It does not measure psychiatric symptoms. It requires completion by a professionally qualified carer. Inter-rater reliability was reported to be low when used in a population with both a psychiatric diagnosis and intellectual disabilities (Rojahn & Helsel, 1991).

The DASH-II measures emotional problems and psychiatric disorder in adults with severe-profound intellectual disabilities. It consists of 84 items that describe aberrant behaviours and psychiatric symptoms, with each item rated on a 3-point Likert scale. Items are derived from DSM-III but as this diagnostic system has limited use in non-verbal adults the validity of some diagnoses made with this scale is questionable.

The RSMB aims to measure maladaptive behaviour and identify individuals who require psychiatric evaluation. It has been used in large populations of adults with mild-profound levels of intellectual disabilities. It consists of 36 items rated on a 3 point scale. Its psychometric properties have been well established but vary across studies (Reiss, 1988; Sturmey et al, 1995) and depending on the sample used (Sturmey et al, 1996).

The PAS-ADD checklist is a screening tool designed for the identification of mental health problems in adults with intellectual disabilities. It is completed by a carer. It has two sections. The first section collects information about life events and the second section lists 29 different psychiatric symptoms which are rated on a four point scale. Its psychometric properties have been examined by the authors as well as independent researchers. It has been described as the most psychometrically sound screening tool (Sturmey et al, 2005) but does not cover all psychiatric disorders, may not identify mild illness and does not identify people with psychosis or bipolar affective disorder in remission.

The DBC-A is a recently developed carer completed checklist of psychopathology for adults with intellectual disabilities which was developed from the existing measure for children with intellectual disabilities, The Developmental Behaviour Checklist (DBC-P) (Einfeld & Tonge, 1992). It has 106 items which are rated on a three point scale. A Total Behaviour Problem

Score is used determine caseness. Reliability studies have shown it to have psychometric properties comparable to the other checklists described above, although it does not yet have any measure of inter-rater reliability between groups of different carers.

The Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) (Moss et al, 1993) is a semi-structured interview with both the person and a key informant, which is designed to detect psychiatric disorder in adults with mod-severe intellectual disabilities. It utilises a scoring algorithm to produce a research diagnosis according to ICD 10, but requires symptoms to be present at the time of the interview so does not reliably diagnose episodic psychiatric disorder such as bipolar affective disorder. Although an interview with a key informant alone is sufficient to generate a diagnosis, the applicability of this is questionable as some categories in ICD 10 rely on subjective report of inner thoughts and feelings. It has been shown to have both reasonable reliability and validity but its use is limited to adults with sufficient verbal ability, the interview is long and the interviewer requires specialist training.

The method used for identifying psychopathology in people with intellectual disabilities can have a significant impact on the rate of illness found. This is demonstrated in a study by Reiss (1990) in which the prevalence rate of mental health problems for the same sample was 11.7% when diagnoses were taken from the case notes, 39% using the Reiss Screen for Maladaptive Behaviour and 59% after clinical assessment. Another confounding factor in identifying mental ill-health in this population is the issue of diagnostic overshadowing, i.e. when mental health symptomatology is mistakenly assumed to be due to the intellectual disabilities rather than an additional mental health problem. This highlights the importance of correctly eliciting and interpreting symptomatology even when assessment tools are used.

The gold standard for assessing and diagnosing psychopathology in adults with intellectual disabilities remains that of a comprehensive assessment carried out by an experienced clinician with specialist training and expertise in mental health problems in this population. We do not as yet have diagnostic criteria with robust psychometric properties that are applicable to this population or an

assessment tool that allows the generation of a diagnosis according to appropriate diagnostic criteria for all levels of ability.

1.5 Prevalence of mental ill-health in adults with intellectual disabilities

Most of the studies that have attempted to measure the prevalence rate of mental health problems in adults with intellectual disabilities have been limited in view of the population chosen for study, the use of inappropriate methods of identification and assessment of cases, the use of inappropriate diagnostic criteria, failure to state whether rates are point, period or life to date prevalence, and small sample sizes. As a result, reported prevalence rates for mental health problems in adults with intellectual disabilities range from 7-97% (Wright, 1982; Borthwick-Duffy & Eyman, 1990; Linaker & Nitter, 1990; King et al, 1994). There have been very few that have used population based samples and of these only three have investigated associated factors (Deb et al, 2001a; Cooper et al, 2007; Bailey, 2008). The next section reviews only the population based prevalence studies that have included the clinical assessment of possible cases.

In a sample of 402 people over 14 years of age, taken from a register of individuals in contact with intellectual disabilities services (which included people with receiving day hospital care and supervised residential care and had a case ascertainment rate of 2.5 per 1000) in the London borough of Camberwell, Corbett (1979) found a total prevalence of ICD-8 mental health problems of 46%. This rate included problem behaviour and past psychiatric disorder but not dementia. The study used an initial screen of the Social and Physical Incapacity Scale (Kushlick et al, 1973). Participants with identified behavioural disturbance or a history of psychiatric disorder in their case notes then underwent psychiatric assessment. Only 40% of the participants had psychological results to confirm the presence of intellectual disabilities (the rest were estimated to have intellectual disabilities on the basis of their self-help skills) so the sample may have included persons without intellectual disabilities. The use of ICD-8 diagnostic criteria means that the reported rate is likely to be an under estimate because of the limitation in using this diagnostic classification system in adults with moderate-profound levels of intellectual disabilities and

limits its comparison with other more recent studies that have used later versions. In addition, ICD-8 was not operationalised. Although 70% of the sample was living in hospital at the time of the study and would not be considered representative in the present day, this was representative of the population at that time.

Lund (1985a) identified a random sample of 302 people aged over 19 years from the Danish National Service for the Mentally Retarded. The register included almost all people with intellectual disabilities in Denmark and all cases on the register fulfilled the World Health Organisation criteria at that time (IQ <85) for a diagnosis of intellectual disabilities. The case ascertainment rate for the register was 4.3 per 1000. Participants were assessed using the MRC handicaps, behaviour and skills schedule (Wing, 1980) supplemented by a checklist of psychiatric symptoms. The MRC handicaps, behaviour and skills schedule is a clinical interview that includes a Vineland Social Maturity Scale (Doll, 1953) and has been shown to have a high inter-rater reliability. It rates autistic and problem behaviours but has only four questions about symptoms of mental illness, hence the need for the additional checklist of psychiatric symptoms. The checklist was devised on the basis of a pilot study consisting of the registration of the symptoms present in 38 patients with well known psychiatric conditions, randomly selected from a hospital for adults with intellectual disabilities. Details of the additional checklist were not described and therefore it is unknown what psychopathology was covered. The results were coded using modified Feighner and DSM-III criteria and restricted to the following diagnoses: schizophrenia, affective disorder, dementia, autism, psychosis of uncertain type, substance abuse, neurosis and behaviour disorder. The modifications made to the diagnostic criteria were not described. A point prevalence rate of 28% was reported. This study is limited by the fact that the assessment schedule used was not designed to produce a diagnosis according to DSM-III, the modifications to the diagnostic criteria are not described at all and approximately 10% of the participants had an IQ above 70. Its strengths are that it was a population based sample and all assessments were carried out by the author.

Cooper & Bailey (2001) identified a random sample of 73 individuals aged 20-64 years and everyone aged 64 years and over from the Leicestershire Intellectual Disabilities Register. The register included all people with intellectual disabilities in contact with health services, social services and private and charitable organisations and had a case ascertainment rate of 2.6 per 1000. The total sample size was 207. Each participant underwent psychiatric assessment by the author, using a variety of semi-structured interview tools and diagnoses were classified according to ICD-10 Research Diagnostic Criteria (ICD-10-DCR). Clearly described modifications to the diagnostic criteria to make them more appropriate for adults with intellectual disabilities were made by the author. All participants had their level of adaptive behaviour formally assessed using the Vineland Adaptive Behaviour Scales (survey form) (Doll, 1953) and the presence and level of intellectual disabilities was confirmed by the author at clinical assessment. A lifetime prevalence rate for all psychiatric disorders including possible dementia, Rett's syndrome and problem behaviour of 49.2% was reported. However, this data has since been re-reported (Cooper et al, 2007) with a point-prevalence (excluding possible dementia and Rett's syndrome) of 37.0%. Limitations of this study are the small sample size, the reporting of lifetime rather than point prevalence rate for depression and the inclusion of possible dementia and Rett's syndrome. Its strengths are the population based sample, detailed psychiatric assessment by the author and the clear statement of the diagnostic criteria used.

Deb et al (2001a) identified a random sample of 101 adults with intellectual disabilities aged 16-64 years from a local social services register in Wales. Case ascertainment rate for the register was 3.2 per 1000. Of these, 90 were screened using the Mini PAS-ADD (Prosser et al, 1998) and those that were identified as possible cases then underwent the full PAS-ADD interview (Moss et al, 1993). Eleven participants with severe intellectual disabilities were excluded because of the questionable validity in using the PAS-ADD interview in this population but were assessed using the DASH questionnaire with two (18%) given a psychiatric diagnosis according to the questionnaire. Diagnoses were classified according to ICD-10 criteria (without any modifications). A point prevalence rate of 14.4% was reported. This rate excludes autism, ADHD, problem behaviour, personality disorder, dementia, autism, alcohol problems

and schizophrenia and bipolar affective disorder not in episode. These exclusions were made to allow valid comparisons with prevalence rates of psychiatric illness reported for the general population. The rate does not exclude, but does not include obsessive compulsive disorder as the PAS-ADD interview does not provide a diagnosis of this disorder. The rate of psychosis, particularly schizophrenia, was found to be significantly higher in the cohort compared to the general population. The rate of phobic disorder was also significantly higher. Limitations of this study include the small sample size, the exclusion of adults with severe intellectual disabilities, register bias, the exclusion of multiple diagnoses and the lack of formal assessment of intellectual disabilities. Its main strength is the use of a validated screening and diagnostic instrument, although the validity of this tool for diagnosing schizophrenia in adults with intellectual disabilities is questionable.

In a large scale epidemiological study by Cooper et al (2007), a population based sample size of 1023 was achieved. This is the largest population based prevalence study to date and was the preliminary work to this thesis. The methods of the prevalence study were identical to that of this thesis and are described in detail in the methods section. Briefly, participants were identified via a comprehensive case ascertainment process within Greater Glasgow Health Board, UK. All adults with intellectual disabilities, known to health or social services, in receipt of paid support or in contact with voluntary organisations were identified. In addition, General Practitioners were asked to identify any adults with intellectual disabilities on their lists and were paid an item of fee per person identified. In Scotland, almost everyone is registered with a General Practitioner. The case ascertainment rate was 3.33 per 1000. Participants underwent a detailed health check which included the use of the PAS-ADD checklist and screening questions for autism and problem behaviours. Any participant identified as having a possible mental health problem was then referred for psychiatric assessment. Psychiatric assessment included the use of the semi-structured psychopathology schedule Psychiatric Present State-Learning Disabilities (PPS-LD) (Cooper, 1997), other purpose designed instruments to collect symptom details for problem behaviours, ADHD and autism, and the Vineland Adaptive Behaviour Scales (Survey Form). Diagnoses were classified according to the clinician's opinion, DC-LD (Royal

College of Psychiatrists, 2001), ICD-10 and DSM-IV diagnostic criteria. Point prevalence rates were reported for each diagnostic criterion with a total prevalence rate (including problem behaviour) of 40.9% for clinician diagnosis, 35.2% for DC-LD diagnosis, 16.6% for ICD-10-DCR diagnosis and 15.7% for DSM-IV-TR diagnosis. The research psychiatrist, Dr Elita Smiley (ES) was responsible for all of the mental ill-health related data and a considerable portion of the psychiatric assessments for this study.

Bailey (2008) identified all adults aged 19 years and over using intellectual disabilities services in the administrative district of North Northamptonshire, England using a process of active case finding. Multiple sources including a variety of health, social work, independent sector and voluntary organisations that provide services for adults with intellectual disabilities were used. As the process is likely to have identified all adults with moderate-profound intellectual disabilities but not all people with mild intellectual disabilities, people with mild intellectual disabilities were excluded from the results. The case ascertainment rate for adults with all levels of intellectual disabilities was 3.7 per 1000 total population. A random sample of 240 was taken from the identified 984 and of these, 121 with moderate-profound intellectual disabilities then underwent clinical assessment that included use of Vineland Adaptive Behaviour Scales (survey form) (Doll, 1953) to confirm presence of intellectual disabilities, a semi-structured assessment of psychopathology using the Psychiatric Present State-Learning Disabilities (PPS-LD) (Cooper, 1997) a checklist for features of autism and the Behaviour Problem Section of the Disability Assessment Schedule (DAS) (Holmes et al, 1982). Clinical diagnoses were made by the intellectual disabilities psychiatrist who carried out all of the interviews. Diagnoses were also made according to DC-LD, ICD-10-DCR and DSM-IV by the author checking symptoms gathered on the PPS-LD, autism checklist and DAS against the relevant diagnostic criteria. The overall rate of psychiatric disorder was reported as 61.2% for clinical diagnosis, 57.0% for DC-LD, 24.8% for ICD-10-DCR and 13.2% for DSM-IV. The main strengths if this study are the comprehensive case finding method, the use of standardised instruments by one intellectual disabilities psychiatrist ensuring a degree of reliability and the use of multiple diagnostic systems allowing comparison with other studies.

However, the study is limited by the small sample size and exclusion of adults with mild intellectual disabilities.

Hassiotis et al (2008) used data from the Second British National Survey of Psychiatry Morbidity (Singleton et al 2000) to examine the prevalence of psychiatric disorders in adults with borderline intellectual disabilities. The survey used a random sample of private households across the UK to generate an eligible sample of 12792 adults aged 16-74 years, 8450 (66%) of whom agreed to participate. A two stage interview process was used to assess the presence of psychiatric disorder. Intellectual functioning was assessed using the National Adult Reading Test (Berry et al, 1994) and borderline intelligence defined as IQ in the range 70-84. Non-psychotic psychiatric disorder was assessed at the first interview using the Clinical Interview Schedule-Revised (CIS-R) (Lewis et al, 1992) which provided diagnoses of depressive episode, obsessive compulsive disorder, panic disorder, phobic disorder, generalised anxiety disorder and mixed/anxiety depressive disorder. Alcohol misuse was assessed at the first interview using the Alcohol Use Disorder Identification Test (AUDIT) (Babor et al, 1992) and the Severity of Alcohol Dependence Questionnaire (SAD-Q) (Stockwell et al, 1983). Drug use was assessed by five purpose designed questions to assess drug dependence at the first interview. Participants identified at the first interview as having possible psychosis or personality disorder were assessed by a psychologist using the Schedule for Assessment in Neuropsychiatry (SCAN) (WHO, 1999) or Structured Clinical Interview for DSM-IV (SCID-II) (First et al, 1997) respectively at a second interview.

One thousand and forty adults (12.3% of the sample) were identified as having borderline intelligence and of them 19.7% had a common mental disorder as measured by CIS-R (>12), 0.8% had probable psychosis, 37.4% had personality disorders, 9.5% had alcohol dependence and 5.5% had drug dependence. The overall rate of psychiatric disorder was not reported for the group with borderline intellectual disabilities. The rate of common mental disorders, personality disorders and substance misuse was significantly higher in the group with borderline intellectual disabilities compared to their counterparts of normal intelligence. The main strengths of this study is the use of a nationally representative sample and the use of standardised clinical

assessments. However, as the study was designed to specifically investigate mental ill-health in adults with borderline intellectual disabilities it cannot be generalised to adults with mild-profound intellectual disabilities.

The above prevalence studies have differing but significant limitations. All have demonstrated a high prevalence of mental health problems in adults with intellectual disabilities. The population based studies with clinical assessment that report overall rates of psychiatric disorder are summarised in Table 1.4.

1.6 Prevalence of problem behaviours in adults with intellectual disabilities

Most of the population based prevalence studies measuring mental health problems in adults with intellectual disabilities have included problem behaviours in the overall rate but Deb et al (2001a) did not. Lund (1985a) reported a rate of 10.5% for behaviour disorder, Cooper & Bailey (2001) 15.1% for DC-LD problem behaviour, Cooper et al (2007) 18.7% for DC-LD problem behaviour and Bailey (2008) 27.3% for DC-LD problem behaviour.

Other studies of the prevalence of problem behaviours have shown a much wider range of results, with reported prevalence rate ranging from 7.6 (Borthwick Duffy, 1994) to 63.9% (Smith et al, 1996). This wide variation reflects the diversity and limitations of the studies, and differences in methodology, preventing comparison of much of the data. Examples include differences in populations, such as institutionalized or community populations; differences in age group; retrospective collection of data from clinical notes and computer databases compiled for other purposes; failure to perform specialist assessments; lack of assessment tools; the use of idiosyncratic definitions: failure to use population appropriate classification systems and failure to exclude problem behaviours that are only symptoms of mental ill-health.

Table 1.4 Population based studies measuring overall prevalence of mental health problems

Study	Sample Size	Age range/source (ascertainment rate)	Level of ID	Diagnostic Criteria	Diagnostic restrictions	Prevalence %
Corbett 1979	402	>14 years Services Register (2.5 per 1000)	Mild-profound	ICD-8	lifetime prevalence that excludes dementia	46
Lund 1985a	302	>19 years National Register (4.3 per 1000)	Borderline-profound	Modified Feighner DSM-III	diagnoses restricted to schizophrenia, affective disorder, dementia, autism, psychosis of uncertain type, substance abuse, neurosis and behaviour disorder	28
Cooper & Bailey 2001	207 (134 aged >64yrs, 73 aged 20-64yrs)	>19 years Services register (2.56 per 1000)	Mild-profound	Modified ICD-10		37
Deb 2001	101	16-64 years Services register (3.2 per 1000)	Mild-moderate	ICD-10	excludes dementia, problem behaviour, personality disorder, autism, substance misuse, OCD, autism, ADHD	14.4
Cooper 2007	1023	> 16 years Population based (from register and primary care) (3.33 per 1000)	Mild-profound	Clinician DC-LD ICD-10-DCR DSM-IV-TR	excludes specific phobia	40.9 35.2 16.6 15.7
Bailey 2008	121	>19 years Active case finding through multiple sources (3.7 per 1000)	Mod-profound	Clinician DC-LD ICD-10-DCR DSM IV		61.2 57.0 24.8 13.2

The relevant features of the population-based problem behaviour prevalence studies in adults with intellectual disabilities are detailed in Tables 1.5.1 and 1.5.2. The studies suggest that problem behaviours occur in 10-20% of adults with intellectual disabilities.

1.7 Risk markers for mental ill-health in people with intellectual disabilities

Although there have been several studies documenting the prevalence of mental ill-health in people with intellectual disabilities, very few have measured the development or chronicity of mental-ill health in this population and even less have measured incidence. As a result, current knowledge on risk markers for mental-ill health in people with intellectual disabilities is seriously deficient and at this point in time only associations and not predictive factors have been reported. Some cross sectional studies have examined factors associated with mental ill-health in people with intellectual disabilities but many have not included population based samples or accounted for the interdependency of variables examined and much of the literature to date is contradictory.

1.7.1 Risk Markers from cross sectional surveys: level of ability

Some studies have found a higher rate of mental ill-health in people with mild intellectual disabilities (Bouras & Drummond, 1992; Jacobson, 1990; Borthwick-Duffy & Eyman, 1990; Iverson & Fox, 1989) but these have all been subject to bias by using referrals to community teams or not all subjects undergoing psychiatric assessment with reliance on clinical diagnoses entered on to administrative databases. Even population based studies with clinical assessment have produced conflicting results. Cooper & Bailey (2001) and Lund (1985a) found a higher rate in people with more severe intellectual disabilities but Corbett (1979) found a similar rate in adults with mild and severe intellectual disabilities and Deb et al (2001a) found a similar rate in adults with mild and moderate intellectual disabilities. However, more recently, a much

Table 1.5.1 Reported Prevalence Rates for Problem Behaviours in individuals with Intellectual Disabilities:1

Author	N	Population	Assessments	Findings
Lund, 1985a	302	Danish National Service Register, random sample of > 22,000 Adults over 20 yrs	MRC-HBS Psychiatric assessment	Behaviour disorder in 10.9%
Lund, 1989	324	Danish National Service Register, random sample of > 22,000 Adults over 20 yrs	MRC-HBS Psychiatric assessment	Behaviour disorder in 17.2% Some kind of deviant behaviour in 41%
Qureshi & Alborz,1992	694	North Western Regional Health Authority, England, UK All ages	Operationalised definition Identification and interview of all ID services Key informant interview	Behaviour problems in 16.7% (65% Physical Attacks, 46% Self Injurious Behaviour, 54% Destruction and 89% other unacceptable behaviour)
Borthwick Duffy,1994	91,164	California Dept of developmental Services register All ages	Client Development Evaluation Report, client database	One or more 'Destructive" Challenging Behaviours occur in: 7.6% - mild ID 13.6% - moderate ID 22.0% - severe ID 32.9% - profound ID
Emerson & Bromley,1995	70	Administrative sample Ages 5 – 58yrs	Operationalised definition Behaviour Problems Inventory Survey of services and key informant interview	PB & ID in 3.3 per 10 000 general population 44% more than one form of PB 26% two PBs 13% three PBs 4% four PBs
Smith et al,1996	2,202	Case Register, UK Adults aged 18 – 93yrs	Disability Assessment Schedule Key informant interview	63.9% at least one current MAB 34.9% at least one MAB which is severe or frequent
Emerson et al, 1997	4,200	North Western Regional Health Authority, England, UK All ages	Operationalised definition Identification and interview of all ID services Key informant interview	10-15% of people with ID in contact with services have PBs 1.91 people per 10,000 general population with severe PB 5.7% adults with ID have PB - 64% of those identified have more demanding PB
Deb & Joyce, 1998	143	Adults with ID and epilepsy South Wales health district, UK	'Behavioural problem' Retrospective case note review +/- carer interview No structured assessment used	55% behavioural problems

Notes: PBs = Problem Behaviours; ID = Intellectual Disability; MRC-HBS = Medical Research Council schedule of Handicaps, Behaviours and Skills; MAB = Maladaptive Behaviour, DC-LD = Diagnostic Criteria for use in adults with Intellectual Disabilities, DAS = Disability Assessment Schedule

Table 1.5.2 Reported Prevalence Rates for Problem Behaviours in Individuals with Intellectual Disabilities:2

Author	N	Population	Assessments	Findings
Deb, Thomas & Bright, 2001b	101	Social Services Register, random sample Adults 16 – 64yrs	Disability Assessment Schedule Face to face interview	60.4% any behaviour
Emerson et al, 2001	264	Total population study All ages	Challenging Behaviour Survey, Individual Schedule, Part 2 & 3 Identification and interview of all ID services: Key informant interview	10 – 15% of people with ID have PBs Behaviour more challenging in 5-10% of people with ID 5.6 per 10,000 base population
Joyce et al, 2001	448	Adults with ID in 3 London boroughs screened for PB	Challenging Behaviour Checklist Identification and interview of all ID services: Key informant interview	Approx. 19% prevalence PB in ID population 6 – 7 per 10, 000 population ID & PB 20 per 10 000 population overall prevalence severe PB and ID
Cooper & Bailey 2001	207	Sample of Adults with ID known to services in Leicester, UK 134 aged >64yrs, 73 aged 20-64yrs	Structured Psychiatric assessment with operationalised definition of behaviour disorder	15.1% prevalence for all types of behaviour disorder
Holden & Gitlesen, 2006	904	Service users of local Health Authority: children and adults	Postal questionnaire – Challenging behaviour survey: Individual schedule	11.1% had problem behaviours
Lowe et al, 2008	901	7 unitary authority areas, South Wales: children over 5yrs and adults	Potential cases identified by all ID services; primary carer interview with Individual Schedule, and Disability Assessment Schedule	4.5 people per 10,000 population (10% of ID population) seriously challenging behaviour
Cooper et al 2007	1023	11 health authority areas in Glasgow, UK. Adults aged >16yrs identified via service register and primary care.	Participants screened with purpose designed PB checklist. Identified potential cases underwent structured psychiatric assessment. Diagnosis according to DC-LD	18.7% prevalence of all types DC-LD problem behaviour
Bailey 2008	121	Random sample from services register in North Northampton shire, UK. Adults with mod-prof ID aged 19yrs and over	Structured psychiatric assessment & Behaviour Problem Section of DAS. Diagnosis according to DC-LD	27.1% prevalence of all types DC-LD problem behaviour

Notes: PBs = Problem Behaviours; ID = Intellectual Disability; MRC-HBS = Medical Research Council schedule of Handicaps, Behaviours and Skills; MAB = Maladaptive Behaviour, DC-LD = Diagnostic Criteria for use in adults with Intellectual Disabilities, DAS = Disability Assessment Schedule

larger study by Cooper et al (2007) used stepwise logistic regression analysis to examine independent associations with psychiatric disorder in 1023 adults with mild-profound intellectual disabilities, and reported that more severe intellectual disabilities was significantly associated with mental ill health. This finding has since been replicated by Bailey (2008) who also used stepwise logistic regression analysis in her study of 121 adults with mod-profound intellectual disabilities, reporting a significantly lower developmental level in the group with mental ill-health. These latter findings are the most robust to date but require further replication and cannot be assumed to be anything more than associations.

1.7.2 Risk Markers from cross sectional surveys: age

Several studies have found no differences in the age distributions of groups with and without mental ill-health (Cooper et al, 2007; Bailey, 2008) but Cooper (1997) found a higher prevalence in older adults whilst Day (1985) found a lower prevalence in older adults. Cooper (1997), using the same sample and methods as Cooper & Bailey (2001) found the prevalence of psychiatric morbidity to be 68.7% in a group aged over 64 years and 47.9% in a group aged 20-64 years, with most of the additional morbidity accounted for by increased rates of depression and dementia. Day (1985), in a retrospective case note survey found a rate of psychiatric disorder of 30% in 357 long stay hospital residents aged 40 years and over with intellectual disabilities. He reported a progressive fall in the prevalence of psychiatric disorder with age which is in contrast to the finding of a statistically significant association between the rate of psychiatric illness and increasing age by Deb et al (2001a) although no allowance for the interdependence of variables was made in Deb's analysis. As Day's study included only hospital residents, relied on case note diagnoses and included some cases with borderline intellectual functioning (IQ>70) his finding needs to be interpreted with some caution. Factors likely to increase the prevalence of mental health problems in older adults with intellectual disabilities include increasing sensory deficits and physical health problems with age, the cumulative effect of life events and the association of certain psychiatric conditions such as dementia, with age. However, the effect

of differential mortality probably operates in the other direction. Larger studies with better methodology and sufficient numbers to allow examination of specific disorders and age categories are required to determine whether any age group is more at risk than others.

1.7.3 Risk Markers from cross sectional surveys: gender

The possible relationship between gender and mental ill-health in this population is also still unclear. A large cross sectional study found that gender was unrelated to the overall rate of mental ill-health in people with intellectual disabilities, (Borthwick-Duffy & Eyman 1990) but this study, although it had a very large sample size at 78,603 is limited by its reliance on clinical diagnoses entered on to a service register. Bailey (2008), Iverson & Fox (1989), and Deb et al (2001a) used population based samples and included some form of clinical assessment, but all failed to find any association between gender and the overall rate of psychiatric disorder. This may well be explained by the small sample sizes and/or the effect of measuring mental ill-health as a whole rather than looking at individual disorders. In the general population female gender is associated with a higher rate of affective and anxiety disorder, whereas male gender is associated with a higher rate of substance misuse and personality disorder (Kessler et al, 1994) and autism. If this finding also applies to adults with intellectual disabilities, it would suggest that any gender difference might be cancelled out when looking at overall rates. However, the large population based prevalence study that included clinical assessment carried out by Cooper et al (2007), found that female gender was significantly associated with mental ill-health. Further population based studies with sufficient numbers to allow the examination of gender differences for specific psychiatric disorders is required.

A meta-analysis of prevalence and cohort studies in children and adults with intellectual disabilities over the last 30 years by McKlintock et al (2003) specifically looked at risk markers for problem behaviours. The meta-analysis included 22 studies and found in two studies that males were significantly more likely to show aggression than females and that individuals with severe/profound intellectual disabilities were significantly more likely to show self-injury and stereotypy. It also found that individuals with a diagnosis of

autism were significantly more likely to show self injury, aggression and disruption and individuals with deficits in receptive and expressive communication were significantly more likely to show self–injury. However, these were not independent associations and the factors overlap to a degree.

1.7.4 Risk Markers from cross sectional surveys: epilepsy

While in the general population it is widely accepted that epilepsy confers an increased risk for mental health disturbance (Titlic et al, 2009), particularly depression and anxiety, and to a lesser extent with bipolar affective disorder and psychosis, in the intellectual disabilities population the relationship between epilepsy and mental ill-health is less clear. Lund (1985b) and Corbett (1979) both found a higher rate of psychiatric disorder in those with epilepsy compared to those without epilepsy, but the large population based study by Cooper et al (2007) that examined independent variables associated with mental ill-health, failed to identify epilepsy as a significant factor. Similarly, Deb et al (2001a) and Deb & Joyce (1998) found no increased rate of problem behaviour or psychiatric illness for adults with intellectual disabilities and epilepsy. Deb & Joyce (1998) retrospectively collected data on the rate of psychiatric illness in 143 adults with intellectual disabilities and epilepsy. The sample was population based with cases identified via agencies providing community based services for adults with intellectual disabilities as well all specialist health services in the area. A purpose designed questionnaire was used together with information from participants, carers and case notes. Retrospective ICD-10 psychiatric diagnoses were made based on the information gathered. 12.6% had a psychiatric diagnosis and 55% had some kind of behavioural problem. The authors compared these rates with various other studies of psychiatric disorder in adults with intellectual disabilities and concluded that the rate of psychiatric disorder in adults with intellectual disabilities and epilepsy was lower and that the rate of behavioural disorder in adults with intellectual disabilities and epilepsy was similar. Deb & Joyce (1998) also found that epilepsy related factors, such as seizure type or frequency did not significantly influence the rates.

1.7.5 Risk Markers from cross sectional surveys: life events and abuse

There has been considerable recent interest in the study of life events in people with intellectual disabilities with several studies examining the relationship between life events and psychiatric symptomatology.

In a study examining the association between life events and behaviour problems in 93 long stay hospital residents in the UK (Owen et al, 2004), cumulative life event scores were found to correlate with aggressive/destructive behaviour but not with self injurious or stereotyped behaviour. The researchers developed their own list of life events and used the PAS-ADD Checklist (Moss et al, 1998) and the Behaviour Problems Inventory (Rojahn et al, 2001) to measure psychopathology and problem behaviour respectively. Significantly more life events were experienced in the preceding 12 months by those who scored above the PAS-ADD checklist cut-off for the affective/neurotic sub-scale compared to those that scored below the cut off.

Hastings et al (2004) examined a large population based sample of 1155 adults with intellectual disabilities and found that one or more life events in the preceding year was significantly associated with a score above threshold on the affective/neurotic sub-scale of the PAS-ADD checklist (Moss et al, 1998) but not with a score above threshold for the organic or psychotic disorder subscales.

A weak but signification association between life events in the preceding two years and emotional and behavioural problems as measured by the Developmental Behaviour Checklist for Adults (DBC-A) (Mohr et al, 2005) was found by Hamilton et al (2005) in a sample of 264 adults with intellectual disabilities in Victoria, Australia. The researchers also reported a positive linear correlation between the number of life events experienced and the DBC-A total score.

Esbensen & Benson (2006) examined a sample of 104 adults with borderline – severe intellectual disabilities recruited from agencies providing services for adults with intellectual disabilities as part of a larger study on the development

of depression. They found that life events were associated with problem behaviour and depressive symptoms but then went on to repeat the measures 4 months later and found that life events in the preceding 4 months predicted problem behaviours and depression, even when controlling for past levels of depressive symptoms and behavioural problems. The Life Experiences Survey (Sarason et al, 1978) provided data for life events and the Anxiety, Depression and Mood Scale (Esbensen et al, 2003) and the Assessment of Dual Diagnosis (Matson & Bamburg, 1998), both of which contain sub-scales relating to depression, were used to measure depression. The Scales of Independent Behaviour-Revised (Bruininks et al 1996) was used to provide data on problem behaviours. Although this study provides some prospective data on the relationship between life events and problem behaviours and depression, it is limited by the inclusion of life events during only the previous 4 months, the use of a life events schedule that is not specific to intellectual disabilities and the over-representation of participants with borderline or mild intellectual disabilities.

Martorell et al (2009) investigated the association of life events and traumatic experiences across the life span and psychiatric disorder in a sample of 177 adults attending sheltered workshops for adults with intellectual disabilities in Madrid. Data on life events during the preceding 12 months and psychiatric symptoms present at the time of assessment was collected using the semi-structured Psychiatric Assessment for Adults with Developmental Disabilities (PAS-ADD) (Moss et al, 1993). In addition, the Trauma History Screen (Allen et al, 1999) was administered to key informants. Binary logistic regression analysis showed that exposure to life events or to one or more traumatic experiences significantly increased the odds of an ICD-10 psychiatric disorder. However, when life events and traumatic experiences were entered together in the model, life events were no longer significant. This finding may be due to the fact that life span traumatic events were counted whereas just life events in the preceding 12 months were counted, plus the likely overlapping of events. The study sample consisted only of adults with mild-moderate intellectual disabilities and was not population based so has limited generalisability.

Cooper et al (2007) examined the relationship between the number of life events in the previous 12 months, recorded using the life events section of the

PAS-ADD checklist, and the presence of psychiatric disorder in a large population based study of adults with mild-profound intellectual disabilities living in Glasgow. Logistic regression analysis was used with more life events in the previous 12 months being found to be significantly independently associated with the presence of psychiatric disorder. However, Bailey (2008) in her study examining the prevalence of psychiatric disorder in a sample of 121 adults with moderate-profound intellectual disabilities living in Northamptonshire, failed to demonstrate a significant independent association between any life event in the past year and DC-LD psychiatric disorder. Details on how life events were recorded are not described by the author which limits the interpretation of this finding.

A case control study by MacHale & Carey (2002) involving 20 adults with intellectual disabilities who had experienced the death of a primary care giver in the previous 2 years, found that compared to non-bereaved controls, the bereaved group had significantly higher scores on the affective/neurotic and organic disorder subscales of the PAS-ADD checklist (Moss et al, 1998). When comparing a group of 50 people with intellectual disabilities who had been bereaved with a matched control group, Hollins & Esterhuyzen (1997) also found a higher rate of depression, anxiety and adjustment disorder, as recorded on the Psychopathology Instrument for Mentally Retarded Adults (Matson et al, 1984), in the bereaved group. However, that group had also experienced more life events, which may have affected this result and many of the symptoms identified are likely to have occurred as part of a normal grief reaction.

A systematic review of the literature on the clinical effects of sexual abuse in people with intellectual disabilities (Sequeira & Hollins, 2003) found several studies suggesting that a range of psychopathology, including traumatic stress reactions, depression, anxiety and behavioural problems (e.g. aggression, self-injury and sexual behaviour) may follow sexual abuse. However, because of methodological limitations the results are not conclusive.

In conclusion, there is some evidence that life events are associated with psychological problems, most likely affective and neurotic symptoms but possibly also other psychiatric disorder in adults with intellectual disabilities but

the direction of this relationship is unclear and most studies to date have important methodological limitations.

1.7.6 Risk Markers from population based cross sectional surveys with clinical assessment and use of diagnostic criteria

Of the population based prevalence studies that have included clinical assessment and the use of diagnostic criteria, only three have investigated factors associated with mental ill-health.

Deb et al (2001a) used chi square analysis to investigate the rate of psychiatric disorder in different subgroups of his cohort of 91 adults with mild-moderate intellectual disabilities. Significant associations with the presence of ICD-10 psychiatric illness and increasing age and the presence of physical disability were found but no allowance in the analysis was made for the probable dependent relationship between these two variables. Non-significant trends for higher rates of psychiatric illness in participants living in group homes, participants with a history of epilepsy, participants receiving psychotropic medication and participants without an identified cause for their intellectual disabilities were found. It is possible that the lack of statistical significance to these trends has been due to lack of power.

Cooper et al (2007) used binary logistic regression analysis to investigate a number of personal, past experiences, lifestyle and supports, and health and disabilities factors. Factors found to be independently significantly associated with psychiatric illness were having severe or profound intellectual disabilities, a higher number of life events in the preceding 12months, a higher number of GP consultations in the preceding 12 months, smoking, living with paid carer support, not having severe physical disabilities, not having immobility, urinary incontinence and being female.

Bailey (2008) in her cohort of 121 adults with moderate-profound intellectual disabilities used forward stepwise logistic regression analysis to identify independent variables associated with DC-LD psychiatric illness. The variables investigated included, age, number of professionals involved, number of

antipsychotic medications, number of physical illnesses, Health of the nation Outcome Score (Wing, Curtis & Beevor, 1996), Health of The Nation Outcome Score-Learning Disabilities (Roy et al, 2002), developmental age, gender and any life event in the past year. Only HoNOS score and developmental age were found to be significantly independently associated with psychiatric illness, with a higher rate of psychiatric illness in the group with lower developmental age and in the group with a higher HoNOS score. Similar analysis examining independent variables associated with DC-LD problem behaviour found that the length of time the participant was known to the informant and HoNOS score were significantly associated, with the group with problem behaviour having shorter length of time known and a higher HoNOS score.

As these studies are all cross sectional surveys, and the factors identified as significantly associated with psychiatric illness were measured at the time of the illness, it is not possible to say whether these associations are cause or effect. A longitudinal study with a large sample size to reduce the risk of Type II error is required to answer this question.

1.8 Longitudinal Studies in people with intellectual disabilities

There have been very few longitudinal studies carried out in cohorts of adults with intellectual disabilities. This may be because of the resources and time required for such studies and also the problems in retaining sufficient numbers of the sample over the study time period. Cohort retention is particularly difficult in adults with intellectual disabilities as they tend to move house more often, are usually reliant on others to process their mail, are less likely to agree to participate, are subject to premature death and tend to have frequent change of carers. The recent implementation of the Adults with Incapacity Act (Scotland) 2000, has added further to these difficulties by deeming that when an adult is incapable of consenting to research only the next of kin or an appointed Welfare Guardian with powers to consent to research on their behalf can give consent. As many adults with intellectual disabilities are not in contact with their next of kin and very few have an appointed Welfare Guardian this legislation prevents a significant proportion of adults with intellectual disabilities who live in Scotland, participating in research.

To date there have been just a few longitudinal studies in adults with intellectual disabilities examining overall psychiatric disorder, individual psychiatric disorder or problem behaviour and even less longitudinal studies in children with intellectual disabilities examining psychiatric disorder or problem behaviour.

1.8.1 Longitudinal studies examining psychiatric disorder or problem behaviour in adults

Reid & Ballinger (1995) undertook a 16-18 year follow up study of 100 adults with severe and profound intellectual disabilities living in hospital. The study specifically measured behaviour symptoms over this time period using carer ratings and psychiatric interview (using the Modified Manifest Abnormality Scale of the Clinical Interview Schedule) (Goldberg et al, 1970). Case notes were also reviewed and participants were given an overall rating of the severity of psychiatric disorder by the assessing psychiatrists. At follow-up, 31 participants had died and two were excluded as they were felt to be functioning above the severe range of intellectual disabilities, leaving a sample of 67. Carer ratings of noisiness and social withdrawal and psychiatrists ratings of suspiciousness, overactivity and hostile irritability were found to be significantly persistent over the time period. Psychiatric disorder ratings were also significantly persistent – both in occurrence and severity, although the authors did note that over the time period some participants moved in or out of psychiatric disorder. This study is limited by the small sample size, it includes only adults with severe and profound intellectual disabilities who were resident in hospital, the definition or assessment method of intellectual disabilities is not described, and the assessment methods are rather dated. It shows a persistence of psychiatric disorder over a 16-18 year period in the cohort but does not report the number of new cases occurring over this time period or examine factors associated with psychiatric disorder.

This same cohort was again examined in 2001, 26 years after the initial assessment, by Thompson & Reid (2002). The attrition rate was high with only 53 of the original 100 adults undergoing reassessment. The same ratings were used, plus an additional behaviour checklist, and again it was shown that a high

number of behavioural symptoms persisted over the follow up period. However, the severity of the symptoms had decreased, particularly in those over 60 years. As in the previous study, the number of new cases occurring within the follow up period was not reported.

Linden & Forness (1986) examined a group of 40 adults with borderline or mild intellectual disabilities (Wechsler or Stanford-Binet IQ 50-85) who had been admitted to hospital in adolescence 10 years earlier for brief treatment of psychiatric disorders. Subjects were contacted by telephone until 40 out of the potential 145 participants were recruited. An interview rating form was used to gather information on adjustment in three areas (occupational, interpersonal and social) with ratings made by the interviewee on a 5 point Likert-type scale. The results showed that when compared to previous follow up samples of intellectual disabled persons without psychiatric disorder and non-intellectual disabled psychiatric patients, overall the participants had a comparatively poor level of adjustment. Participants that had a longer hospital stay were even less well adjusted. This study is limited by the inclusion of only adults with mild or borderline intellectual disabilities, selection bias, the small sample size and the absence of any validated measure of adjustment. It did not measure the presence of psychiatric illness at the 2 year follow up or the onset of psychiatric illness within the 2 year period.

McCarthy & Boyd (2001) carried out a cohort study following up 193 children with Down's syndrome into adulthood. Only 52 (26.9%) of the original 193 participated in the follow up study, 16 years after the original assessment. Participants had psychiatric assessment at both points in time that included use of the PAS-ADD Interview (Moss et al, 1993), the Additional Behaviour Inventory (ABI) (a 26 item checklist covering aggressive, self injurious, stereotypic and social unacceptable/difficult behaviours) (Gath & Gumley,1986) and an autism screen taken from the Developmental Disorders section of the Mini PAS-ADD (Prosser et al, 1998). A reported prevalence rate of psychiatric disorder according to ICD-10 criteria of 35% in adulthood and 38% in childhood was reported. Factors predictive of psychiatric disorder in adulthood were investigated. There was no significant association between childhood problem behaviour or childhood psychiatric disorder or childhood level of functioning with

psychiatric disorder in adulthood. A significant association between childhood social adversity (social class IV-V semi-skilled, unskilled) and adult psychiatric disorder was found. Concurrent variables of life events in the past 2 years and neurological disorder were not significantly associated with adulthood psychiatric disorder but adult level of functioning was.

Further analysis of this cohort has since been carried out by McCarthy (2008) to examine childhood risk factors for behaviour problems in adulthood. She found that childhood psychopathology (defined by diagnosis of ICD-10 psychiatric disorder) and lower level of functioning in childhood (as measured on the American association for Mental Retardation Adaptive Behaviour Scale Part 1 (Nihira et al, 1993)) was associated with behaviour problems (as measured by the ABI) in adulthood. Also, and in contrast to the findings for psychiatric disorder in adulthood, childhood family environment was not associated with problem behaviour in adulthood. The author concludes that social class of the family is not a long-term predictor for behaviour disorder in adults with Down's syndrome.

This study is limited by the small sample size, high attrition rate, use of ICD-10 diagnostic criteria (which has limited use in adults with severe-profound intellectual disabilities) but benefits from the fact that all participants underwent clinical psychiatric assessment at both points using similar tools. This study did not identify any link between childhood psychopathology or functioning and adult psychiatric illness but did for adult behaviour disorder. The author suggests that it may be that behaviour persists over time and childhood psychiatric disorder is a risk factor for chronic behaviour disorder. This study did not report on the number of people who developed a psychiatric illness over the follow up period or measure the course of the psychiatric illness or behaviour problems identified in childhood.

In 1995, Kiernan et al (1997) followed up 272 (68.3%) children and adults out of an original 398 identified in 1988 through a survey of the complete administratively defined population of people with intellectual disabilities living in a defined area of the North East of England. The median age of the follow-up sample was 27 years with the age range 5-80 years. Similar, but not identical,

carer completed assessments of problem behaviour were carried out at both time points and participants were categorised, according to set criteria related to frequency and severity, as having “less demanding” or “more demanding” problem behaviour. Of the 179 persons who were categorised as “more demanding” in 1988, 66 (36.9%) were “less demanding” in 1995, while 113 (63.1%) remained in the “more demanding” category. Of the 93 people categorised as “less demanding” in 1988, 36 (38.7%) were categorised as “more demanding” in 1995. In other words, more severe problem behaviour persisted over the seven year follow-up period for almost two thirds of the group and almost a third of the group with less severe problem behaviour developed more severe problem behaviour during the seven year follow-up period. This study is limited by the absence of clinical or psychiatric assessment and reliance on carer report but does demonstrate that although problem behaviours in adults and children with intellectual disabilities can improve over time, most persist, and some worsen. The study did not measure the incidence of problem behaviour.

1.8.2 Longitudinal studies examining affective symptoms in adults

Maughan et al (1999) examined prospective data on a birth cohort of 1700 children born in Britain in 1958, comparing people with mild intellectual disabilities with those without intellectual disabilities. Participants were categorised as having mild intellectual disabilities if their score on a standardised general ability test administered at 11 years of age was at or below 1.94 standard deviations below the mean (equivalent to IQ < or equal to 70) and they were not attending a specialist school for children with severe intellectual disabilities. At 33 years of age, only 100 (36.4%) of the original 275 children with mild intellectual disabilities and only 7205 (54.8%) out of the original 13150 children without intellectual disabilities had sufficient data collected to be included in the study. Participants with mild intellectual disabilities were found to have significantly higher scores on The Malaise Inventory (Rutter et al, 1970). Higher scores on the Malaise Inventory were associated with childhood sensory and neurological problems (odds ratio 3.1) and childhood social disadvantage (odds ratio 1.4), although the lower limit of the 95% confidence intervals for odds ratios for each of these was 1.0. Links

with general ability or childhood behaviour ratings were not identified. This study is limited by the high attrition rate, reliance on self-report and absence of psychiatric assessment. As it only includes people with mild intellectual disabilities and specifically excludes people with severe intellectual disabilities it is not generalisable to the intellectual disabilities population as a whole. However, it does suggest that childhood sensory and neurological problems and social disadvantage might be associated with the presence of affective symptoms at 33 years of age in people with mild intellectual disabilities. The authors point out that these factors accounted for only modest proportions of the risks observed. The study did not measure the incidence of affective symptoms.

Collishaw et al (2003) further investigated this cohort using similar methodology to examine the extent to which adult socio-economic disadvantage and ill health contribute to the risk of affective disorder in adults with mild intellectual disabilities at 43 years of age. In keeping with the findings of Maughan et al (1999) mild intellectual disabilities continued to confer an increased risk of affective disorder at 43 years when compared to the group without intellectual disabilities and especially so for those with chronic depressed mood at ages 23, 33 and 43 years. Adult social disadvantage and self-rated health were strongly associated with Malaise Inventory scores at 43 years of age. However, as both these measures were administered at the same time as the assessment for the presence of affective symptoms, these associations could be either cause or effect. Although this study suggests that some adults with mild intellectual disabilities experience chronic depressive symptoms it does not provide any information on the incidence of affective symptoms in this population. It is also limited by the high attrition rate (44% of the group with mild intellectual disabilities provided data at 43 years) and reliance on self-report measures.

A similar study carried out by Richards et al (2001) investigated data from the British 1946 birth cohort specifically to examine the risk of affective disorder in adults with mild intellectual disabilities and to ascertain whether this risk was accounted for by disadvantage in child or adulthood. Participants were repeatedly interviewed and examined and data on socio-demographic factors, medical, cognitive and psychological functioning collected. Overall,

approximately 50% of the cohort had sufficient data to be included at 46 years of age, but this was only 29% for the group with mild intellectual disabilities. 41 subjects had mild intellectual disabilities (IQ 50-69 at 16 years) and the other 2119 adults served as the comparison group. Psychiatric measures used were the Present State Examination at 36 years and the Psychiatric Symptom Frequency scale at 46 years. The Maudsley Personality Inventory performed at 26 years of age provided a measure of neuroticism. The intellectual disabilities group was found to have a fourfold increase in risk of affective disorder that was not accounted for by social and material disadvantage or by medical disorder. The study also found that people with intellectual disabilities were significantly more likely than the comparison group to score positively on the psychiatric measure at both 36 years and 43 years, suggesting a higher rate of recurrence and/or chronicity in the intellectual disabilities group. This is an interesting study but is limited by the attrition rate, small number of intellectual disabilities participants and use of two different psychiatric rating scales that have not been validated for use in the intellectual disabilities population. The results are not generalisable to the intellectually disabled population as a whole as it only included adults with mild intellectual disabilities/people able to complete the measures, and it did not investigate incidence of affective disorder.

1.8.3 Longitudinal study examining incidence of affective disorder and dementia in adults

van Schrojenstein Lantman-de Valk et al (1997) examined the incidence of health problems in people with intellectual disabilities living in residential facilities in the Netherlands using a prospective cohort study design. The study sample consisted of 1602 people and included all ages (range 0 - >70yrs). People living with their families were not included. Data were collected by means of two questionnaires completed annually over the three year period, 1990-1993. The medical questionnaire was completed by the persons general practitioner and included criteria specifying whether or not to include a patient in a given health category. These criteria were not described. Only 893 (56%) participants had sufficient data to allow calculation of the three year incidence rate and the number of new cases occurring within the sample over the three year period was sufficient to calculate 3 year incidence rates for only two

psychiatric disorders. For adults aged 20 years and over the three year incidence rate of dementia was 3.0% and the three year incidence rate of affective disorder was 3.5%. This study is significantly limited by the attrition rate (non-responders were significantly less able and of older age), its failure to describe the criteria for categorising diagnoses and the fact that the incidence data were based on registered data and not on actual re-testing. It has restricted generalisability as it did not include people with intellectual disabilities living with family carers.

1.8.4 Longitudinal studies examining incidence of dementia in adults

Holland et al (2000) investigated the incidence of dementia in a population based sample of 68 people with Down's syndrome aged 30 years and over. Participants were followed up over an 18 month period and assessed at both time points using the Cambridge examination for Mental Disorders of the Elderly (CAMDEX: Roth et al, 1986). Thirteen participants (19.1%) were found to have developed dementia over the 18 month period. This study is limited by its small sample size and the short follow up period (considering the time course of dementia). In addition, the results cannot be generalised to adults with intellectual disabilities not due to Down's syndrome.

Zigman et al (2004) carried out a longitudinal cohort study of 126 adults with intellectual disabilities not due to Down's syndrome, aged 65 years and over, living in New York, to ascertain the prevalence and incidence of dementia in this population. Participants were assessed for the presence of dementia at baseline and then at 18 month intervals with 126 completing the first follow up assessment, 104 the second and 52 (41%) the third follow up assessment. Assessments were comprehensive and included case note review, informant interviews, cognitive assessments and physical/neurological examination for those suspected of having dementia. Diagnosis of dementia was determined at a consensus meeting. A prevalence rate of 0.103 % (95% CI 0.042 - 0.164) for possible/definite dementia or "uncertain with complications" was reported for adults age over 65 years with intellectual disabilities not due to Down's syndrome. This rate is within the range of rates of Alzheimer's disease for

adults aged over 65 years without intellectual disabilities living in America and the authors were unable to demonstrate a significant difference. Three cases of possible/definite dementia plus 5 cases of “uncertain with complications” were identified during the follow up period. Including all of these gives cumulative incidence rates of dementia for this population similar to the cumulative incidence of Alzheimer’s disease for the general population. The authors do not think that their estimated rates are erroneously low due to difficulties with assessment and diagnosis in this population but this is a real possibility and not including individuals who tested negative for dementia at time1 but then who may have developed dementia in the following 18 months will have resulted in an erroneously low rate. The biggest limitation of this study is the small sample size and in particular the small number of identified cases – this means that the reported non-significant difference between rates in this population and the general population could simply be a Type II error. In addition, the sample was not population based. It probably missed adults living in nursing homes who are more likely to develop dementia. This finding of a lower prevalence of dementia in adults with intellectual disabilities not due to Down’s syndrome contradicts that reported by Cooper (1997) and Strydom et al (2007).

1.8.5 Longitudinal study examining psychiatric disorder in children

Wallander et al (2006) examined risk factors for psychopathology in a random sample of children aged 6-16 years, living at home and attending specialist schooling in the Netherlands. Children with IQ<80 were included. Assessments were carried out at baseline on 987 (69.3% of those eligible) and one year later on a random sample of these children (n=557). 86.8% of those eligible to participate in the follow up took part. Methods of assessment at the two points in time were identical and relied heavily on parent report. Individual levels of psychopathology were highly consistent from Time 1 to Time 2. Multiple regression analysis was conducted to identify Time 1 factors associated with the development of psychopathology between Time 1 and Time 2. Psychopathology, physical symptoms, parental distress and family dysfunction at Time1 predicted the development of psychopathology. This study is one of the few to actually measure risk factors for onset of psychopathology but the results are limited by the sample including children that do not have intellectual

disabilities and sample bias towards children with less severe intellectual disabilities, the reliance on parent report and the use of a psychopathology assessment tool designed for use in the general population. The authors also point out that the 1 year follow up period may not have been sufficient time for the postulated risk factors to exert their effect. The authors did not report the number of children developing psychopathology over the follow up period.

1.8.6 Longitudinal studies examining problem behaviour in children

Eyman et al (1981) re-assessed 426 children (average age 12 years) with intellectual disabilities out of an original 2,736, two years after their initial contact with regional intellectual disabilities services for children in California, USA. The Adaptive Behaviour Scale (Nihira, 1975) was used at both assessments to measure maladaptive behaviour with the finding that maladaptive behaviour identified at the first assessment had not significantly changed over the two year period. This finding was present in the both the institutionalised and non-institutionalised groups. This study is limited by the high attrition rate and subsequent sample bias (nearly half of the sample were not available for follow up because no request for out of home placement or further service were made after the initial evaluation). It did not measure the incidence of problem behaviour over the 2 year period or investigate associations.

Murphy et al (2005) examined the chronicity of challenging behaviour over a 12 year period in a cohort of 150 children less than 15 years of age who had either severe intellectual disability or impairments in social interaction, language or behaviour. Children were assessed using a number of psychometric measures and carers were interviewed using the Handicaps, Behaviours and Skills (HBS) schedule (Wing, 1996) at both time 1 and at time 2, 12 years later, with a follow up rate of 94%. A reduction in the overall prevalence of most abnormal behaviours over the 12 year period was reported. The number of new cases of abnormal behaviour occurring during the follow up period was not reported. Predictors of abnormal behaviour at follow up were found to be a diagnosis of autistic spectrum disorder, the presence of social impairment at baseline, the

degree of expressive language at baseline and the presence of abnormal behaviour at baseline. This study is limited by the small sample size, restricted generalisability, reliance on carer report and the failure to account for the interdependence of the variables studied.

1.8.7 Summary of longitudinal studies

Longitudinal studies have examined childhood risk factors associated with the identification of psychiatric symptoms, psychiatric disorder or problem behaviour in adulthood. Maughan et al (1999) reported a non significant association of childhood sensory and neurological problems and childhood social disadvantage with affective symptoms in adulthood. McCarthy & Boyd (2001) reported a significant association between childhood social adversity and adult psychiatric disorder for people with Down's syndrome and McCarthy (2008) reported a significant association between childhood psychiatric disorder and lower level of functioning in childhood and behaviour problems in adulthood for people with Down's syndrome. Wallander et al (2006) identified physical health symptoms, parental mental health treatment and family dysfunction as predictive of the onset of psychopathology in children.

Murphy et al (2005), Thomson & Reid (2002) and Kiernan et al (1997) have demonstrated a persistence of problem behaviours over time in children and adults. Just three of the longitudinal studies have actually measured incidence rates during the follow-up period (Holland et al, 2000; Zigman et al, 2004; van Schrojenstein Lantman-de Valk et al, 1997). Only incidence rates for dementia and affective disorder have been reported.

These longitudinal cohort studies demonstrate the difficulties in retaining adult participants over the follow up period, with an average follow up rate of less than 50% amongst the adult studies. In some studies the high attrition rate is due to the very long follow up period, but in other studies it is due to the difficulty tracing participants and then obtaining consent from them. Most of the studies are limited by sample size, sample bias, a high attrition rate, reliance on carer report, lack of clinical assessment and diagnosis of psychiatric disorder

according to diagnostic criteria, and failure to account for the interdependency of the risk factors investigated.

1.9 Conclusions

The prevalence of intellectual disabilities in adults living in the United Kingdom is likely to be somewhere between 3.31 (Beange & Taplin, 1996) and 6.34 (McConkey et al, 2006) per 1000 adult population.

Research examining mental ill-health in this population has been limited by a number of methodological problems that include difficulties identifying and retaining suitable study populations, confusion over the definition of mental-ill health, use of inappropriate diagnostic classificatory systems, limitations in the currently available assessment tools and the rarity of studies that have included structured psychiatric assessment.

Although it has been demonstrated that adults with intellectual disabilities have a higher prevalence of mental ill-health when compared to that reported for the general population (Bailey, 2008; Cooper et al, 2007; Cooper & Bailey, 2001; Lund, 1985a, Corbett ,1979), and some studies have shown a degree of persistence of behavioural problems and affective symptoms over time (Thompson & Reid, 2002; Collishaw et al, 2003), there is insufficient evidence to answer the question of whether this high prevalence is due to a high level of enduring mental ill-health or a high incidence of mental health, or indeed a combination of the two. To date, three studies (Holland et al, 2000; Zigman et al, 2004; van Schrojenstein Lantman-de Valk et al, 1997) have measured the incidence of dementia and only one study (van Schrojenstein Lantman-de Valk et al, 1997) has attempted to measure the incidence of affective disorder. No study has measured the overall incidence of mental ill-health in this population.

Similarly, although the population based prevalence studies by Deb et al (2001a), Cooper et al (2007) and Bailey (2008) have identified some associations with mental ill-health it is unknown whether these are cause or effect. Murphy et al (2005) has identified risk factors for the chronicity of problem behaviour in children, Wallander et al (2005) has identified risk factors

for the onset of psychopathology in children, McCarthy & Boyd (2001) and McCarthy (2008) have investigated childhood risk factors for mental ill-health in adults with Down's syndrome but no study to date has identified any adult risk factors for the onset of all types of mental-ill health in adults with all levels and causes of intellectual disabilities.

A large scale, longitudinal cohort using validated screening tools, the "gold standard" psychiatric assessment by an intellectual disabilities psychiatrist and categorisation according to appropriate diagnostic criteria is required to ascertain the incidence of mental ill-health in adults with intellectual disabilities. Such a study would also allow risk factors for the onset of mental ill-health in this population to be ascertained.

Chapter 2 AIMS AND HYPOTHESES

2.1 Aims

The aims of this study were:

- To measure the incidence of mental-ill health in a large population of adults with intellectual disabilities who have previously been screened for ill-health and referred into clinical services for treatment, and draw a comparison with published general population data.
- To gain a better understanding of mental ill-health in adults with intellectual disabilities and the factors underpinning its incidence.
- To examine the 2 year chronicity of mental-ill health in adults with intellectual disabilities.

2.2 Research Questions

- What is the incidence of mental ill-health over a 2-year period, in adults with intellectual disabilities?

- Does the incidence of mental ill-health in adults with intellectual disabilities differ from published general population data?

- Can vulnerability factors for onset of mental ill-health be identified? Are there associations with age, gender, marital status, smoking, level of ability, Down's syndrome, personal or family history of mental ill-health, previous long-stay hospital residence, type of supported living arrangement/supported accommodation, employment/day opportunities, social deprivation, epilepsy, experience of life events, pre-existing sensory impairments or physical disabilities?

- Can vulnerability factors for the 2 year chronicity of mental ill-health be identified? Are there associations with age, gender, marital status, smoking, level of ability, Down's syndrome, personal or family history of

mental ill health, previous long-stay hospital residence, type of supported living arrangement/supported accommodation, employment/day opportunities, social deprivation, epilepsy, experience of life events, pre-existing sensory impairments or physical disabilities?

2.3 Hypotheses

- The incidence of mental ill-health in adults with intellectual disabilities is no different from reported general population rates.
- The onset of mental ill-health in adults with intellectual disabilities is not associated with age, gender, marital status, smoking, level of ability, Down's syndrome, personal or family history of mental ill-health, previous long-stay hospital residence, type of supported living arrangement/supported accommodation, employment/day opportunities, social deprivation, epilepsy, experience of life events, pre-existing sensory impairments or physical disabilities.
- The 2 year chronicity of mental ill-health in adults with intellectual disabilities is not associated with age, gender, marital status, smoking, level of ability, Down's syndrome, personal or family history of mental ill-health, previous long-stay hospital residence, type of supported living arrangement/supported accommodation, employment/day opportunities, social deprivation, epilepsy, experience of life events, pre-existing sensory impairments or physical disabilities.

Chapter 3 METHODS

3.1 Design of the study

A large scale population based study of the prevalence of mental ill-health in adults with intellectual disabilities living in Glasgow, undertaken during 2002-2003 (Cooper et al, 2007), provided the opportunity to carry out a prospective longitudinal cohort design study, with the prevalence study providing the sample and baseline data.

A 2 year follow up period was chosen to ensure sufficient incident cases occurred during the follow up period to allow exploration of risk factors for the onset of mental ill-health but also to lessen the risk of attrition and recall bias. All participants were assessed using a two stage process - screening then detailed psychiatric assessment of potential cases, at baseline (the prevalence study) and the 2 year follow-up. At baseline, each participant underwent a detailed assessment by one of a team of six specialist Intellectual Disabilities Nurses who were trained in the use of the assessment instruments. At the 2 year follow up interview, assessment was repeated by one of the two research assistants, Janet Finlayson (JF) and Alison Jackson (AJ), using the same assessment tools plus additional ones. All participants identified with possible mental ill-health at baseline or occurring at any point during the two year follow-up period were referred for psychiatric assessment.

A power calculation was not performed as there is no current literature on the incidence of mental ill-health in adults with intellectual disabilities and use of incidence rates for the general population was not felt to be appropriate due to significantly differing prevalence rates and patterns of mental ill-health in the intellectual disabilities population (Cooper et al, 2007).

3.2 Ethical Approval

Ethical approval was granted by the Multi Centre Research Ethics Committee-Scotland A and the Local Research Ethics Committee. See Appendix I

3.3 Identification of sample

One thousand and twenty three adults with intellectual disabilities who took part in a previous research project (Cooper et al, 2007) to measure the prevalence of mental ill-health in adults with intellectual disabilities, plus an additional 179 persons who were not included in the prevalence study analysis but had had identical baseline measurements of the presence/absence of mental ill-health plus various other health, social and demographic details and had consented to be re-contacted, provided the cohort for follow up 2 years after the initial assessment. This sample was chosen because all people with mental ill-health identified during the baseline measurements were referred into specialist mental health services for treatment, thus minimising the confounding factor of a high level of chronic unidentified mental ill-health in this population.

The original 1202 were identified from a database of adults with intellectual disabilities aged 16 years and over living in the Greater Glasgow Health Board Area. The Greater Glasgow Health Board Area covers a total population of approximately 900,000. The database was established by combining information from social work services for people with intellectual disabilities, local authority funding arrangements for persons receiving paid support of any kind, local specialist health services for adults with intellectual disabilities, the Health Board and the Scottish Executive Statistical Department. At the time of the study there was no long stay hospital accommodation within the Greater Glasgow Health Board area with all previous long stay hospital accommodation residents already resettled in the community. In addition, all General Practitioners working within the Greater Glasgow Health Board area were asked to identify any adults with intellectual disabilities on their lists. Registration with a General Practitioner is almost universal in Scotland and every General Practitioner responded to this request. Each General Practitioner was paid an item of service fee for every person with intellectual disabilities they identified. This lead to an initial over identification of possible cases– mainly people of low intellectual functioning with additional needs – but these people were subsequently excluded from the sample if they did not meet our definition of intellectual disabilities (see next section for details of definition used). Thus,

rather than just being an administrative sample of the intellectual disabilities service this sample included people identified through primary care.

The case ascertainment rate for the database was 3.33 per 1000. This ascertainment rate is similar to that of other large scale case ascertainments in Europe (Farmer et al, 1993; McGrother et al, 2001; Felce, 2004; van Schrojenstein Lantman de-Valk et al, 2006).

Approximately three quarters of the total population identified through the database were selected for the baseline prevalence study by including everyone living within a geographically defined area. At the time of the study, the Greater Glasgow Health Board area was divided into 16 smaller areas called Local Health Care Co-operatives (LHCC's). 11 of the 16 LHCC's were selected to provide a representative sample for the study. The 11 LHCC's had a total population of 604,412. 1548 adults with intellectual disabilities were identified within the 11 LHCC's and all were invited to take part in the baseline prevalence assessment. 1023 (66.1%) of the 1548 prevalence study potential population underwent the initial baseline assessment and consented to be re-contacted. These participants plus the 179 persons who had also had baseline assessments but were not living within the defined geographical areas for the prevalence study then became the cohort sample and were re-contacted 2 years later and invited to participate in the follow up study. See Figure 3.1.

3.4 Definition and method of assessment of level of intellectual disabilities

Only potential participants who met our definition of intellectual disabilities were included in the sample. The definition of intellectual disabilities used in this study was the World Health Organisation ICD-10 definition = "a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifest during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities".

Not all potential participants had a full assessment of their intellectual functioning and adaptive behaviour at baseline but all were confirmed at baseline as having intellectual disabilities based on clinical observations and the outcome of an abbreviated version of the Vineland Adaptive Behaviour Scales (survey form) within the C21st health check made during the baseline assessment, any results of tests of adaptive behaviour and intellectual functioning available within primary care case notes, and for those that underwent psychiatric assessment, any results of tests of adaptive behaviour and intellectual functioning contained within psychiatry or psychology case notes plus the clinical opinion of the assessing psychiatrist.

The abbreviated version of the Vineland Adaptive Behaviour Scales (survey form) has been shown to highly correlate with developmental age as measured by the Vineland Adaptive Behaviour Scale (survey form) (Pearson's correlation r= 0.812; P< 0.001). For those without documented testing of adaptive behaviour or intellectual functioning to confirm the presence of intellectual disabilities and inform categorisation of the level of ability, results from the abbreviated version of the Vineland Adaptive Behaviour Scales were used, taking into account the effects of non-cognitive factors on functioning such as cerebral palsy. Any cases with loss of skills due to organic disorder or severe mental illness were classified according to their best ever rather than current level of functioning. Any dubious cases were scrutinised by the research psychiatrist (ES).

This process resulted in the exclusion of several adults receiving specialist intellectual disabilities services that were of borderline or normal intellectual functioning and had additional mental health or autistic spectrum disorders and allowed the classification of all participants into the differing levels of ability according to the ICD-10-DCR criteria as detailed below.

Category	**IQ range**	**Mental Age (years)**
Mild	50-69	9 to under 12
Moderate	35-49	6 to under 9
Severe	20-34	3 to under 6
Profound	below 20	Less than 3

In addition, all participants at the 2 year follow up interview were assessed using the Vineland Adaptive Behaviour Scales (survey form) (Sparrow et al, 1984) and no one was subsequently classified as non-intellectually disabled.

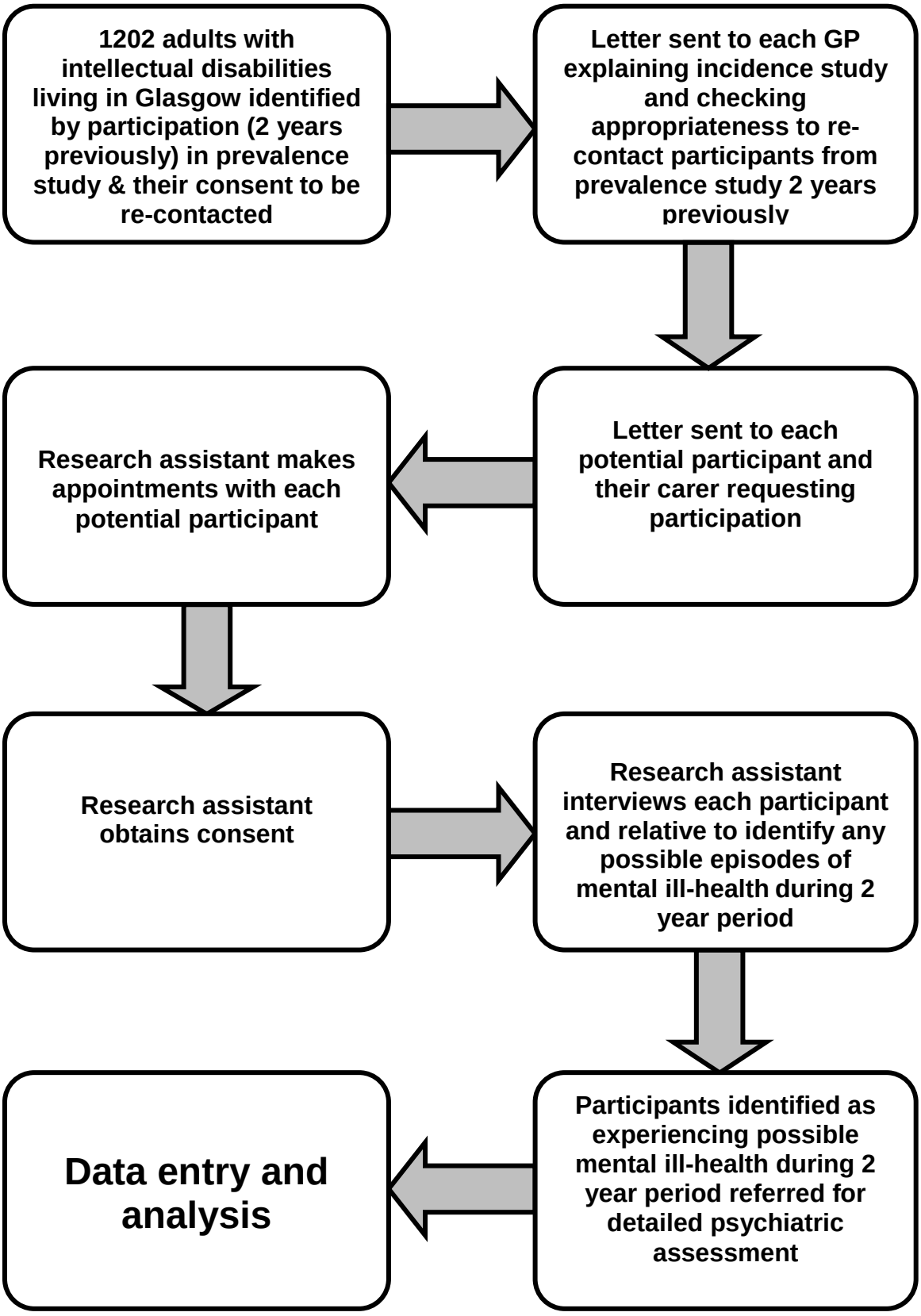
3.5 Consent

The entire original potential 1202 cohort had agreed to be re-contacted by the research team. Consent to participate in the follow up study was taken by one of two research assistants employed on the study using developmentally appropriate explanations supplemented by gestures and picture aids where appropriate. Consent was taken from the person with intellectual disabilities as far as they were able to consent. For those that were not able to consent, consent on their behalf was taken from their Next of Kin or Welfare Guardian, in keeping with Part 5 of The Adults With Incapacity (Scotland) 2000 Act. Those that did not have capacity to consent, an appointed Welfare Guardian with powers to consent to research on their behalf or a known Next of Kin, had to be excluded. Both research assistants had training in communicating with adults with intellectual disabilities and experience of taking informed consent. Information sheets in easy to read formats were provided for participants and their carers, next of Kin's and Welfare Guardians. The information sheet was also available on Audiotape and other languages on request.

3.6 The 2 year follow up research interview (T2)

The General Practitioner of all potential participants was contacted by letter to confirm the current address of the participant and to check whether there was any reason not to contact the person e.g. death, terminal illness. Participants were then invited to participate by letter. This was followed by a telephone call made by one of the research assistants and if appropriate an appointment arranged for a visit at home or any other site chosen by the participant. If the participant was not able to give informed consent, contact with their Welfare Guardian or Next of Kin was attempted by letter and followed by a telephone call. Arrangements to meet with the Welfare Guardian or Next of Kin were made if requested. If consent was obtained, the research interview was then carried out by one of the two research assistants (see Figure 3.1).

Figure 3.1 Study flow chart



The research interviews took between 2-4 hrs. Information was gathered from the participant and the person supporting them. Where the person supporting them was not aware of the full 2 year history (because they had not known them that long), an alternative informant who was aware of this information was contacted. Participants, who had moved out with the area, wherever possible, were traced to their new address and interviewed there. Sometimes a second visit or additional telephone calls were required to gather all of the required information. In addition, contact with a relative was made for the completion of a specific questionnaire.

Measurements were made during the face – to face interviews using the same research tools that were used at the baseline assessment, plus some additional ones to gather further information on potential risk factors.

3.7 Assessment tools used in follow up research interview (T2)

3.7.1 PAS-ADD checklist (see Appendix II)

A modified version of the PAS-ADD checklist (Moss et al, 1998) was used to screen all participants for possible mental ill-health present in the four weeks prior to the research interview and also to gather information on life events experienced during the previous year.

The PAS-ADD checklist is a screening tool designed for the identification of mental health problems in adults with intellectual disabilities. It is a questionnaire that is designed to be completed by a carer who has known the individual for at least 6 months and helps to decide whether a fuller assessment of an individual's mental health is required.

It has two sections. The first section collects information about life events in the previous year. Various life events e.g. death of a parent, serious illness, moved home are listed with the respondent asked to tick any that have occurred in the previous year. There is also space to record any other significant events that have occurred in the previous year. The second section lists 29 different

psychiatric symptoms with the respondent asked to rate whether the symptom has been present for the person.

The respondent has to choose one of four possible responses

1. Has not happened in the past 4 weeks
2. Has happened in past 4 weeks but has not been a problem
3. Has been a problem for the person in the past 4 weeks
4. Has been a serious problem for the person in the past 4 weeks

The four possible responses for each of the 29 symptoms have a score attached to them. The 29 psychiatric symptoms are grouped into 5 sections (A,B,C,D and E) and a total score for each section is calculated. The section scores are then added up according to the following instructions to give three total scores.

Total Score 1= A+B+C.	Threshold =6
Total Score 2 =C+D.	Threshold =5
Total Score 3 = E	Threshold =2

If the individual scores are above any threshold it is recommended that they receive more detailed assessment. Breaking the threshold on Total score 1 is indicative of a possible affective or neurotic disorder, Total Score 2 a possible organic disorder and Total Score 3 a possible psychotic disorder. It is also recommended that any individual scoring near to a threshold but not exceeding it should be monitored regularly and frequently.

The psychometric properties of the PAS-ADD checklist have been examined by the authors (Moss et al, 1998; Simpson, 1999) and more recently, by independent researchers (Sturmey et al, 2005). Moss et al (1998) and Sturmey et al (2005) both reported reasonable internal consistencies for the affective/neurotic and organic threshold scales (Cronbach's alpha >0.6) but low internal consistency for the psychotic threshold (Cronbach's alpha 0.51 and 0.6). The lower internal consistency for the psychotic threshold scales is presumably because of the small number of items relating to the psychotic threshold score. Moss et al (1998) examined inter-rater reliability by using two

key informants for each sample member. Spearman rank correlations for the total score and threshold scores were all above 0.55, with a total score correlation of 0.79. However, individual item agreements were less good with an average Cohen's Kappa of 0.42. The authors felt that this reflected the problem of using untrained raters with no glossary of symptom definitions to guide the ratings. Moss et al (1998) and Sturmey et al (2005) both reported good validity for the PAS-ADD checklist, with Moss et al (1998) demonstrating that the probability of detection increased with the severity of the illness. Sturmey et al (2005) reported a sensitivity of 66% and specificity of 70% both of which are lower than the rates of 78% and 86% calculated from the findings of Moss et al (1998). This level of sensitivity is less than most other screening instruments and in view of this Sturmey et al (2005) recommended that although the PAS-ADD checklist is the best measure available it should not be used as the sole screening method for identifying possible psychiatric illness in people with intellectual disabilities, particularly since it does not cover all psychiatric disorders, may not identify mild illness and does not identify people with psychosis or bipolar affective disorder in remission. However, detailed study of the psychometric properties of the PAS-ADD checklist by Simpson (1999) that included receiver operating characteristic analysis for various possible ways of completing and scoring it, found that when the PAS-ADD checklist was completed by the person's main carer and a threshold of any two positive items was used, the tool had 100% sensitivity to detect people meeting criteria for ICD-10 diagnosis with a false positive rate of 58%, and 95% sensitivity to detect people meeting criteria for DSM-IV diagnosis with a false positive rate of 53%.

Modifications were thus made to the PAS-ADD checklist in an attempt to overcome these problems and in particular, as the aim of this study was to measure the incidence of mental ill-health, to improve the overall sensitivity.

The possible response of "has happened in the past 4 weeks but has not been a problem for the person" was removed and the possible response of "has been a problem for the person in the past 4 weeks" was changed to "has occurred for the person in the past 4 weeks". This removed the subjective decision by the carer of whether or not a symptom was a problem or not with the result that they only had to decide whether the symptom was present or not, and if present,

whether it was serious or not. It is also made the questionnaire more straightforward and easier to use.

Six symptom questions were added. This was done specifically to improve the detection rate of mania and psychosis. The following symptom questions were added:

1.“Increased lability of mood; mood rapidly alternating between misery and elation”

2.“Excessive talking, singing or laughing, more so than usual for the person”

3.“Loss of usual social inhibitions, indiscretion, or inappropriate social behaviour e.g. talking to strangers, over familiarity which is out of keeping with usual behaviour”

4.“Increased interest in sex, or sexual indiscretions which are out of keeping with usual behaviour”

5.“More tearful than usual”

6.“Concern that people or the television are referring to her/him, or giving her/him messages or instructions (when this is not the case)”

Also, the text of 6 questions was altered. This consisted of additional explanation of the symptom in question and did not involve the deletion of any of the original statement.

“Sudden intense fear or panic triggered by situations or things, such as being alone, crowds, thunder, etc.” was changed to “sudden intense fear, anxiety or panic triggered by situations or things, such as being in crowds, **social situations**, **alone**, thunder, **spiders** etc. **Also please specify the feared thing……..**”

“avoids social contact more than usual for the person” was changed to “avoids social contact more than usual for the person **(socially withdrawn), or reduced speech/communication**”

“restless or pacing, unable to sit still” was changed to “restless or pacing, unable to sit still; **or increased over-activity**”

“irritable or bad tempered” was changed to “**more** irritable or bad tempered than usual **or reduced tolerance**”

“less able to use self-care skills such as dressing, bathing, using the toilet, and cooking” was changed to “less able or less willing to use self-care skills such as dressing, bathing, using the toilet, and cooking **(or requiring more prompting)**”

“more forgetful or confused than usual, such as forgetting what has been said or getting lost in familiar places” was changed to “more forgetful and confused than usual, such as forgetting what has been said or getting lost in familiar places; **or more forgetful of people’s names; or less able to follow instructions**”

In addition, a Glossary was developed by the research psychiatrist (ES) based on the Glossary of Symptoms for the MINI PAS-ADD by Prosser et al (1998). The glossary contained detailed instructions on how to use the modified PAS-ADD checklist, including how to score chronic symptoms and differentiate between trait and sate, and more detailed descriptions of each of the 35 symptom questions. See Appendix II.

Finally, the scoring system was altered. This alteration was made to improve the sensitivity, albeit at the cost of specificity. Taking into consideration the results of the receiver operating characteristic analyses reported by Simpson (1999), a scoring system of any two positive items (excluding question 4 on phobias because of the high frequency of phobias) was adopted with no differentiation made whether the “has occurred” or the “has been a serious problem” response was ticked. Any score of 2 ticks or above resulted in referral for detailed psychiatric assessment. In addition, any one of the following high risk symptoms also triggered the second stage detailed psychiatric assessment:

Question12: “Attempts suicide or talks about suicide”
Question 18: “Suspicious, untrusting, behaving as if someone is trying to get at or harm her/him”
Question 30:“Strange experiences for which other people see no cause, such as hearing voices or seeing things that other people do not”

Question 31: “Strange or new beliefs for which other people can see no reason, such as the person believing someone or something is controlling her/his mind or that she/he has special powers”
Question 32: “Concern that people or the television are referring to her/him, or giving her/him messages or instructions (when this is not the case)”

These high risk items were chosen to improve detection of psychotic disorders and ensure that all people with suicidal ideation went on to have a detailed psychiatric assessment.

Although these modifications mean that we can no longer assume that the previously reported reliability and validity testing results still apply, as the modifications were essential additions made specifically to improve the sensitivity of the instrument without significant alteration to the original content, and the scoring cut-off used was significantly lower than the original, we can assume that the modifications have improved rather than hampered the sensitivity of the PAS-ADD checklist as a screening tool. This was at the cost of specificity but the two stage process of all high scorers then receiving detailed psychiatric assessment meant that this was of no significance to the final results.

In all cases, the PAS-ADD checklist was completed by a carer in the presence of the research interviewer who was then able to provide further information and explanation of each item as required, possibly increasing the reliability and in keeping with the recommendations made by the authors (Moss et al, 1998). Both research assistants (JF & AJ) received training in the use of the modified PAS-ADD checklist and glossary from the research psychiatrist (ES).

3.7.2 Identification of mental ill-health not well covered by the PAS-ADD checklist

Psychiatric disorders not well covered by the PAS-ADD checklist include problem behaviours, autism, eating disorders, ADHD, sexual disorder within the context of problem behaviour and bipolar affective disorder and schizophrenia disorders in remission. To ensure no-one with any of these disorders was

missed, additional checklists for problem behaviour and autism were used and anyone scoring below the threshold on the PAS-ADD checklist but in contact with psychiatry or psychology services at any point during the 2 year period had their case notes reviewed to identify if they possibly had any episodes of mental ill-health. It was assumed that anyone with any of these diagnoses would have been in contact with health services at some point but this cannot be stated with certainty.

3.7.3 Problem Behaviour Checklist (within C21st Health Check-sampled) (see Appendix II)

The Problem Behaviour Checklist is a purpose designed checklist that facilitates the collection of information about problem behaviour that is required to make a diagnosis according to DC-LD (Royal College of Psychiatrists, 2001). The most common types of problem behaviour (verbal aggression, physical aggression, destructiveness to property, oppositional behaviour, self-injury, sexually inappropriate behaviour, excessively demanding behaviour, wandering behaviour, faecal smearing and pica) are specifically enquired about and there is also a section for collecting information on any other reported problem behaviours. Information about severity, frequency, where the behaviour occurs, whether it is related to physical or psychiatric illness, whether it requires specialist intervention and support, whether it has a significant impact on the person's quality of life or others and whether or not it presents significant risks to the health and safety of the person or others is collected. The checklist covers problem behaviours present at the time of the assessment or at any time during the previous 2 year period.

Both research assistants had training in the use of the problem behaviour checklist. All information collected on problem behaviours by the research assistants during the research interviews using the checklist was subsequently discussed with the research psychiatrist (ES). If further information was required, this was sought by the research assistant or research psychiatrist. Any participant with new problem behaviour, not previously assessed problem behaviour or worsening of known problem behaviour was referred for detailed psychiatric assessment and diagnosis. Any participants with identified problem

behaviour that did not require referral for detailed psychiatric assessment were allocated a DC-LD diagnosis by the research psychiatrist.

3.7.4 The Pervasive Developmental Disorder Questionnaire (see Appendix II)

This purpose designed questionnaire was based on the Developmental Disorder section from the Mini PAS-ADD assessment schedule (Prosser et al, 1998). The Mini PAS-ADD assessment schedule is designed for use by non-psychiatrists to help them recognise clinically significant psychiatric conditions in adults with intellectual disabilities. It has reasonable reliability and validity (Prosser et al, 1998). All items from the developmental disorders section were used with the addition of one extra statement;

Question18: “Person has no verbal communication skills”

to clarify requirement for the other verbal items. In addition, the scoring system was modified to a minimum of 8 positive items, at least 4 of which must be in Questions 1-7 and three of which must be in Questions 12-17. This was altered to increase the sensitivity and ensure that people without verbal communication could still score positively. Anyone scoring above the threshold that was not already known to have a diagnosis of autistic spectrum disorder was referred for detailed psychiatric assessment and diagnosis. Both research assistants had training in the use of the questionnaire by the research psychiatrist (ES). In addition, a Glossary of symptoms based on the Glossary of Symptoms for the MINI-PAS-ADD by Prosser et al (1998) was developed by the research psychiatrist (ES). This provided instructions on how to rate items and more descriptive details for items (see Appendix II).

3.7.5 Past 2 years mental health history questionnaire (see Appendix II)

This was a purpose designed questionnaire to gather information on possible episodes of mental ill-health occurring during the 2 year period but not present at the time of the follow up interview. It was completed only at the follow up

interview. It contained specific prompts for the interviewer to ask about any possible episodes of mental ill-health in the past two years and any contacts with GP, Hospital, Specialist Intellectual Disabilities Health Services or treatment for mental health or behavioural problems given over the previous 2 years. If any possible episodes of mental ill-health were identified through these prompts further information was gathered using the modified PAS-ADD checklist retrospectively. If any service contact was identified, the case records were reviewed to gather further information.

3.7.6 Retrospective modified PAS-ADD Checklist (see Appendix II)

This was completed for any identified episode of mental ill-health that was no longer present at the time of the research interview i.e. any episode of mental ill-health with both onset and recovery within the 2 year period. It was completed only at the follow up interview. The retrospective modified PAS-ADD checklist was identical to the modified PAS-ADD checklist but was completed with reference to symptoms occurring during the period of identified possible mental ill-health rather than the usual previous 4 weeks time period. The same scoring method was used and anyone scoring positively who had not had assessment by the Specialist Intellectual Disabilities Psychiatry service at the time of the episode was referred for detailed psychiatric assessment. This ensured that detailed psychiatric information on any cases of mental-ill health occurring within the 2 year period which did not come to the attention of specialist health services or were treated in primary care or by the general adult psychiatric service was still collected.

3.7.7 Sampled C21st Health Check (see Appendix II)

In addition to the sections on problem behaviours and past 2 years mental health described above, sections from the C21st Health Check covering known health problems, current health concerns, medications, health promotion and epilepsy were used. At baseline, all participants underwent the complete C21st heath check. This included physical examination, assessment of hearing and vision and blood tests where indicated.

3.7.8 Vineland Adaptive Behaviour Scales (survey form)

The Vineland Adaptive behaviour Scales (Sparrow et al, 1984) are well known and widely used as measures of adaptive functioning. The survey form has been demonstrated to have a high degree of reliability and validity in both normally developing children (Sparrow et al, 1984) and children with intellectual disabilities (de Bildt et al, 2005). It is the recommended measure of social competence within most European and North American Cultures (WHO, 1993).

All participants had their level of adaptive behaviour assessed using the Vineland Adaptive Behaviour Scales (survey form) at the follow up interview. The Vineland Adaptive Behaviour Scales were administered by the research assistants during the research interviews. Both research assistants had training in the use of the Vineland Adaptive Behaviour Scales by the research psychiatrist (ES). An Informant that had known the participant for at least 6 months was used.

3.7.9 Demographics and past 2 years needs questionnaire (see Appendix II)

This was a purpose designed semi-structured questionnaire. It collected information on demographics and levels of social and professional support. It also included postcode data to allocate individuals to quintiles of Carstairs Deprivation Index, a Scottish measure of socio-economic deprivation (Carstairs & Morris, 1989). Similar information was collected at baseline.

3.7.10 Past and Personal History Questionnaire (see Appendix II)

This was a purpose designed questionnaire, used to collect information on past and personal history that may be aetiologically relevant to mental ill-health in adults with intellectual disabilities. Information was collected from a relative wherever possible and included details on early experiences and traumatic/distressing events. This information was not collected at baseline.

3.7.11 Relatives Questionnaire (see Appendix II)

This was a purpose designed questionnaire, used to collect information on the participants' early life experiences and family history. It was completed by the research assistant with a relative acting as informant.

3.8 Psychiatrist review of research interview

Each research interview was discussed in detail with the research psychiatrist (ES) and using the information collected during the research interview a decision was made as to whether detailed psychiatric assessment or a case note review was required. At the same time, problem behaviours were allocated a diagnosis according to DC-LD criteria and the information collected on epilepsy was classified by the research psychiatrist according to the International League Against Epilepsy guidelines. In addition, all medication and physical health information was checked by the research psychiatrist.

All individuals who scored above the lowered threshold on the modified PAS-ADD checklist or retrospective modified PAS-ADD checklist (if they did not have specialist psychiatric assessment at the time of the episode) or had new problem behaviour or not previously assessed problem behaviour or worsening of known problem behaviour or required diagnostic clarification of a possible autistic spectrum disorder or for any other reason were felt by the research assistant or research psychiatrist to have had a possible episode of mental ill-health during the two year follow up period (that did not result in specialist psychiatric assessment) were referred to the Glasgow University Centre for Excellence in Developmental Disabilities (UCEDD) for detailed psychiatric assessment and diagnosis.

Any individuals identified as having had an episode of mental ill-health during the 2 year period who were in contact with intellectual disabilities psychiatry at that time and any individuals for whom no episode of mental ill-health was identified but were known to have had contact with any mental health service at any time during the 2 years plus all individuals referred to the Glasgow UCEDD were allocated for case note review.

A structured form (see Appendix II) completed by the research assistant and reviewed by the research psychiatrist was used to ensure identification of all participants for Glasgow UCEDD referral and all participants for case note review. All referrals to the Glasgow UCEDD were made by the research psychiatrist and copied to the General Practitioner.

3. 9 Detailed psychiatric assessment at Glasgow UCEDD

The Glasgow University Centre for Excellence in Developmental Disabilities is run by two academics who are also qualified Consultant Psychiatrists specialised in working with adults with intellectual disabilities. All participants referred to the Glasgow UCEDD had a face-to-face comprehensive semi-structured psychiatric assessment carried out by one of the two academic Consultants or a Non-Consultant Specialist Psychiatrist working under their supervision.

66% of the follow up assessments were carried out by one of the academic Consultants, 32% by a Specialist Registrar in the final year of training to be eligible for consultant posts in intellectual disabilities psychiatry and 3% by a Senior House Officer in intellectual disabilities.

All individuals referred to the research clinic were assessed at home. The initial appointment was scheduled for 1.5 hours and follow up visits were made until all the necessary information was collected.

The assessing psychiatrist followed a semi-structured format that included the use of several different tools. Contact was made with relatives wherever possible to collect additional personal and development history. All available case notes were reviewed in detail. Records kept by paid carers were also reviewed where appropriate. A detailed mental state examination was carried out. Physical examination and investigations were carried out where appropriate.

3.10 Assessment tools used to supplement clinical assessment by Glasgow UCEDD

3.10.1 Case note review form

Relevant case notes were reviewed by the assessing psychiatrist using a purpose designed semi-structured form to gather essential current and background information. Relevant medical, psychology, psychiatry and Institution case notes were reviewed where available.

3.10.2 The Psychiatric Present State-Learning Disabilities (PPS-LD) (see Appendix III)

The Psychiatric Present State–Learning Disabilities (Cooper, 1997) is an assessment tool designed to illicit psychopathology in adults with intellectual disabilities. The 116 item semi-structured interview, that differentiates between state and trait, can be administered to either individuals with intellectual disabilities or their informants. It is based on the Schedules for Clinical Assessment in Neuropsychiatry (SCAN; World Health Organization, 1999) and facilitates the collection of all the information required to make the diagnosis of most psychiatric disorders (it does not cover sexual dysfunction or eating disorders) according to DC-LD, ICD-10-DCR and DSM-IV-TR criteria. There is no scoring system. The clinician interprets the collected information against the diagnostic criteria as being indicative of a psychiatric disorder or not. It has been shown to have good face validity and inter-rater reliability (Fitzgerald, 1998). The PAS-ADD interview schedule was not chosen as it does not cover all psychiatric disorders, does not allow the identification of bipolar affective disorder or schizophrenia currently in remission, provides only an ICD-10 diagnosis and not according to any other diagnostic criteria and because its reliance on verbal report has significant limitations of use in adults with more severe levels of intellectual disabilities.

3.10.3 Problem Behaviour Checklist (see Appendix III)

The Problem Behaviour checklist is a purpose designed instrument that serves as a prompt to ensure that the clinician gathers all the information about problem behaviour required to allow classification according to DC-LD criteria. Items are ticked as present or absent. There is no scoring system – the information collected is interpreted by the clinician against the diagnostic criteria as indicative of a disorder or not.

3.10.4 ADHD checklist (see Appendix III)

The ADHD checklist is a purpose designed instrument that serves as a prompt to ensure that the clinician collects information on all symptomatology covered within the DC-LD, ICD-10-DCR and DSM-IV-TR diagnostic categories for ADHD/hyperkinetic disorder. There is no scoring system. The information collected is interpreted by the clinician against the diagnostic criteria as indicative of a disorder or not.

3.10.5 Pervasive Developmental Disorders Checklist (see Appendix III)

Previously described in section 3.7.4. However, when used within the psychiatric assessment, no scoring system was used and instead it was used only as a prompt to ensure that all symptomatology suggestive of an autistic spectrum disorder was expanded upon by the assessing psychiatrist. This information was then interpreted by the psychiatrist against the diagnostic criteria as being indicative of an autistic spectrum disorder or not.

3.10.6 Test for Severe Impairment

The Test for Severe Impairment (Albert & Cohen, 1992) was used in any individuals in whom a diagnosis of dementia was being considered. The instrument provides a measure of current cognitive functioning for comparison with previous and future assessments.

3.10.7 Vineland Adaptive Behaviour Scales (survey form)

All participants referred to the Glasgow UCEDD had their level of ability assessed using the Vineland Adaptive Behaviour Scales (survey form) and this information was then used to inform the diagnostic process. This assessment tool was also used to provide a measure of current functioning and best ever functioning in individuals who were being considered as having possible dementia.

3.11 Consensus Diagnosis

Once all clinical information was gathered and the relevant features summarised, each case was presented to at least one of the academic Consultant Psychiatrists and the assigned diagnostic categories agreed upon. This provided a degree of consistency and the discussion and review by at least two specialist psychiatrists, with at least one at consultant level improved the validity of the diagnoses. All participants seen within the Glasgow UCEDD were assigned diagnoses in this manner according to clinical opinion, DC-LD, ICD-10-DCR and DSM-IV-TR diagnostic criteria.

3.12 Case note review to extract diagnoses

The psychiatry case notes of all individuals referred to the Glasgow UCEDD for detailed psychiatric assessment were reviewed by the research psychiatrist (ES), a Consultant in Intellectual Disabilities Psychiatry, to extract the diagnostic categories assigned by the Glasgow UCEDD plus other psychiatric data. In addition, the case notes of any individual identified as being in contact with psychiatry or psychology services over the 2 year period for any reason were also reviewed. In these cases, symptomatology was extracted from the case notes (using a purpose designed checklist-see Appendix IV) and classified by the research psychiatrist into the clinician's opinion and DC-LD, ICD-10-DCR and DSM-IV-TR categories. If the diagnosis was not immediately clear from the information within the case notes it was discussed with the clinician responsible and some cases were then referred to the Glasgow UCEDD for diagnostic clarification. Information was also collected on aetiological factors identified by

the assessing clinician and the duration of each identified episode of mental-ill health with onset defined as when DC-LD diagnostic criteria first met and recovery as when DC-LD diagnostic criteria no longer met or the treating clinician described them as having recovered.

3.13 Summary of study process and assessment tools used

A summary of the study process and the assessment tools used at baseline (T1) and 2 year follow up interviews (T2), the detailed psychiatric assessments at T1/T2 and the case note reviews at T1/T2 are detailed in Table 3.1

3.14 Diagnostic groupings

Diagnoses were grouped to facilitate analysis. The names of the diagnostic groupings differ in the different diagnostic manuals (e.g. 'schizophrenia, schizotypal and delusional disorders' in ICD-10-DCR but 'non-affective psychotic disorders' in DC-LD), but operationalised criteria within each manual were strictly applied. The specific code numbers in each diagnostic grouping for each manual are detailed in Table 3.2.

3.15 Data Analysis

All data collected were entered into the statistical software package SPSS Version 11.5 on a personal computer.

3.16 Sample bias

Possible bias among potential participants for whom consent was refused was examined with regards to age, gender, level of ability, type of accommodation and support, and prevalence of mental ill-health at T1 (baseline). This indicated that weighting of the sample was not required.

Table 3.1 Assessment tools used at baseline (T1) and follow up (T2)

Tool	Purpose	Used at T1	Used at T2
C21st Health Check	Identify physical ill-health	Yes	In part
Modified PAS-ADD checklist	Identify possible mental ill-health at time of assessment & life events in previous year	Yes	Yes & during previous 2 years
PDD checklist	Identify possible autism	Yes	yes
Problem behaviour checklist	Identify possible problem behaviour at time of assessment	Yes	Yes & during previous 2 years
Past 2 years mental health questions	Identify episodes of mental ill-health & problem behaviour occurring during previous two years	No	Yes & during previous 2 years
Retrospective PAS-ADD	Identify possible episodes of mental ill-health during previous 2 years	No	Yes & during previous 2 years
Vineland Adaptive Behaviour Scales (survey form)	Measure of adaptive behaviour	Yes – shortened version, or full version if referred to UCEDD	Yes
Past and Personal History Questionnaire	Collect data on possible risk factors	No	Yes
Relatives Questionnaire	Collect data on possible risk factors	No	Yes
Demographics	Collect data on possible risk factors	Yes	Yes
Past 2 years needs	Collect data on possible risk factors	No	Yes
If referred to research clinic for detailed psychiatric assessment (possible mental ill-health/PB identified)			
PPS-LD	Assist psychiatrist with identification of psychopathology	Yes	Yes
ADHD checklist	Assist psychiatrist with identification of ADHD	Yes	Yes
PDD checklist	Assist psychiatrist with identification of autism	Yes	Yes
PB checklist	Assist psychiatrist with identification of problem behaviour	Yes	Yes
TSI	Assist psychiatrist with assessment of possible dementia	Yes – if possible dementia	Yes – if possible dementia
LD psychiatric assessment and consensus diagnosis	Diagnosis of mental ill-health / problem behaviour at time of assessment	Yes	Yes – and any episode occurring during previous 2 years
If identified as having any mental-ill health or problem behaviour or being in contact with mental health services (whether or not referred to UCEDD)			
Case note review by LD Psychiatrist	Extract diagnoses according to diagnostic criteria and other psychiatric data	Yes	Yes

Table 3.2 Disorders included within each of the diagnostic categories

Diagnostic category	Diagnostic codes		
	DC-LD	ICD-10-DCR	DSM-IV-TR
Psychotic disorder	3.1, 3.2	F20.0-20.3, F20.5, F22.0, F23.0-23.2 F25.0-25.2, F6.0-6.2, F10.5, F12.5	295.10-295.70, 295.90, 297.1, 298.8, 293.81-293.82, 291.3, 291.5, 292.11, 292.12
Affective disorder	4.1-4.3 (excluding 4.1iv)	F30.0-30.2, F31.0-31.7, F32.0-32.3, F33.0-33.3, F34.0, F34.1, F38.0, F6.3	296.00-296.89 (excluding 296.25, 296.26, 296.35, 296.36, 296.8), 293.83, 300.4, 301.13
Anxiety disorder	5.1, 5.2, 5.4, 5.5, 5.9, 5.10	F40.0, F40.1, F41.0-41.1, F43.0-43.2 F6.4	300.01, 300.02, 300.21,-300.23, 308.3, 309.81, 309.0, 309.24-309.4, 309.9
OCD	5.8	F42.0-42.2	300.3
Organic disorder	1.1-1.4, 2.1	F0.0-0.2, F1.0-1.3, F2.0-2.8, F3, F4, F5.0, F5.1, F10.4, F10.6	290.0-290.43, 291.0-291.2, 292.81, 293.0, 294.0, 294.1, 294.9, 294.10
Alcohol/substance use disorder[l]		F10.1, F10.2, F12.1, F12.2	303.9, 305.0, 304.3, 305.2
Pica	6.9		307.52
Sleep disorder[l]		F51.0, F51.2	307.42, 307.45
ADHD	7.1, 7.2	F90.0, F90.1	314.00, 314.01
Autistic-spectrum disorder	1.1, 1.2	F84.0, F84.1	299.00
Problem behaviour	1.2-1.12	F91.0-91.3	312.8, 313.81, 312.34
Personality disorder	1.1-1.7	F60.0-60.8, F7.0-7.2	301.0, 301.2-301.22, 301.4-301.83, 310.1
Other mental ill-health[l]		F65.0, F65.4, F95.2	302.2, 302.81, 307.23

ADHD, attention-deficit hyperactivity disorder; OCD, obsessive-compulsive disorder.
l. For DC-LD, ICD-10-DCR diagnoses included as per the instructions within DC-LD.

3.17 Point prevalence rates

Point prevalence rates with 95% confidence intervals were calculated for individual psychiatric disorders and total psychiatric disorder at T1 and T2 for the whole cohort, mild and moderate-profound intellectual disabilities groups, males and females.

3.18 Incidence rates

Total incidence rates with 95% confidence intervals for individual types and total episodes of mental-ill health occurring over the 2 year period were calculated by calculating the proportion of individuals with the onset of a new episode of illness at any time in the two year period. This was repeated for the mild and moderate-profound intellectual disabilities groups, males and females.

3.19 Standardised incident ratios

Incidence rates were compared with those reported for the general population and standard incident ratios with 95% confidence intervals calculated. Standardised incident ratios were calculated by dividing the number of cases observed in the cohort by the number of cases expected in the cohort according to the general population incidence rates selected for comparison.

3.20 Selection of general population data for comparison and calculation of standardised incident ratios

The selection of comparative studies measuring the incidence of mental ill-health in the general population proved a difficult task primarily because of the different methodology, tendency to report rates for specific disorders rather than overall psychiatric disorder and the different pattern of psychiatric disorder in the general population.

3.20.1 Comparative studies for the overall incidence rate of mental-ill health

Singleton & Lewis (2003) reported general population data on the incidence of common mental disorders (depressive episode, phobias, generalised anxiety disorder, panic disorder, obsessive compulsive disorder and mixed anxiety and depressive disorder). They used a sampling strategy to select 3536 persons from an original cohort of 8580 adults aged 16-74 years, living in private households in England, Wales and Scotland, to be reassessed 18 months after initial assessments. Of the 3536 persons selected, they were able to contact 3045, of whom assessments were completed with 2413 (68%). Information was collected face to face using computer assisted interviewing based on the Clinical Interview Schedule (CIS-R). Episode onset was defined as the proportion of non-cases on the CIS-R at T1 who were cases at T2. Of the 1656 people who were considered not to have a common mental disorder at T1, 184 were found to have a disorder at T2. The estimated rate of onset of episodes of the common mental disorders amongst those that were well at T1 was 6% (after weighting) but this rate does not include any subjects who might have had a common mental disorder between the two points in time. As the median duration of an episode of depression in the general population is thought to be 3 months (Spijker et al, 2002), a considerable proportion of incidence may not have been counted in this rate. Although this study had a large sample size, it did not include persons in hospital or residential facilities and psychiatric assessment was carried out by lay interviewers, rather than clinicians. These factors, along with the exclusion of psychosis, mania, dementia, eating disorders and problem behaviours from the overall incidence of mental disorders limits it use as a comparative study. However, the 18 month incidence rate for clinician diagnoses of the same common mental disorders in the intellectual disabilities cohort was calculated and used with the Singleton & Lewis (2003) rate to calculate a standardised incident ratio with 95% confidence intervals. As in Singleton & Lewis (2003), the denominator used for calculating the incidence rate included only those without any of the common mental disorders at Time 1.

Bijl et al (2002) investigated the 12 month incidence of DSM-IIIR mental disorder in a representative sample of the Dutch population aged 18-64 years. DSM-IIIR diagnoses of depression, dysthymia, bipolar disorder, panic disorder, agoraphobia, simple phobia, social phobia, generalised anxiety disorder, obsessive compulsive disorder, alcohol abuse, alcohol dependence, drug abuse, drug dependence, schizophrenia and other non-affective psychosis, and eating disorders were counted, but personality disorders, developmental disorders, somatoform disorders, sexual and gender identity disorders, sleep disorders, adjustment disorders and organic disorders were not counted. The original sample size was 7076 with an initial participation rate of 69.7% and retention rate of 79.4%. 5618 were interviewed at the second wave. The Composite International Diagnostic Interview was used by non-clinical trained interviewers to determine diagnoses according to DSM-IIIR. All participants were interviewed at home by the non-clinical trained interviewers. Only participants with psychotic symptoms had a clinical evaluation. The first incidence rate of DSM-IIIR mental disorders was reported as 5.68 per 100 person years. This study is limited by the lack of clinical assessment for the very large majority of cases but benefits from being population based and the use of operationalised diagnostic criteria. The incidence rate for the same 15 diagnoses, but according to clinician diagnosis rather than DSM-IV-TR (because of the limitations in using this diagnostic system in adults with moderate-profound intellectual disabilities), and counting only those that did not have or a history of either of these diagnoses at T1, was calculated for the intellectual disabilities cohort. This rate was then compared with the incidence rate reported by Bijl et al (2002) to calculate a standardised incident ratio, with 95% confidence intervals, for the intellectual disabilities cohort.

This comparison was then repeated counting all clinician diagnoses, rather than just the 15 specified diagnoses as the pattern of psychiatric disorder in the intellectual disabilities population differs so much from that in the general population, particularly with regard to problem behaviours which account for a significant proportion of psychiatric disorder in the intellectual disabilities population but are rarely described in the general population.

3.20.2 Comparative study for the incidence rate of psychosis

The 3 Centre AESOP study (Kirkbride et al, 2006) carried out a prospective survey of clinically relevant first onset psychotic syndromes in adults aged 16-64 years presenting to services over a 2 year period (1997-1999). The three centres were South East London (exclusively urban), Bristol (exclusively urban) and Nottingham (mixture of urban, suburban and rural) with Nottingham providing approximately half of the person years. One million six hundred thousand person years yielded 568 subjects presenting to services with probable psychosis who were further assessed using the Schedules for Clinical assessment in Neuropsychiatry (SCAN) and diagnoses made by consensus according to DSM-IV criteria. The overall incidence rate for all psychotic disorders according to DSM-IV criteria (including depression or mania with psychotic symptoms) was 34.8 per 100 000 person years and for DSM-IV non-affective psychosis (including schizophrenia, schizoaffective disorder, delusional disorder, brief psychotic disorder, and psychotic disorders not otherwise specified) was 23.2 per 100, 000 person years. This latter figure was selected as comparison with the intellectual disabilities cohort and calculation of the standardised incident ratio, with 95% confidence intervals, for non-affective psychosis.

3.20.3 Comparative studies for the incidence rate of mania

An epidemiological study carried out in South East London by Kennedy et al (2005) examined all cases of first episode of mania in adults aged 16 years and over presenting to Camberwell psychiatric services over a 35 year period (1965-1999). Case notes were reviewed using the Operational Criteria Checklist for Psychotic Disorders (OPCRIT) and a diagnosis assigned according to DSM-IV criteria. Cases with a previous history of mania or psychosis or an organic cause were excluded from the study. In total, 246 cases met criteria for DSM-IV Bipolar I disorder, first manic episode, giving an incidence rate of 5.86 per 100,000 person years.

The three centre AESOP study (Lloyd et al, 2005) also examined the incidence of bipolar affective disorder and reported a similar rate of 3.067 per 100,000

person years incidence rate for first episode mania according to ICD-10 in adults aged 16-64 years. Although both studies were felt suitable for comparison with the intellectual disabilities cohort, the higher rate reported by Kennedy et al (2005) was chosen for comparison and calculation of the standardised incident ratio, with 95% confidence intervals, as the geographical area covered by this study was more similar in nature to Glasgow than the AESOP study. This time, as DSM-IV criteria appear to be appropriate for the diagnoses of mania in adults with intellectual disabilities, only DSM-IV first episodes of mania in the intellectual disabilities cohort were counted for the comparison.

3.20.4 Comparative studies for the incidence rate of bipolar affective disorder

The AESOP study (Lloyd et al, 2005) reported a 4.6 per 100,000 person years incidence rate for bipolar affective disorder according to ICD-10 in adults aged 16-64 years. However, this rate counted subjects with a diagnosis of manic episode as having bipolar affective disorder, whether or not they had had a previous depressive episode, so is in fact the rate for first episode mania and bipolar affective disorder combined. Of the subjects categorised by Lloyd et al (2005) with bipolar affective disorder, 33% had had a previous depressive disorder, which gives a 1.533 per 100,000 person years incidence rate for new onset ICD-10 bipolar affective disorder.

In the Kennedy et al (2005) study, 52 (22%) of the participants with first episode mania had had a previous depressive episode, giving a first incidence rate for bipolar affective disorder (not counting Bipolar I disorder, single manic episode) according to DSM-IV of 1.2892 per 100,000 person years. However, this rate does not include participants first meeting diagnostic criteria for bipolar affective disorder after two episodes of mania and therefore the higher incidence rate for ICD-10 bipolar affective disorder reported by Lloyd et al (2005) was chosen for comparison with the intellectual disabilities cohort and calculation of the standardised incident ratio.

3.20.5 Comparative studies for the incidence rate of depression

Lehtinen (2005) has estimated the annual incidence rate for all depressive disorders, including both first time and recurrent episodes, as 28.5 per 1000 for adults aged 18-64 years and an annual incidence rate for first ever depressive episode of 20.5 per 1000. A random population sample consisting of 2,999 participants was selected from one urban and one rural area in Finland. Participants were screened for depression using the Beck Depression Inventory and the SCAN-2 interview was used to assign caseness at baseline and then again at 1 year follow up. Participation rate at baseline was 64.7% (1939) and of these 75.3% (1412) participated at the 1 year follow up. ICD-10 single or recurrent depressive disorder, dysthymia or adjustment disorder were counted as cases of depression. The incidence rate for first time and recurrent episodes of depression reported by Lehtinen (2005) was used to calculate the standardised incident ratio for the intellectual disabilities cohort. Separate comparisons with ICD-10 and DC-LD first ever and recurrent episodes of depression, dysthymia and adjustment disorders in the intellectual disabilities cohort were made.

Lihtenen (2005) also reported an estimated annual incidence rate of 20.5 per 1000 for first ever depressive disorders (including dysthymia and adjustment disorder). This rate was used to calculate standardised incident ratios for first ever depressive episodes in the intellectual disabilities cohort for both ICD-10 and DC-LD diagnoses. However, this comparison is limited by recall bias which will have affected both cohorts but the intellectual disabilities cohort more so because of the reliance on informant history.

3.20.6 Comparative study for the incidence rate of substance misuse

The study by Bijl et al (2002) (described in section 3.20.1) was also used for calculation of the standardised incidence ratio for substance misuse. Bijl et al (2002) reported a first incidence rate for DSM-IIIR substance misuse of 1.85 per 100 person years and this was compared with the DSM-IV-TR rate for substance misuse in the intellectual disabilities cohort.

3.20.7 Comparative study for the incidence rate of anxiety disorders

Bijl et al (2002) also reported a first incidence rate per 100 person years for DSM-IIIR anxiety disorders (panic disorder, agoraphobia, simple phobia, social phobia, generalised anxiety disorder and obsessive compulsive disorder) of 2.93. This figure was used for calculation of the standardised incidence ratio for the intellectual disabilities cohort. Again, in keeping with Bijl et al's (2002) methodology, only subjects without any prior history of these disorders were counted. This comparison is limited, as in the intellectual disabilities cohort not all persons with specific phobia identified at the initial interview stage were progressed to full psychiatric assessment so the incidence rate in this cohort is an undercount, compared to Bijl et al (2002) where all cases of specific phobia were subject to a diagnostic interview. Clinician rather than DSM-IV-TR diagnoses in the intellectual disabilities cohort were used because of the high number of criteria within DSM-IV-TR anxiety disorders that rely on subjective report.

3.20.8 Comparative study for the incidence rate of early onset dementia

Mercy et al (2008) estimated the incidence of early onset dementia in a defined area of Cambridgeshire, UK. Cases were identified via specialist memory and dementia clinics at Addenbrookes Hospital. Cases included all adults aged 45-64 years given a multidisciplinary consensus diagnosis of dementia according to standard diagnostic criteria during the 2000-2006 study period. The incidence for all cases of primary dementia for the age range 45-64 years was estimated to be 11.5 cases per 100 000 person years. This finding was felt to be the most comparable available and was used for the calculation of the standardised incidence ratio for early onset dementia in the intellectual disabilities cohort.

3.20.9 Comparative study for the incidence rate of dementia

The Incidence of all types of dementia in persons aged over 65 yrs is generally accepted to be around 15-20 per 1000 person years (Mathews & Brayne,

2005). The lower and upper limits of this range were used for calculation of the standardised incidence ratio for all types of DC-LD dementia in persons with intellectual disabilities aged over 65 years.

3.21 Risk Factor Analysis: Incidence

Three subgroups of incident outcomes were further investigated:

1. Participants with incidence of an episode of mental ill-health during the 2 year follow up period – excluding dementia, delirium and problem behaviours. Dementia and delirium were excluded as it is likely that these disorders have different aetiology. Problem behaviours were excluded because of the ongoing debate about the nosology of these and because of their co-morbidity with other types of mental ill-health.

2. Participants with incidence of an episode of problem behaviour during the 2 year follow up period - defined as any participant with the onset of any type of problem behaviour during the 2 year period.

3. Participants with incidence of an episode of depression during the 2 year follow up period - defined as any participant with an episode of clinician diagnosed unipolar depression, occurring within the two year follow up period.

Possible associations with incident mental ill-health, as described within the three subgroups, were examined using univariate analysis. Four groups of factors were investigated separately for each sub-group of incident mental ill-health.

Personal Factors

1. older age
2. female gender
3. more severe intellectual disabilities
4. Down's Syndrome
5. mental ill-health in the past
6. mental ill-health within a biological family member

Past experiences

1. death of parent/parental figure before age 19 years
2. divorce of parent before age 19 years
3. raised outside a family home before age 19 years
4. other adversity before age 19 years (compulsory removal from family home, known abuse, neglect or exploitation, financial poverty, other traumatic experiences)
5. known adult abuse, neglect or exploitation
6. previous long stay hospital residence during adulthood

Lifestyle and supports measured atT1

1. type of accommodation/support (not living with a family carer)
2. having no employment/day opportunities
3. Carstairs quintile (living in more deprived areas)
4. single status
5. smoking
6. experiencing preceding life events

Health and disabilities measured at T1

1. visual impairment
2. hearing impairment
3. bowel incontinence
4. urinary incontinence
5. impaired mobility
6. severe physical disabilities
7. epilepsy
8. special communication needs

Definitions and sources of information for each of the variables investigated are detailed in Tables 3.3-3.6.

The analysis was conducted in discrete stages. Initially the distribution of the outcomes of interest and each factor were assessed individually. Second, for each of the four groups of factors described above, a backwards stepwise

method was used to determine the set of factors within the group independently related to each incident outcome.

Finally, the independently related factors from these four factor group-specific models were entered into a single global model and a backward stepwise method was used again to reach the final model for that outcome.

Table 3.3 Definitions and sources of information for personal factors investigated

Personal Factors	Definition	Source/s of information
Older age		Age at time of T1 interview
Female gender		C21st health check at T1
More severe intellectual disabilities	Mild Moderate (compared with mild) Severe (compared with mild) Profound (compared with mild)	Ability level measured on Vineland Adaptive Behaviour scales at T2 with scores of all cases with severe mental illness, physical immobility or dementia cross checked with medical case notes and categorised by psychiatrist on combined information
Down's Syndrome	Clinical diagnosis	C21st Health check, GP notes, psychiatric notes where available
Mental ill-health in the past	Any clinician diagnosis of mental ill-health	C21st Health Check at T1, case notes for those referred to UCEDD or identified as open to psychiatry or psychology
Mental ill-health in biological family member	Family history of any mental ill-health in biological relative	Personal history questionnaire administered to relative at T2

Table 3.4 Definitions and sources of information for past experiences factors investigated

Past Experiences	Definition	Source/s of information
Death of parental figure before age 19 years	Death of any parent or parental figure before 19 years of age	Personal history questionnaire administered to relative at T2
Divorce of parent before age 19 years		Personal history questionnaire administered to relative at T2
Raised outside a family home before aged 19 years		Personal history questionnaire administered to relative at T2
Other adversity before 19 years of age	Compulsory removal from family home, known abuse, neglect or exploitation, financial poverty, other traumatic experiences – not death or divorce of parents	Personal history questionnaire administered to relative at T2
Known adult abuse, neglect or exploitation		Personal history questionnaire administered to relative at T2
Previous long-stay hospital residence during adulthood		Health board database of long-stay hospital residents

Table 3.5 Definitions and sources of information for lifestyle and supports factors investigated

Lifestyles and supports	Definition	Source/s of information
Type of accommodation (not living with family carer)		C21st health check at T1 – categorised into living with family carer, lives independently, lives with paid support, congregate setting (nursing home, residential home or large group >10)
Having no employment/day opportunities	no daytime occupation of any type	C21st Health Check at T1
Carstairs Quintile (living in more deprived area)		From postcode at T1 – deprivation scores in quintiles
Single status	Single or otherwise (vs. living with partner/married)	C21st Health Check at T1
Smoking		C21st Health check at T1
Experiencing preceding life events	Number of life events during previous 12 months	PAS-ADD checklist at T1

Table 3.6 Definitions and sources of information for health and disabilities factors investigated

Health and disabilities	Definition	Source/s of information
Visual impairment	vision impaired (not including impairment corrected by glasses) or not impaired	Visual assessment at T1
Hearing Impairment	hearing impaired (not including impairment corrected by aid) or not impaired	Hearing assessment at T1
Bowel incontinence	continent or not	C21st Health check at T1
Urinary incontinence	continent or not	C21st Health check at T1
Impaired mobility	Fully mobile or not	C21st Health check at T1
Severe physical disabilities	has spastic quadriplegia or is using moulded chair	C21st Health check at T1
Epilepsy	any history of epilepsy or not	C21st health check at T1 – including review of GP case notes and current medication
Special communication needs	special communication needs or not	C21st Health Check at T1 - health professional's opinion

Likelihood ratios were used in the stepwise procedures to determine statistical significance for removal of each criterion factor. The removal criterion was set at 0.05.

The three final models were checked for goodness of fit using the Hosmer-Lemeshow test, in which the study sample is divided into deciles of predicated risk and the numbers of observed and expected events compared using Chi squared test. Because of the small numbers of expected events in some deciles of predicted risk, the lowest risk groups were combined until the expected number of events exceeded 3 in all groups.

3.22 Risk Factor Analysis: Endurance

Three further sub-groups were examined to identify factors associated with the endurance of mental-ill health. Persons with mental ill-health present at T1 that had not recovered from this within the two year follow up period were compared with the rest of the cohort. Recovery was defined as when the person no longer met diagnostic criteria or the treating clinician had described them as recovered. The three sub-groups investigated were:

1. All participants with mental ill-health at T1 that was still present at T2 - excluding problem behaviours, bipolar affective disorder in remission, psychosis of any type in remission, recurrent depressive disorder in remission, dementia, delirium, autism, and personality disorders. These exclusions were made because recovery from dementia, autism and personality disorders is not expected and delirium has a clear organic aetiology.

2. All participants with any type of DC-LD problem behaviour at T1 that was still present at T2.

3. All participants with clinician unipolar depression at T1 or the onset of unipolar depression within the first year of follow up and duration of the depressive episode of > 1year.

Possible associations with the endurance of mental ill-health, as described within the three subgroups, were examined using univariate analysis. The same four groups of factors as described in Tables 3.3-3.6 were investigated separately for each sub-group as detailed above.

The analysis was conducted in discrete stages. Initially the distribution of the outcomes of interest and each factor were assessed individually. Second, for each of the four groups of factors described above, a backwards stepwise method was used to determine the set of factors within the group independently related to each outcome.

Finally the independently related factors from these four factor group-specific models were entered into a single global model and a backward stepwise method was used again to reach the final model for that outcome.

Likelihood ratios were used in the stepwise procedures to determine statistical significance for removal of each criterion factor. The removal criterion was set at 0.05.

The three final models for the endurance group were checked for goodness of fit using the Hosmer-Lemeshow test, in which the study sample is divided into deciles of predicated risk and the numbers of observed and expected events compared using Chi squared test. Because of the small numbers of expected events in some deciles of predicted risk, the lowest risk groups were combined until the expected number of events exceeded 3 in all groups.

3.23 Reliability of DC-LD categorisation of problem behaviours at Stage 1 of T2 research interview

Eighteen participants were diagnosed with problem behaviour according to DC-LD criteria based on information collected at the research interview only and were not referred on to the Glasgow UCEDD for more detailed psychiatric assessment. These were participants with longstanding problem behaviours that were known to have been previously assessed and were not felt to have changed during the 2 year period. Problem behaviours were categorised by the

research psychiatrist (ES) according to the information collected during the research interview, with any missing information or additional information required gathered by telephone.

To test inter–rater reliability of the process for categorising problem behaviour according to DC-LD criteria from data collected at the first stage (research interview), 30 participants were blindly rated by another rater (SAC). To test intra-rater reliability, the original rater (ES) re-categorised 30 participants 1 year after completion of data collection. The original categorisation information was not available to the rater at this stage. Although it was possible that they might have remembered the original categorisation this was unlikely given the large number of participants rated by the research psychiatrist over the period of the study and the delay of a 1 year period after the original data collection. Reliability was assessed using the Kappa statistic.

The 30 participants in the inter-rater reliability sample consisted of 20 who were categorised as having at least one problem behaviour according to DC-LD criteria and 10 who were categorised as having no problem behaviours according to DC-LD criteria. For the inter-rater reliability sample there were in total 85 problem behaviours meeting DC-LD criteria. 7 categories of problem behaviour were investigated - verbal aggression, physical aggression, destructiveness to property, aggression of any three types, self injurious behaviour, other problem behaviours (oppositional, sexually inappropriate, excessively demanding, faecal smearing, wandering and other) and any problem behaviour. Thus, 210 pairs of problem behaviour categorisation were compared (30x each of the 7 categories). The inter-rater reliability for the seven categories ranged from 0.72 to 1.00 indicating excellent inter-rater reliability. Individual kappa scores for each of the seven categories are detailed in Table 3.7.

The intra-rater reliability study was also on 210 pairs of problem behaviour categorisation. Kappa scores for intra-rater reliability ranged from (0.791-1.00) indicating that there was consistency in the ratings across the study. Individual Kappa scores for the 7 problem behaviour categories are detailed in table 3.8.

Table 3.7 Inter-rater reliability scores

Problem Behaviour Category	Inter-rater reliability Kappa score
Verbal aggression	0.92
Physical aggression	0.72
Destructiveness to property	1.00
Aggression of any three types	0.79
Self injurious behaviour	1.00
Other problem behaviours	0.83
Problem behaviour of any type	0.86

Table 3.8 Intra-rater reliability scores

Problem Behaviour Category	Intra-rater reliability Kappa score
Verbal aggression	1.00
Physical aggression	0.79
Destructiveness to property	1.00
Aggression of any three types	0.93
Self injurious behaviour	1.00
Other problem behaviours	0.91
Problem behaviour of any type	1.00

Chapter 4 RESULTS

4.1 Cohort characteristics at T1

Baseline assessments at T1 were completed on 70.6% (1094) of the total eligible population for the prevalence study. Valid consent or assent for research was recorded for 92.7% with a resulting cohort of 1023, 66.1% of the population with intellectual disabilities overall. This, combined with the additional 179 subjects who also underwent baseline assessment, but were not included in the prevalence study analysis, gave a potential cohort of 1202.

The prevalence study cohort at T1 comprised 562 men (54.9%) and 461 (45.1%) women and had a mean age of 43.9 years (range 16-83). Levels of ability ranged from mild in 398 (38.9%), through moderate in 248 (24.2%) and severe in 193 (18.9%), to profound intellectual disabilities in 184 (18.0%). 390 (38.1%) participants lived with a family carer, 467 (45.6%) lived with paid carer support, 102 (10.0%) lived independently of paid or family support and 64 (6.3%) lived in congregate care setting, such as nursing home designed to care for older, frail people. The very large majority (95.7%) of the cohort were single and white (96.4%). One hundred and eighty six (18.2%) participants had Down's syndrome. These characteristics are reported in Table 4.1.

4.2 Point prevalence rates of mental ill-health in prevalence cohort at T1

The point prevalence rates, with 95% confidence intervals, of mental-ill health in the prevalence cohort at T1, according to the different diagnostic criteria, are reported in table 4.2. The overall rate of mental ill-health was 40.9% according to clinical diagnosis, 35.2% according to DC-LD, 16.6% according to ICD-10 DCR and 15.7% according to DSM-IV-TR.

The point prevalence rates, with 95% confidence intervals, of mental ill-health in the prevalence cohort at T1 according to clinical diagnosis at different ability levels (mild, mod-profound, all ability levels) are reported in Table 4.3.

The point prevalence rates, with 95% confidence intervals, of mental ill-health in the prevalence cohort at T1 according to clinical diagnosis for men and women are reported in Table 4.4.

Table 4.1 T1 Prevalence cohort characteristics (N=1023)

Characteristic		**Number (%)**
Age	Mean =43.9 years Range =16-83 years	
Gender	Male	562 (55.0)
	Female	461 (45.1)
Ability	Mild	398 (38.9)
	Moderate	248(24.2)
	Severe	193 (18.9)
	Profound	184 (18.0)
Marital status	Single	979 (95.7)
	Married/live in partner	44 (4.3)
Ethnicity	White	986 (96.4)
	Non-white	37 (3.6)
Down's Syndrome	No	834 (81.8)
	Yes	186 (18.2)
Accommodation/support	Lived with family	390 (38.1)
	Lived with paid support	467 (45.6)
	Lived independently of paid support	102 (10.0)
	Lived in congregate care setting	64 (6.3)

Table 4.2 Point prevalence rates of mental ill-health at T1 (n=1023)

Diagnostic Category	Clinical Diagnosis		DC-LD Diagnosis		DCR-ICD10 Diagnosis		DSM-IV-TR Diagnosis	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Psychotic disorder*	45	4.4 (3.2-5.8)	39	3.8 (2.7-5.2)	27	2.6 (1.8-3.8)	35	3.4 (2.4-4.7)
Affective Disorder	68	6.6 (5.2-8.4)	57	5.7 (4.3-7.3)	49	4.8 (3.6-6.3)	37	3.6 (2.6-5.0)
Anxiety Disorder†	39	3.8 (2.7-5.2)	32	3.1 (2.2-4.4)	29	2.8 (1.9-4.1)	25	2.4 (1.6-3.6)
OCD	7	0.7 (0.3-1.4)	5	0.5 (0.2-1.1)	2	0.2 (0.0-0.7)	2	0.2 (0.0-0.7)
Organic Disorder	22	2.2 (1.4-3.3)	21	2.1 (1.3-3.1)	19	1.9 (1.1-2.9)	17	1.7 (1.0-2.7)
Alcohol/substance misuse	10	1.0 (0.5-1.8)	8	0.8 (0.3-1.5)	8	0.8 (0.3-1.5)	8	0.8 (0.3-1.5)
Pica	20	2.0 (1.3-3.1)	20	2.0 (1.2-3.0)	0	0 (0.0-0.0)	9	0.9 (0.4-1.7)
Eating Disorder††	0	0 (0.0-0.0)	0	0 (0.0-0.0)	0	0 (0.0-0.0)	0	0 (0.0-0.0)
Sleep Disorder	6	0.6 (0.2-1.2)	4	0.4 (0.1-1.0)	2	0.2 (0.0-0.7)	2	0.2 (0.0-0.7)
ADHD	15	1.5 (0.08-2.4)	12	1.2 (0.6-2.0)	5	0.5 (0.2-1.1)	4	0.4 (0.1-1.0)
Autistic Spectrum Disorder	77	7.5 (6.0-9.3)	45	4.4 (3.2-5.8)	22	2.2 (1.3-3.4)	20	2.0 (1.2-3.0)
Problem Behaviour	230	22.5 (20.0-25.2)	191	18.7 (16.3-21.2)	1	0.1 (0.0-0.5)	1	0.1 (0.0-0.5)
Personality Disorder	10	1.0 (0.5-1.8)	8	0.8 (0.3-1.5)	7	0.7 (0.3-1.4)	7	0.7 (0.3-1.4)
Other mental ill health	14	1.4 (0.8-2.3)	8	0.8 (0.3-1.5)	7	0.7 (0.3-1.4)	4	0.4 (0.1-1.0)
Mental ill health of any type, excluding problem behaviours and autism†	229	22.4 (19.9-25.1)	195	19.1 (16.7-21.6)	148	14.5 (12.4-16.8)	142	13.9 (11.8-16.2)
Mental ill health of any type, excluding autism†	378	37.0 (34.1-40.1)	336	32.8 (30.0-35.8)	149	14.6 (12.5-16.9)	143	14.0 (11.9-16.3)
Mental ill health of any type, excluding problem behaviours†	290	28.3 (25.6-31.2)	229	22.4 (19.9-25.1)	169	16.5 (14.3-18.9)	160	15.6 (13.5-18.0)
Mental ill health of any type†	418	40.9 (37.8-43.9)	359	35.2 (32.2-38.2)	170	16.6 (14.4-19.0)	161	15.7 (13.6-18.1)

*Includes schizoaffective disorders, †Excludes specific phobias, ††Excludes pica, ADHD= attention deficit hyperactivity disorder, OCD= obsessive compulsive disorder

Table 4.3 Point prevalence rates of clinical diagnosis of mental ill-health at T1 at different ability levels

Diagnostic Category	Mild intellectual disabilities (n=398)		Moderate-profound intellectual disabilities (n=625)		All ability levels (n=1023)	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Psychotic disorder*	23	5.8 (3.7-8.6)	22	3.5 (2.2-5.3)	45	4.4 (3.2-5.8)
Affective Disorder	26	6.5 (4.3-9.4)	42	6.7 (4.9-9.0)	68	6.6 (5.2-8.4)
Anxiety Disorder†	24	6.0 (3.9-8.8)	15	2.4 (1.4-4.0)	39	3.8 (2.7-5.2)
OCD	3	0.8 (0.2-2.2)	4	0.6 (0.2-1.6)	7	0.7 (0.3-1.4)
Organic Disorder	7	1.8 (0.7-3.6)	15	2.4 (1.4-4.0)	22	2.2 (1.4-3.3)
Alcohol/substance misuse	7	1.8 (0.7-3.6)	3	0.5 (0.1-1.4)	10	1.0 (0.5-1.8)
Pica	1	0.3 (0.0-1.4)	19	3.0 (1.8-4.7)	20	2.0 (1.3-3.1)
Eating Disorder††	0	0 (0.0-0.9)	0	0 (0.0-0.6)	0	0 (0.0-0.0)
Sleep Disorder	2	0.5 (0.1-1.8)	4	0.6 (0.2-1.6)	6	0.6 (0.2-1.2)
ADHD	0	0 (0.0-0.9)	15	2.4 (1.4-4.0)	15	1.5 (0.08-2.4)
Autistic Spectrum Disorder	14	3.5 (1.9-5.8)	63	10.1 (7.8-12.7)	77	7.5 (6.0-9.3)
Problem Behaviour	52	13.1 (9.9-16.8)	178	28.5 (25.0-32.2)	230	22.5 (20.0-25.2)
Personality Disorder	3	0.8 (0.2-2.2)	7	1.1 (0.5-2.3)	10	1.0 (0.5-1.8)
Other mental ill health	4	1.0 (0.3-2.6)	10	1.6 (0.8-2.9)	14	1.4 (0.8-2.3)
Mental ill health of any type, excluding problem behaviours and autism†	89	22.4 (18.4-26.8)	140	22.4 (19.2-25.9)	229	22.4 (19.9-25.1)
Mental ill health of any type, excluding autism†	128	32.2 (27.6-37.0)	250	40.0 (36.1-44.0)	378	37.0 (34.1-40.1)
Mental ill health of any type, excluding problem behaviours†	101	25.4 (21.2-30.0)	189	30.2 (26.7-34.0)	290	28.3 (25.6-31.2)
Mental ill health of any type†	137	34.4 (29.8-39.3)	281	45.0 (41.0-49.0)	418	40.9 (37.8-43.9)

*Includes schizoaffective disorders, †Excludes specific phobias, ††Excludes pica, ADHD= attention deficit hyperactivity disorder, OCD= obsessive compulsive disorder

Table 4.4 Point prevalence rates of clinical diagnosis of mental ill-health at T1 by gender

Diagnostic Category	Men (n=562)		Women (n=461)		Total (n=1023)	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Psychotic disorder*	24	4.3 (2.8-6.3)	21	4.6 (2.8-6.9)	45	4.4 (3.2-5.8)
Affective Disorder	31	5.5 (3.8-7.7)	37	8.0 (5.7-10.9)	68	6.6 (5.2-8.4)
Anxiety Disorder†	19	3.4 (2.1-5.2)	20	4.3 (2.7-6.6)	39	3.8 (2.7-5.2)
OCD	2	0.4 (0.0-1.3)	5	1.1 (0.3-2.5)	7	0.7 (0.3-1.4)
Organic Disorder	12	2.1 (1.1-3.7)	10	2.2 (1.0-3.9)	22	2.2 (1.4-3.3)
Alcohol/substance misuse	8	1.4 (0.6-2.8)	2	0.4 (0.0-1.6)	10	1.0 (0.5-1.8)
Pica	14	2.5 (1.4-4.1)	6	1.3 (0.5-2.8)	20	2.0 (1.3-3.1)
Eating Disorder††	0	0 (0.0-0.6)	0	0 (0.0-0.8)	0	0 (0.0-0.0)
Sleep Disorder	4	0.7 (0.2-1.8)	2	0.4 (0.0-1.6)	6	0.6 (0.2-1.2)
ADHD	7	1.2 (0.5-2.5)	8	1.7 (0.7-3.4)	15	1.5 (0.08-2.4)
Autistic Spectrum Disorder	59	10.5 (8.1-13.3)	18	3.9 (2.3-6.1)	77	7.5 (6.0-9.3)
Problem Behaviour	110	19.6 (16.4-23.1)	120	26.0 (22.1-30.3)	230	22.5 (20.0-25.2)
Personality Disorder	5	0.9 (0.3-2.1)	5	1.1 (0.3-2.5)	10	1.0 (0.5-1.8)
Other mental ill health	4	0.7 (0.2-1.8)	10	2.2 (1.0-4.0)	14	1.4 (0.8-2.3)
Mental ill health of any type, excluding problem behaviours and autism†	119	21.2 (17.8-24.8)	110	23.9 (20.0-28.0)	229	22.4 (19.9-25.1)
Mental ill health of any type, excluding autism†	191	34.0 (30.1-38.1)	187	40.6 (36.0-45.2)	378	37.0 (34.1-40.1)
Mental ill health of any type, excluding problem behaviours†	164	29.2 (25.5-33.1)	126	27.3 (23.3-31.7)	290	28.3 (25.6-31.2)
Mental ill health of any type†	219	39.0 (35.0-43.1)	199	43.2 (38.6-47.8)	418	40.9 (37.8-43.9)

*Includes schizoaffective disorders, †Excludes specific phobias, ††Excludes pica, ADHD= attention deficit hyperactivity disorder, OCD= obsessive compulsive disorder

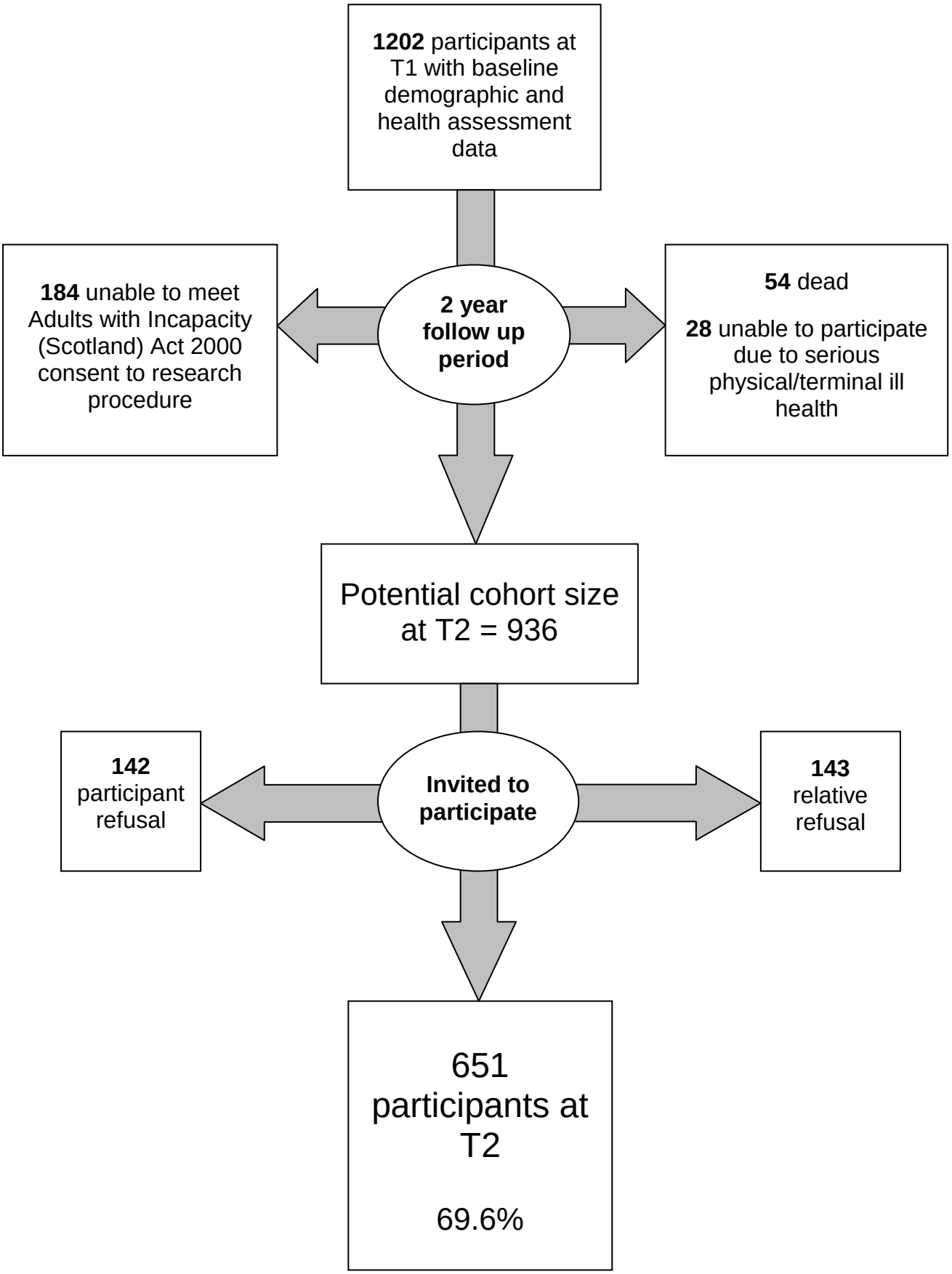
4.3 Cohort characteristics at T2

At time point 2, 266 of the potential cohort had to be excluded. Fifty four of the original cohort had died during the two year follow up. Implementation of the Adults with Incapacity (Scotland) Act 2000 during the two year follow up period meant that 184 of the original cohort could not participate in the 2 year follow up assessment because they were unable to meet the Adults with Incapacity (Scotland) Act 2000 consent to research procedure i.e. they were not able to give informed consent, did not have a Welfare Guardian with powers to consent to research on their behalf and had no traceable next of kin to consent on their behalf. At T1, prior to the implementation of the Adults with Incapacity (Scotland) Act 2000, these participants were included via assent given by their primary carer as agreed by the research ethics committee at that time. Twenty eight of the original cohort were also excluded due to other circumstances such as serious physical or terminal ill health or physical ill health of their primary carer. The potential cohort was therefore 936 (1202-266). Of the potential 936 participants, 142 declined to participate and for 143, their nearest relative declined on their behalf. Six hundred and fifty one adults participated at both T1 and T2. This gave a participation rate of 69.6% (651/936) and allowed the collection of data for 1302 person years. A flow chart of the follow up outcomes is presented in Figure 4.1.

At T2, the cohort comprised of 355 (54.5%) men and 296 (45.5%) women and had a mean age of 46.1 years (range 18.2 – 80.8). Levels of ability ranged from mild in 254 (39.0%), through moderate in 140 (21.5%) and severe in 126 (19.4%) to profound intellectual disabilities in 131 (20.1%). 242 (37.2%) participants lived with a family carer, 294 (45.2%) lived with paid carer support, 46 (7.1%) lived independently of paid or family support and 69 (10.6%) lived in a congregate care setting such as nursing homes designed to care for older, frail people. The very large majority (96.5%) of the cohort were single and white (97.5%). 134 (20.5%) participants had Down's syndrome. These characteristics are detailed in Table 4.5.

Of the participants living in rented accommodation, 32.8% were previously long-stay hospital residents, as were 31.1% of those living in a congregate care

Figure 4.1 Follow up outcomes



setting. 147 (22.6%) of participants had no daytime opportunities or occupation, 24 of whom were of retirement age (65 years or over).

Table 4.5 T2 cohort characteristics (n=651)

Characteristic		Number (%)
Age	Mean =46.1 years Range =18-81 years	
Gender	Male	355 (54.5)
	Female	296 (45.5)
Ability	Mild	254 (39.0)
	Moderate	140 (21.5)
	Severe	126 (19.4)
	Profound	131 (20.1)
Marital status	Single	628 (96.5)
	Married	23 (3.5)
Ethnicity	White	635 (97.5)
	Non-white	37 (3.6)
Down's Syndrome	No	517 (79.5)
	Yes	134 (20.5)
Accommodation/support	Lived with family	242 (37.2)
	Lived with paid support	294 (45.2)
	Lived independently of paid support	46 (7.1)
	Lived in congregate care setting	69 (10.6)

4.4 Comparison of characteristics of incidence study participants and non-participants

There was no significant difference in terms of age at T1, gender, level of intellectual disabilities, type of accommodation/support at T1 or prevalence of mental ill-health at T1 between the 651 participants and those for whom consent was not gained at T2, and therefore the data did not require to be weighted. Results of the participant bias analysis are detailed in Table 4.6.

Table 4.6 Comparison of characteristics of incidence study participants and non-participants

Characteristics at T1			Participants (n=651)	Non-participants (n=285)	P-value
Age	Years	Mean (SD)	43.6 (14.2)	43.9 (14.4)	0.764
Gender	Male	n (%)	355 (54.5%)	156 (54.8%)	0.953
	Female	n (%)	296 (45.5%)	129 (45.2%)	
Ability	Mild	n (%)	254 (39.0%)	118 (41.4%)	0.127
	Moderate	n (%)	140 (21.5%)	73 (25.6%)	
	Severe	n (%)	126 (19.4%)	53 (18.6%)	
	Profound	n (%)	131 (20.1%)	41 (14.4%)	
Type of living / support arrangement at T1	Lived with family	n (%)	258 (39.7%)	113 (39.9%)	0.673
	Lived with paid support	n (%)	297 (45.7%)	122 (42.8%)	
	Lived independently of paid support	n (%)	51 (7.8%)	28 (9.9%)	
	Lived in congregate care setting	n (%)	44 (6.8%)	22 (7.8%)	
Prevalence of mental ill-health at T1[†]	including PB and autism	n (%)	243 (37.3%)	103 (36.1%)	0.729
	excluding PB, including autism	n (%)	170 (26.1%)	74 (26.0%)	0.962
	excluding PB and autism	n (%)	136 (20.9%)	56 (19.6%)	0.665

[†] excludes specific phobia, PB=problem behaviours

4.5 Comparison of characteristics of incidence study participants and prevalence study participants

There was also no significant difference in terms of age at T1, gender, level of intellectual disabilities, type of accommodation/support at T1 or prevalence of mental ill-health at T1 between the population based prevalence study participants and the 651 participants in this incidence study. Results of this participant characteristics analysis are detailed in Table 4.7.

Table 4.7 Comparison of characteristics of prevalence and incidence study participants

Characteristics at T1			Prevalence cohort (n=1023)	Incidence cohort (n=651)	P-value
Age	Years	Mean (SD)	43.9 (16-83)	43.6 (16-78)	0.691
Gender	Male	N (%)	562 (55.0)	355 (54.5)	0.871
	Female	N (%)	461 (45.0)	296 (45.5)	
Ability	Mild	N (%)	398 (38.9)	254 (39.0)	0.512
	Moderate	N (%)	248 (24.2)	140 (21.5)	
	Severe	N (%)	193 (18.9)	126 (19.4)	
	Profound	N (%)	184 (18.0)	131 (20.1)	
Type of living / support arrangement at T1	Lived with family	N (%)	390 (38.1)	258 (39.7)	0.498
	Lived with paid support	N (%)	467 (45.6)	298 (45.8)	
	Lived independently of paid support	N (%)	102 (10.0)	51 (7.8)	
	Lived in congregate care setting	N (%)	64 (6.3)	44 (6.8)	
Down's syndrome	No	N (%)	837 (81.8)	517 (79.4)	0.223
	Yes	N (%)	186 (18.2)	134 (20.6)	
Prevalence of mental ill-health at T1[†]	Including PB and autism	N (%)	418 (40.9)	243 (37.3)	0.149
	Excluding PB, including autism	N (%)	289 (28.3)	170 (26.1)	0.339
	Excluding PB and autism	N (%)	229 (22.4)	136 (20.9)	0.470

[†] excludes specific phobia, PB=problem behaviours

4.6 Point prevalence of mental ill-health at T2

The point prevalence rates, with 95% confidence intervals, of mental ill-health in the cohort at T2, according to the different diagnostic criteria, are reported in table 4.8. The overall rate of mental ill-health was 35.9% according to clinician diagnosis, 32.6% according to DC-LD, 19.8% according to ICD-10-DCR and 17.5% according to DSM-IV-TR.

Point prevalence rates, with 95% confidence intervals, for mental ill-health in the cohort at T2 according to clinician diagnosis at different ability levels (mild, mod-profound, all ability levels) were calculated and are reported in Table 4.9.

Point prevalence rates, with 95% confidence intervals, for mental ill-health in the cohort at T2 according to clinician diagnosis for men and women were calculated and are reported in Table 4.10.

4.7 Timing of T2 assessment

The mean and median length of time between T1 and T2 assessments were both 26 months but to ensure the standard of clinical data collection, only episodes of mental ill-health occurring within 2 years of the T1 assessment were counted. Therefore, data on 1302 person years was collected.

4.8 Participants with identified possible, probable or definite mental ill-health occurring during the two year follow up period

Three hundred and twenty seven (50.2%) participants were identified as having possible, probable or definite mental ill-health occurring during the 2 year follow up period. Of them, 18 were clearly identified as having problem behaviour and were diagnosed by the research psychiatrist (ES) based on information collected at the T2 interview and information from the T1 case note review. One hundred and sixty five participants were newly referred to the Glasgow UCEDD for detailed psychiatric assessment and an additional 144 were identified as having received care from psychiatry or psychology services during the 2 year period and had their case notes reviewed by the research psychiatrist to extract

Table 4.8 Point Prevalence of mental ill-health at T2 for whole cohort (N=651)

Diagnostic Category	Clinical Diagnosis		DC-LD Diagnosis		DCR-ICD10 Diagnosis		DSM-IV-TR Diagnosis	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Psychotic disorder*	26	4.0 (2.6-5.8)	24	3.7 (2.3-5.4)	21	3.2 (2.0-4.9)	23	3.5 (2.3-5.3)
Affective Disorder	48	7.4 (5.5-9.7)	39	6.0 (4.3-8.1)	33	5.1 (3.5-7.1)	26	4.0 (2.6-5.8)
Anxiety Disorder†	27	4.1 (2.8-6.0)	23	3.5 (2.3-5.3)	21	3.2 (2.0-4.9)	14	2.2 (1.2-3.6)
OCD	3	0.5 (0.1-1.3)	2	0.3 (0.0-1.1)	1	0.2 (0.0-0.9)	1	0.2 (0.0-0.9)
Organic Disorder	22	3.4 (2.1-5.1)	22	3.4 (2.1-5.1)	18	2.8 (1.7-4.3)	17	2.6 (1.5-4.2)
Alcohol/substance misuse	7	1.1 (0.4-2.2)	7	1.1 (0.4-2.2)	7	1.1 (0.4-2.2)	7	1.1 (0.4-2.2)
Pica	14	2.2 (1.2-3.6)	14	2.2 (1.2-3.6)	0	0 (0.0-0.6)	6	0.9 (0.3-2.0)
Eating Disorder††	1	0.2 (0.0-0.9)	1	0.2 (0.0-0.9)	1	0.2 (0.0-0.9)	1	0.2 (0.0-0.9)
Sleep Disorder	3	0.5 (0.1-1.3)	1	0.2 (0.0-0.9)	1	0.2 (0.0-0.9)	1	0.2 (0.0-0.9)
ADHD	14	2.2 (1.2-3.6)	12	1.8 (1.0-3.2)	4	0.6 (0.2-1.6)	3	0.5 (0.1-1.3)
Autistic Spectrum Disorder	49	7.5 (6.5-9.8)	36	5.5 (3.9-7.6)	25	3.8 (2.5-5.6)	20	3.1 (1.9-4.7)
Problem Behaviour	107	16.4 (13.7-19.5)	95	14.6 (12.0-17.6)	0	0 (0.0-0.6)	0	0 (0.0-0.6)
Personality Disorder	8	1.2 (0.5-2.4)	7	1.1 (0.4-2.2)	6	0.9 (0.3-2.0)	5	0.8 (0.3-1.8)
Other mental ill health	6	0.9 (0.3-2.0)	5	0.8 (0.3-1.8)	4	0.6 (0.2-1.6)	2	0.3 (0.0-1.1)
Mental ill health of any type, excluding problem behaviours and autism†	153	23.5 (20.3-27.0)	138	21.2 (18.1-24.5)	107	16.4 (13.7-19.5)	98	15.1 (12.4-18.0)
Mental ill health of any type, excluding autism†	209	32.1 (28.5-35.8)	193	29.6 (26.2-33.3)	107	16.4 (13.7-19.5)	98	15.1 (12.4-18.0)
Mental ill health of any type, excluding problem behaviours†	188	28.1 (25.4-32.5)	164	25.2 (21.9-28.7)	129	19.8 (16.8-23.1)	114	17.5 (14.7-20.7)
Mental ill health of any type†	234	35.9 (32.3-39.8)	212	32.6 (29.0-36.3)	139	19.8 (18.3-24.7)	114	17.5 (14.7-20.7)

*Includes schizoaffective disorders, †Excludes specific phobias,††Excludes pica, ADHD= attention deficit hyperactivity disorder, OCD= obsessive compulsive disorder

Table 4.9 Point prevalence rates of clinical diagnosis of mental ill-health at T2 at different ability levels

Diagnostic Category	Mild intellectual disabilities (n=254)		Moderate-profound intellectual disabilities (n=397)		All ability levels (n=651)	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Psychotic disorder*	13	5.1 (2.7-8.6)	13	3.3 (1.8-5.5)	26	4.0 (2.6-5.8)
Affective Disorder	18	7.1 (4.2-11.0)	30	7.6 (5.2-10.6)	48	7.4 (5.5-9.7)
Anxiety Disorder†	12	4.7 (2.5-8.1)	15	3.8 (2.1-6.2)	27	4.1 (2.8-6.0)
OCD	2	0.8 (0.1-2.8)	1	0.3 (0.0-1.4)	3	0.5 (0.1-1.3)
Organic Disorder	5	2.0 (0.6-4.5)	17	4.3 (2.5-6.8)	22	3.4 (2.1-5.1)
Alcohol/substance misuse	5	2.0 (0.6-4.5)	2	0.5 (0.1-1.8)	7	1.1 (0.4-2.2)
Pica	1	0.4 (0.0-2.2)	13	3.3 (1.8-5.5)	14	2.2 (1.2-3.6)
Eating Disorder††	0	0 (0.0-0.01)	1	0.3 (0.0-1.4)	1	0.2 (0.0-0.9)
Sleep Disorder	0	0 (0.0-0.01)	3	0.8 (0.2-2.2)	3	0.5 (0.1-1.3)
ADHD	0	0 (0.0-0.01)	14	3.5 (1.9-5.8)	14	2.2 (1.2-3.6)
Autistic Spectrum Disorder	11	4.3 (2.2-7.6)	38	9.6 (6.9-12.9)	49	7.5 (6.5-9.8)
Problem Behaviour	20	7.9 (4.9-11.9)	87	21.9 (17.9-26,3)	107	16.4 (13.7-19.5)
Personality Disorder	5	2.0 (0.6-4.5)	3	0.8 (0.2-2.2)	8	1.2 (0.5-2.4)
Other mental ill health	2	0.8 (0.1-2.8)	4	1.0 (0.3-2.6)	6	0.9 (0.3-2.0)
Mental ill health of any type, excluding problem behaviours and autism†	52	20.5 (15.7-26.0)	101	25.4 (21.2-30.0)	153	23.5 (20.3-27.0)
Mental ill health of any type, excluding autism†	61	24.0 (18.9-29.7)	148	37.3 (32.5-42.2)	209	32.1 (28.5-35.8)
Mental ill health of any type, excluding problem behaviours†	60	23.6 (18.5-29.3)	128	32.2 (27.7-37.1)	188	28.1 (25.4-32.5)
Mental ill health of any type†	67	26.4 (21.1-32.2)	167	42.1 (37.2-47.1)	234	35.9 (32.3-39.8)

*Includes schizoaffective disorders, †Excludes specific phobias, ††Excludes pica, ADHD= attention deficit hyperactivity disorder, OCD= obsessive compulsive disorder

Table 4.10 Point Prevalence rates of clinical diagnosis of mental ill-health at T2 by gender

Diagnostic Category	Men (n=355)		Women (n=296)		Total (n=651)	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Psychotic disorder*	14	3.9 (2.2-6.5)	12	4.1 (2.1-7.0)	26	4.0 (2.6-5.8)
Affective Disorder	23	6.5 (4.1-9.6)	25	8.4 (5.5-12.2)	48	7.4 (5.5-9.7)
Anxiety Disorder†	16	4.5 (2.6-7.2)	11	3.7 (1.9-6.5)	27	4.1 (2.8-6.0)
OCD	0	0 (0.0-1.0)	3	1.0 (0.2-2.9)	3	0.5 (0.1-1.3)
Organic Disorder	9	2.5 (1.2-4.8)	13	4.4 (2.4-7.4)	22	3.4 (2.1-5.1)
Alcohol/substance misuse	7	2.0 (0.8-4.0)	0	0 (0.0-1.2)	7	1.1 (0.4-2.2)
Pica	10	2.8 (1.4-5.1)	4	1.4 (0.4-3.4)	14	2.2 (1.2-3.6)
Eating Disorder††	1	0.3 (0.0-1.6)	0	0 (0.0-1.2)	1	0.2 (0.0-0.9)
Sleep Disorder	2	0.6 (0.1-2.0)	1	0.3 (0.0-1.9)	3	0.5 (0.1-1.3)
ADHD	7	2.0 (0.8-4.0)	7	2.4 (1.0-4.8)	14	2.2 (1.2-3.6)
Autistic Spectrum Disorder	41	11.5 (8.4-15.3)	8	2.7 (1.2-5.3)	49	7.5 (6.5-9.8)
Problem Behaviour	69	19.4 (15.4-24.0)	38	12.8 (9.2-17.2)	107	16.4 (13.7-19.5)
Personality Disorder	1	0.3 (0.0-1.6)	7	2.4 (1.0-4.8)	8	1.2 (0.5-2.4)
Other mental ill health	2	0.6 (0.1-2.0)	4	1.4 (0.4-3.4)	6	0.9 (0.3-2.0)
Mental ill health of any type, excluding problem behaviours and autism†	79	22.3 (18.0-27.0)	74	25.0 (20.2-30.3)	153	23.5 (20.3-27.0)
Mental ill health of any type, excluding autism†	118	33.2 (28.4-38.4)	91	30.7 (25.5-36.3)	209	32.1 (28.5-35.8)
Mental ill health of any type, excluding problem behaviours†	109	30.7 (25.9-35.8)	79	26.7 (21.7-32.1)	188	28.1 (25.4-32.5)
Mental ill health of any type†	138	38.9 (33.8-44.2)	96	32.4 (27.1-38.1)	234	35.9 (32.3-39.8)

*Includes schizoaffective disorders, †Excludes specific phobias, ††Excludes pica, ADHD= attention deficit hyperactivity disorder, OCD= obsessive compulsive disorder

diagnostic and other psychiatric data. This information is displayed in Figure 4.2.

4.9 Participants referred to Glasgow UCEDD

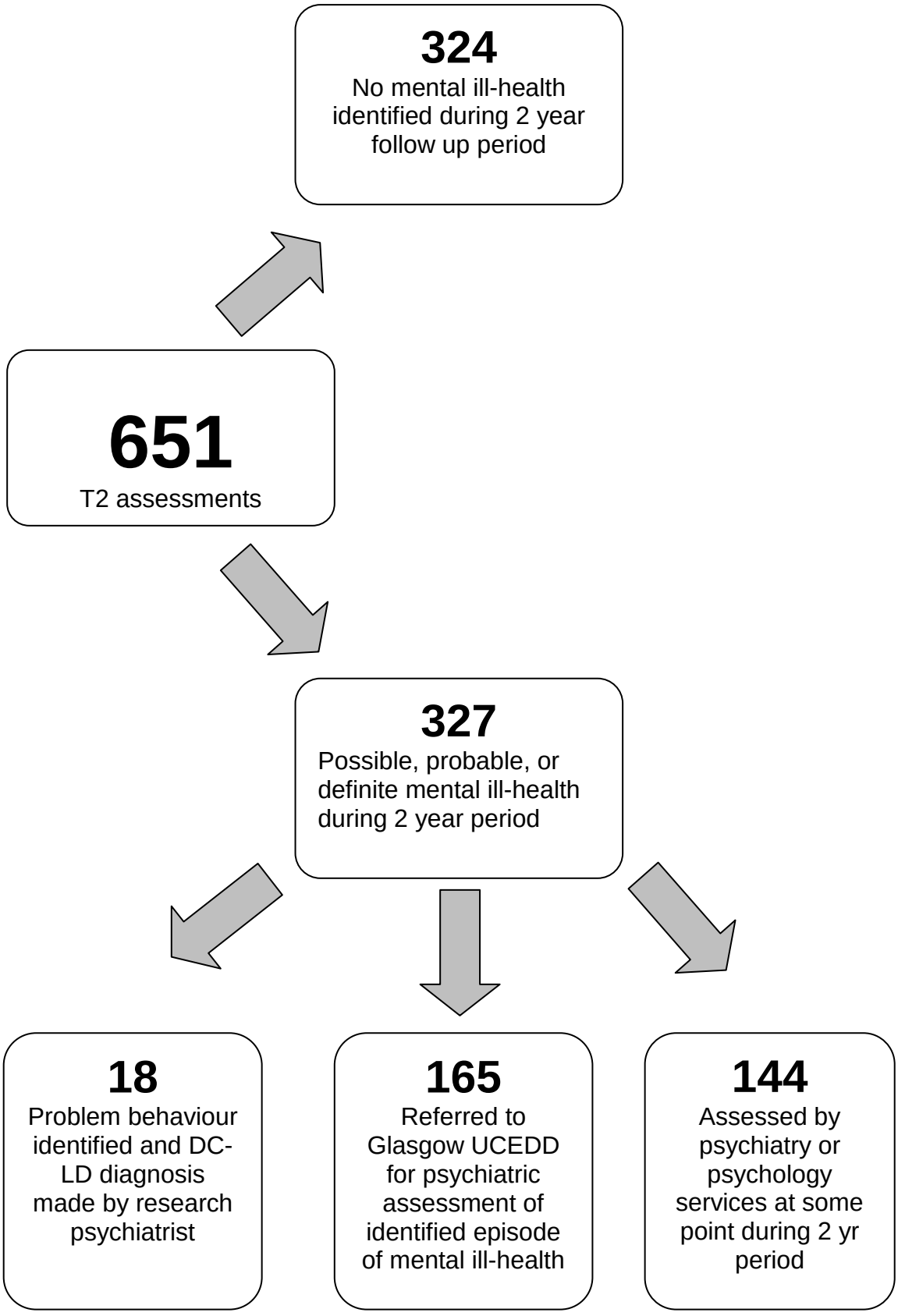
One hundred and sixty five participants were referred to Glasgow UCEDD for structured psychiatric assessment. One hundred and twenty were referred because they scored above the lowered threshold on the modified PAS-ADD checklist completed during the T2 interview, 6 because of newly identified or worsening problem behaviour and 19 because they were known to have mental ill-health and received treatment during the 2 year follow up period from psychiatry or psychology and more detailed diagnostic clarification was required, and 19 for further assessment of a possible interim episode of mental ill-health (an episode of mental ill-health occurring within the 2 year follow up period but no longer present at the time of the T2 interview).

Of the one hundred and twenty participants referred to Glasgow UCEDD because they scored above the lowered threshold on the modified PAS-ADD checklist at T2, four failed to attend the appointments offered to them and did not undergo the Glasgow UCEDD structured psychiatric assessment. Of these four, two were already receiving psychiatric care and had their case notes reviewed by the research psychiatrist (ES) to identify any possible episode of mental ill-health occurring in the two year period. The other two participants had had previous contact with psychiatry and also had their case notes reviewed by the research psychiatrist (ES) but it is possible that episodes of mental ill-health occurring for these two participants were missed.

Six participants were referred to Glasgow UCEDD solely because of newly identified or worsening problem behaviour (most participants with problem behaviour also scored above the lowered threshold on the modified PAS-ADD Checklist and so were also referred for that reason).

Of the nineteen participants referred to Glasgow UCEDD for further assessment of a possible interim episode of mental ill-health, eighteen were referred because they scored above the lowered threshold on the retrospective modified

Figure 4.2 T2 assessment mental health outcomes



PAS-ADD Checklist and one was referred because it was noted that the GP had prescribed antidepressant medication during the two year follow up period.

One participant was referred to the Glasgow UCEDD because although they did not score above the lowered threshold on the modified PAS-ADD Checklist at T2 or the retrospective modified PAS-ADD Checklist and problem behaviour had not been identified, the research assistant was concerned that they appeared anxious and it was agreed with the research psychiatrist (ES) that more detailed psychiatric assessment was appropriate.

One hundred and seven (65%) of the referrals to Glasgow UCEDD were seen by one of the UCEDD consultants, 50 (30%) were seen by the UCEDD Specialist Registrar under supervision by one of the UCEDD Consultants and 4 (2%) were seen by the UCEDD Senior House Officer under supervision by one of the UCEDD Consultants. All assessments were discussed with the UCEDD Consultants for consensus diagnosis, including those conducted by the UCEDD Consultants.

One hundred and sixty three of the participants referred to Glasgow UCEDD had their case notes reviewed by the research psychiatrist (ES) to extract diagnostic and other psychiatric data. Two participants refused consent for their case notes to be reviewed by the research psychiatrist (ES) and in both cases the diagnostic and psychiatric data was provided (with consent) by the Glasgow UCEDD psychiatrist who had conducted the psychiatric assessment.

4.10 Participants scoring on the modified PAS-ADD checklist or retrospective modified PAS-ADD checklist or PDD questionnaire or Problem Behaviour Checklist but not referred to Glasgow UCEDD

One participant scored above the lowered threshold on the retrospective modified PAS-ADD Checklist but after discussion with the research psychiatrist (ES) was not referred to Glasgow UCEDD. Low mood and tearfulness were identified as occurring for a few weeks following the death of his mother and was thought to be part of a normal bereavement reaction and not an episode of

mental ill-health. The participant did not score above threshold on the T2 modified PAS-ADD checklist.

Five other participants scored above the lowered threshold on the T2 modified PAS-ADD checklist and after discussion with the research psychiatrist (ES) were not referred to Glasgow UCEDD. Three were not referred as the symptoms identified on the modified PAS-ADD Checklist were explained by acute physical ill-health (chest infection, renal failure, arthritis), one because the two symptoms identified were confirmed with her key worker as being very mild in nature and not impacting at all on her daily living and one because the two symptoms identified were known to be due to an already established diagnosis of ADHD (delay in falling asleep and restlessness).

One participant identified as having problem behaviour and under the care of a Consultant Psychiatrist completed the T2 research interview in full and gave consent to participate in the research but did not give consent for her case notes to be reviewed by the research psychiatrist (ES). However, although the participant had contact with psychiatry throughout the 2 year period no episodes of mental ill-health occurring during the two year period were indentified during the T2 research interview and it was concluded that that she had not had an episode of mental-ill health during the follow up period.

Eighteen participants were identified as having problem behaviour which was then categorised by the research psychiatrist (ES) based on the research interview data according to DC-LD criteria. They were not referred to the Glasgow UCEDD because the behaviours were longstanding and were known, from case note review carried out at T1, to have been previously assessed.

Two participants identified as having substance misuse that had previously been assessed were not referred to Glasgow UCEDD but had their case notes reviewed to identify any episodes of mental ill-health occurring within the two year follow up period.

4.11 Participants not identified during T2 interview as having had any mental ill-health episode during the two year period but known to have received care from psychiatry or psychology at some point during the two year follow up period

One hundred and forty two participants who did not score above the lowered threshold on the modified PAS-ADD Checklist, retrospective modified PAS-ADD Checklist or problem behaviour checklist were identified during the T2 interview as having received care from psychiatry or psychology at some point during the two year follow up period. All of these participants had their case notes reviewed by the research psychiatrist (ES) to ensure any episodes of mental-ill health that had occurred during the follow up period were counted.

4.12 Number of participants receiving care from psychiatry or psychology at time of T2 assessment

Of the 651 participants, 190 (29.2%) were receiving care from psychiatry or psychology services at the time of the T2 assessment.

4.13 Timing of Psychiatric Assessment

The mean length of time between the T2 assessment and the first appointment with the Glasgow UCEDD Psychiatrist was 2.4 months, the median was 2 months, range 0-12 months. Seventy five percent of those referred to Glasgow UCEDD were seen within 3 months of the T2 interview date. The psychiatric assessment was on the episode in question, whether current at T2 or not.

For those in contact with psychiatry or psychology during the 2 year period, the mean length of time between the most recent contact with a psychologist or psychiatrist and the T2 interview was 2.0 months, the median was less than 1 month and the range 0 – 23 months. Seventy five percent of those in contact with psychiatry or psychology who had not been referred to Glasgow UCEDD, had been reviewed by psychiatry or psychology within 3 months of the T2 interview date.

4.14 Number of case notes reviewed

A total of 309 out of the 651 participants had psychiatry or psychology case notes, which were therefore reviewed. One hundred and forty two of these because they had received care from psychiatry or psychology at some point during the two year follow up period, 165 because they were referred to Glasgow UCEDD and 2 because they were known to have a psychiatric disorder but were not currently open to psychiatry or psychology or referred to Glasgow UCEDD.

4.15 Episodes of mental ill-health

Fife hundred and forty five people had no identified new or incident episode of mental-ill health during the two year follow up period. One hundred and six individuals were identified as having at least one new episode of mental-ill health during the two year follow up period.

Most people with mental ill-health had only one episode, but 13 persons had two episodes, 2 persons had three episodes, and 1 person had four episodes.

Table 4.11 Episodes of mental ill-health

Episodes of mental ill health per person in 2 year period	Participants, N (%)
0	545 (83.7%)
1	90 (13.8%)
2	13 (2.0%)
3	2 (0.3%)
4	1 (0.2%)

In total, 126 episodes of mental-ill health were identified as occurring within the two year period.

There were nine episodes of acute psychosis, three of whom had never been psychotic before. There were 50 episodes of depression, by far the most

frequent episode of mental ill-health. Twenty four of these episodes were first ever episodes of depression (as far as could be determined), 20 were part of recurrent depressive disorders and six of bipolar affective disorders. There were seven episodes of mania. Four were first ever episodes of mania, two of whom had had a previous depressive episode and were newly diagnosed with bipolar affective disorder, and two were diagnosed with a single manic episode. There was one episode of mixed affective disorder. There were 12 episodes of anxiety disorders. Six people developed dementia. There were six episodes of delirium with two persons each experiencing two episodes of delirium.

There were 30 episodes of problem behaviour. Eighteen of these were in people with no known past history of problem behaviour (as far as could be determined) and 12 were in people who had displayed problem behaviour in the past, either at T1 or prior to T1.

There were five other episodes of mental ill-health identified: 1 pica, 1 anorexia nervosa, 2 substance misuse and 1 premenstrual tension syndrome.

4.16 Incidence rates of mental ill-health

Incidence rates were calculated by person rather than by episode (some people had more than one episode). Some people had incident episodes in two different diagnostic groupings, in which case both were included in the relevant diagnostic grouping (but the total incidence remains reported by person rather than by episode). Incidence rates were calculated by dividing the number of participants with at least one episode of the diagnostic grouping occurring between T1 and T2 (even if no longer present at T2 and not counting episodes with onset prior to or at T1) divided by the number of people in the cohort (n = 651).

The names of the diagnostic groupings differ in the different diagnostic manuals (e.g. ‘schizophrenia, schizotypal and delusional disorders’ in ICD-10-DCR but ‘non-affective psychotic disorders’ in DC-LD), but operationalised criteria within each manual were strictly applied. The specific code numbers in each

diagnostic grouping for each manual are detailed in the methods chapter (Table 3.2).

Two year incidence rates, with 95% confidence intervals, for the different diagnostic groupings according to clinical diagnosis, DC-LD, ICD-10-DCR and DSM-IV-TR criteria were calculated. Results are reported in table 4.12.

Two year incidence rates, with 95% confidence intervals, for the different diagnostic groupings according to clinical diagnosis, at different ability levels (mild, mod-profound, all ability levels) were calculated. Results are reported in Table 4.13.

Two year incidence rates, with 95% confidence intervals, for the different diagnostic groupings according to clinical diagnosis for men and women are reported in Table 4.14.

The two year incidence rate for any episode of mental ill-health (excluding specific phobias) was 16.3%. Eighty two individuals (12.6%) had an incident episode of mental ill-health excluding problem behaviours, of whom 74 (11.4%) had an incident of mental-ill health excluding problem behaviours, dementia and delirium. Thirty (4.6%) had an incident episode of problem behaviour.

4.17 Standardised incidence ratios

4.17.1 Overall rate of mental ill-health

Based on the findings from Singleton & Lewis (2003), 31 episodes of common mental disorder are expected in the intellectual disabilities cohort. Out of the 390 participants who did not have what could be termed a common mental disorder at T1 i.e. any mental disorder other than psychosis, 34 had what could be termed a common mental disorder at T2. This gives a first incidence rate of 4.4 per 100 person years and a standardised incident ratio of 1.09 (95% CI 0.75-1.52) suggesting that the incidence of common mental disorder in the intellectual disabilities population is similar to that in the general population. However, this comparison is limited by the notably differing methodology.

Table 4.12 Two year incidence rates for episodes of mental ill-health for whole cohort, n= 651

Diagnostic Category	Clinical Diagnosis		DC-LD Diagnosis		DCR-ICD10 Diagnosis		DSM-IV-TR Diagnosis	
	n	% (95% CI)	n	% (95% CI)	n	% (95%C I)	n	% (95% CI)
Psychotic disorder*	9	1.4 (0.6-2.6)	9	1.4 (0.6-2.6)	6	0.9 (0.3-2.0)	8	1.2 (0.5-2.4)
Affective Disorder	54	8.3 (6.3-10.7)	50	7.7 (5.8-10.0)	33	5.1 (3.5-7.1)	23	3.5 (2.3-5.3)
Anxiety Disorder†	11	1.7 (0.9-3.0)	10	1.5 (0.7-2.8)	10	1.5 (0.7-2.8)	6	0.9 (0.3-2.0)
OCD	0	0 (0.0-0.6)	0	0 (0.0-0.6)	0	0 (0.0-0.6)	0	0 (0.0-0.6)
Organic Disorder	10	1.5 (0.7-2.8)	8	1.2 (0.5-2.4)	7	1.1 (0.4-2.2)	7	1.1 (0.4-2.2)
Alcohol/substance misuse	2	0.3 (0.0-1.1)	2	0.3 (0.0-1.1)	2	0.3 (0.0-1.1)	2	0.3 (0-1.1)
Pica	1	0.2 (0.0-0.9)	1	0.2 (0.0-0.9)	0	0 (0.0-0.6)	0	0 (0.0-0.6)
Eating Disorder††	1	0.2 (0.0-0.9)	1	0.2 (0.0-0.9)	1	0.2 (0-0.9)	1	0.2 (0-0.9)
Sleep Disorder	0	0 (0.0-0.6)	0	0 (0.0-0.6)	0	0 (0.0-0.6)	0	0 (0.0-0.6)
Problem Behaviour	30	4.6 (3.1-6.5)	23	3.5 (2.3-5.3)	0	0 (0.0-0.6)	0	0 (0.0-0.6)
Other mental ill-health	1	0.2 (0.0-0.9)	1	0.2 (0.0-0.9)	1	0.2 (0-0.9)	0	0 (0.0-0.6)
Mental ill-health of any type, excluding problem behaviours†	82	12.6 (10.1-15.4)	77	11.8 (9.5-14.6)	55	8.4 (6.4-10.9)	44	6.8 (5.0-9.0)
Mental ill-health of any type, excluding organic disorders†	98	15.1 (12.4-18.0)	89	13.7 (11.1-16.6)	49	7.5 (5.6-9.8)	38	5.8 (4.2-7.9)
Mental ill-health of any type, excluding problem behaviours and organic disorders†	74	11.4 (9.0-14.1)	70	10.8 (8.5-13.4)	49	7.5 (5.6-9.8)	38	5.8 (4.2-7.9)
Mental ill-health of any type†	106	16.3 (13.5-19.4)	96	14.7 (12.1-17.7)	55	8.4 (6.4-10.9)	44	6.8 (5.0-9.0)

*Includes schizoaffective disorders, †Excludes specific phobias,††Excludes pica, OCD=obsessive compulsive disorder

Table 4.13 Two year incidence rates for episodes of mental ill-health by clinical diagnosis at different ability levels

Diagnostic Category	Mild intellectual disabilities n=254		Moderate-profound intellectual disabilities n=397		All ability levels n=651	
	n	% (95% CI)	n	% (95% CI)	n	% (95%C I)
Psychotic disorder*	3	1.2 (0.2-3.4)	6	1.5 (0.6-3.3)	9	1.4 (0.6-2.6)
Affective Disorder	17	6.7 (4.0-10.5)	37	9.3 (6.7-12.6)	54	8.3 (6.3-10.7)
Anxiety Disorder†	5	2.0 (0.6-4.5)	6	1.5 (0.6-3.3)	11	1.7 (0.9-3.0)
OCD	0	0 (0.0-1.4)	0	0 (0.0-0.9)	0	0 (0.0-0.6)
Organic Disorder	1	0.4 (0.0-2.2)	9	2.3 (1.0-4.3)	10	1.5 (0.7-2.8)
Alcohol/substance misuse	1	0.4 (0.0-2.2)	1	0.3 (0.0-1.4)	2	0.3 (0.0-1.1)
Pica	0	0 (0.0-1.4)	1	0.3 (0.0-1.4)	1	0.2 (0.0-0.9)
Eating Disorder††	0	0 (0.0-1.4)	1	0.3 (0.0-1.4)	1	0.2 (0.0-0.9)
Sleep Disorder	0	0 (0.0-1.4)	0	0 (0.0-0.9)	0	0 (0.0-0.6)
Problem Behaviour	9	3.5 (1.6-6.6)	21	5.3 (3.3-8.0)	30	4.6 (3.1-6.5)
Other mental ill-health	1	0.4 (0.0-2.2)	0	0 (0.0-0.9)	1	0.2 (0.0-0.9)
Mental ill-health of any type, excluding problem behaviours†	26	10.2 (6.8-14.6)	56	14.1 (10.8-18.0)	82	12.6 (10.1-15.4)
Mental ill-health of any type, excluding organic disorders†	32	12.6 (8.8-17.3)	66	16.6 (13.1-20.7)	98	15.1 (12.4-18.0)
Mental ill-health of any type, excluding problem behaviours and organic disorders†	25	9.8 (6.5-14.2)	49	12.3 (9.3-16.0)	74	11.4 (9.0-14.1)
Mental ill-health of any type†	33	13.0 (9.1-18.8)	73	18.4 (14.7-22.6)	106	16.3 (13.5-19.4)

*Includes schizoaffective disorders, †Excludes specific phobias,††Excludes pica, OCD=obsessive compulsive disorder

Table 4.14 Two year incidence rates for episodes of mental ill-health by clinical diagnosis by gender

Diagnostic Category	Men n=355		Women n=296		Total n=651	
	n	% (95% CI)	n	% (95% CI)	n	% (95%C I)
Psychotic disorder*	7	2 (0.8-4.0)	2	0.7 (0.1-2.4)	9	1.4 (0.6-2.6)
Affective Disorder	27	7.6 (5.1-10.9)	27	9.1 (6.1-13.0)	54	8.3 (6.3-10.7)
Anxiety Disorder†	9	2.5 (1.2-4.8)	2	0.7 (0.1-2.4)	11	1.7 (0.9-3.0)
OCD	0	0 (0.0-1.0)	0	0 (0.0-1.2)	0	0 (0.0-0.6)
Organic Disorder	3	0.8 (0.2-2.5)	7	2.4 (1.0-4.8)	10	1.5 (0.7-2.8)
Alcohol/substance misuse	2	0.6 (0.1-2.0)	0	0 (0.0-1.2)	2	0.3 (0.0-1.1)
Pica	1	0.3 (0.0-1.6)	0	0 (0.0-1.2)	1	0.2 (0.0-0.9)
Eating Disorder††	1	0.3 (0.0-1.6)	0	0 (0.0-1.2)	1	0.2 (0.0-0.9)
Sleep Disorder	0	0 (0.0-1.0)	0	0 (0.0-1.2)	0	0 (0.0-0.6)
Problem Behaviour	19	5.4 (3.3-8.2)	11	3.7 (1.9-6.6)	30	4.6 (3.1-6.5)
Other mental ill-health	0	0 (0.0-1.0)	1	0.3 (0.0-1.9)	1	0.2 (0.0-0.9)
Mental ill-health of any type, excluding problem behaviours†	45	12.7 (9.4-16.6)	37	12.5 (9.0-16.8)	82	12.6 (10.1-15.4)
Mental ill-health of any type, excluding organic disorders†	56	15.8 (12.1-20.0)	42	14.2 (10.4-18.7)	98	15.1 (12.4-18.0)
Mental ill-health of any type, excluding problem behaviours and organic disorders†	42	11.8 (8.7-15.7)	32	10.8 (7.5-14.9)	74	11.4 (9.0-14.1)
Mental ill-health of any type†	59	16.6 (12.9-20.9)	47	15.9 (11.9-20.6)	106	16.3 (13.5-19.4)

*Includes schizoaffective disorders, †Excludes specific phobias,††Excludes pica, OCD=obsessive compulsive disorder

Based on the findings from Bijl et al (2002), 61 episodes of DSM-III mental disorder are expected in the intellectual disabilities cohort. Out of the 536 participants who had no history at or prior to T1 of the 15 diagnoses included by Bijl et al (2002), 36 had a clinical diagnoses of one or more of the specified diagnoses by T2. This gives a first incidence rate for the 15 specified mental disorders (according to clinical diagnosis) of 3.36 per 100 person years with a standardised incident ratio of 0.59 (95% CI 0.41-0.82). This suggests that the incidence rate of the specified mental disorders is less in the intellectual disabilities population. However, including all diagnoses in the intellectual disabilities cohort rather than just the 15 specified diagnoses, gives a first incidence rate of 5.80 per 100 person years which is very close to that reported by Bijl et al (2002) with a standardised incident ratio of 1.02 (95% CI 0.74-1.37). Of the 126 episodes of mental ill-health counted in this comparison, only 16 were disorders excluded by Bijl et al (2002) (6 adjustment disorders, 10 organic disorders) and of note is that the rate for specific phobia in the intellectual disabilities cohort was incomplete. This comparison is limited by the differing methodology but particularly by the differing pattern of mental-ill health in the intellectual disabilities population and the incomplete identification of participants with specific phobia in the intellectual disabilities cohort. Problem behaviours account for a significant proportion of the overall incidence in this population but are rarely reported in the general population.

4.17.2 Psychosis

Using Kirkbride et al's (2006) reported incidence rate for DSM-IV non-affective psychosis, less than 1 (0.3) new episode of non-affective psychosis would be expected in the intellectual disabilities cohort. Three persons had DSM-IV-TR new onset non-affective psychosis. This gives a first incidence rate of 230.4 per 100,000 person years and a standardised incident ratio of 9.93 (95% CI 2.05-29.02).

4.17.3 Mania

Taking Kenendy et al's (2005) reported rate for DSM-IV first episode mania, less than 1 (0.08) new episode of first episode mania is expected in the intellectual disabilities cohort. Four persons had first episode DSM-IV-TR mania during the two year follow up, giving a first incidence rate of 307 per 100,000 person years and a standardised incident ratio of 52.43 (95% CI 14.28-134.23).

4.17.4 Bipolar Affective Disorder

Based on the findings from the AESOP study (Lloyd et al, 2005) less than one (0.02) new case of ICD-10 bipolar affective disorder is expected in the intellectual disabilities cohort. Two subjects developed ICD-10-DCR bipolar affective disorder. This gives a first incidence rate of 153.6 per 100,000 person years and a standardised incident ratio of 100.20 (95% CI 12.14-361.96) for new onset bipolar affective disorder.

4.17.5 Depression

Based on the findings from Lehtinen et al (2005), 26.9 episodes of first ever ICD-10 depressive disorders (including dysthymia and adjustment disorders) are expected in the intellectual disabilities cohort. Twenty seven subjects had a first ever ICD-10-DCR depressive disorder (including dysthymia and adjustment disorders) and 30 had a first ever DC-LD depressive disorder (including dysthymia and adjustment disorders). This gives incidence rates of 20.7 and 23.0 per 1000 person years and standardised incident ratios of 1.01 (95% CI 0.67-1.47) for ICD-10 and 1.12 (95% CI 0.76-1.61) for DC-LD first ever depressive episodes. This comparison is limited by the high likelihood of missed previous episodes of depression in the intellectual disabilities cohort and as a consequence of this, some first ever episodes actually being recurrent episodes.

Using the reported rate for all depressive disorder, including first ever and recurrent episodes, also reported by Lehtinen et al (2005), 37 episodes of ICD-

10 depressive disorder are expected in the intellectual disabilities cohort. Thirty episodes of ICD-10-DCR and 45 episodes of DC-LD depressive disorder were observed. This gives incidence rates of 23.0 and 34.6 per 1000 person years and standardised incident ratios of 0.81 (95% CI 0.55-1.16) for ICD-10 and 1.22 (95% 0.89-1.63) for DC-LD depressive episodes.

Using the NEMESIS study (Bijl et al, 2002) first episode in lifetime annual incidence for DSM-IV depressive disorders, 24 episodes in the intellectual disabilities cohort are expected. Thirteen DSM-IV-TR, 21 ICD-10-DCR and 24 DC-LD first ever depressive disorders were observed. This gives standardised incident ratios of 0.55 (95% CI 0.29-0.93) for DSM IV-TR, 0.88 (95% CI 0.55-1.35) for DCR- ICD10 and 1.01 (95% CI 0.65-1.50) for DC-LD depressive disorders.

There does not seem to be a significantly increased rate of first ever or recurrent episodes of depression episodes in this population compared to the general population (in contrast to the findings for psychosis, mania, and bipolar affective disorder) and the increased prevalence of depression in this population is presumably related to increased duration of episodes and/or the failure to detect less severe cases.

4.17.6 Substance misuse

Using the NEMSIS study findings (Bijl et al, 2002), 24 episodes of DSM-IIIR substance misuse are expected in the intellectual disabilities cohort. Six hundred and thirty seven subjects were at risk of new onset substance misuse and of these, only one developed DSM-IV-TR substance misuse during the follow up period. This gives a first incidence rate for substance misuse of 0.08 per 100 person years and a standardised incident ratio of 0.04 (95% CI 0.00-0.24).

4.17.7 Anxiety disorders

Using the NEMESIS study findings (Bijl et al, 2002), 36 first ever episodes of DSM-IIIR anxiety disorders (panic disorder, agoraphobia, specific phobia, social

phobia, generalised anxiety disorder and obsessive compulsive disorder) are expected in the intellectual disabilities cohort. Out of the 607 subjects with no known history of these disorders, 6 developed at least one of the disorders according to clinical diagnosis during the follow up period. This gives a first ever incidence rate of 0.49 per 100 person years and a standardised incident ratio of 0.17 (95% CI 0.06-0.37). This is not a suitable comparison as specific phobias contributed to a large proportion of the overall incidence of anxiety in the study by Bijl et al (2002) and not all participants in the intellectual disabilities cohort with specific phobia identified at screening were progressed to a full psychiatric assessment (and therefore the rate of specific phobia is a definite undercount).

4.17.8 Early Onset Dementia

Based on the findings of Mercy et al (2008), less than one (0.06) new case of early onset dementia is expected in the intellectual disabilities cohort. Four out of the 265 subjects aged 45-64 years developed dementia during the two year follow up. This gives an incidence rate for early onset dementia in adults age 45-64 years of 754.7 per 100 000 person years and a standardised incident ratio of 66.67 (95% CI 18.16-170.69).

4.17.9 Dementia

Based on the range for the incidence of dementia in adults aged over 65 years suggested by Mathews & Brayne (2005), 1.4-1.8 episodes of dementia are expected in the intellectual disabilities cohort. Of the 45 subjects aged 65yrs or over, 1 person developed dementia during the two year follow up. This gives an incidence rate for all types of dementia in adults aged over 65 years of 11.11 per 1000 person years and a range for the standardised incident ratio of 0.56 (95% CI 0.01-3.10) - 0.74 (95% CI 0.02-4.13).

4.18 Summary of incident ratio findings

When comparing rates of CIS-R cases or DSM IV disorders in the general population with clinician diagnosis in the intellectual disabilities cohort, the overall incidence of common mental disorders in adults with intellectual

disabilities appears to be similar to that reported for the general population. However, the rates for individual types of mental disorder are different with some with a very much higher incidence (psychosis, first episode mania, bipolar affective disorder and early onset dementia – even when identical diagnostic criteria are used in the comparison), some with very much lower incidence (substance misuse and possibly anxiety disorders), and some of similar incidence (depression and dementia in over 65yrs) and some disorders (problem behaviours) that are not reported in the general population at all.

Making comparisons of the findings of this study with that reported for the general population is severely hampered by the differing methodology of the studies used for comparison, the limitations of using ICD-10 and DSM-IV in the intellectual disabilities cohort and the differing patterns of mental-ill health in the two populations. In particular, the calculated first ever incident rates may be over estimates, except for dementia and early onset dementia, because of the difficulties in identifying previous episodes and consequent misclassification of recurrent episodes as first ever episodes in this population. Table 4.15 summarises the incident ratio findings.

4.19 Factors related to the incidence of mental ill-health (excluding problem behaviour, dementia and delirium)

Results from the initial univariate analysis, exploring the relationship of each individual variable of interest with the incidence of mental ill-health (excluding problem behaviours, dementia and delirium) are detailed in the Tables 4.16.1-4.16.4.

At the second stage of analysis (group specific models), one participant had an incomplete data set (but did not have incident mental ill-health) for personal factors, there was no incomplete data set for past experiences, three participants had incomplete data sets for lifestyle/supports, none of whom had incident mental ill-health and 16 had incomplete data sets for health/disabilities, of whom one had incident mental ill-health. At the third stage of the analysis (the global model) one participant had incomplete dataset, but did not have an incident episode.

Table 4.15 Summary of Incident ratio findings

Disorder	Standardised Incident ratio	95% Confidence Intervals
Common mental disorder		
Singleton & Lewis (2003) comparison (CIS-R cases vs clinician diagnosis)	1.09	0.75-1.52
Bijl et al (2002) comparison† (DSM-IIIR vs clinician diagnosis)	0.59	0.41-0.82
Bijl et al (2002) comparison counting all psychiatric disorders in ID cohort†† (DSM-IIIR vs clinician diagnosis)	1.02	0.74-1.37
First ever non-affective psychosis (DSM-IV vs DSM IV)	9.93	2.05-29.02
First ever manic episode (DSM-IV vs DSM-IV)	52.43	14.28-134.23
Bipolar affective disorder (ICD-10 vs ICD-10)	100.20	12.14-361.96
Depressive episodes		
ICD-10 vs ICD-10	0.81	0.55-1.16
ICD-10 vs DC-LD	1.22	0.89-1.63
First ever depressive episodes†††		
ICD-10 vs ICD-10	1.01	0.67-1.47
ICD-10 vs DC-LD	1.12	0.76-1.61
First ever anxiety disorders (DSM-IIIR vs clinician diagnosis)	0.17	0.06-0.37
First ever substance misuse (DSM-IIIR vs DSM-IV)	0.04	0.00-0.24
Dementia 45-64 yrs (Consensus vs clinician diagnosis	66.67	18.16-170.69
Dementia >65yrs (ICD-10 vs DC-LD)	0.56-0.74	0.01-3.10 0.02-4.13

†= counting only the 15 diagnoses included by Bijl et al and excluding personality disorders, developmental disorders, somatoform disorders, sexual and gender identity disorders, sleep disorders, adjustment disorders and organic disorders

††= counting all clinician diagnosed psychiatric disorders in the intellectual disabilities cohort

†††= including first ever dysthymia and first ever adjustment disorder

Table 4.16.1 Relationship between individual personal factors at T1 & incident episodes of mental ill-health

		Whole cohort	Incident mental ill-health (excluding problem behaviour, dementia and delirium)	
		N=651	74 events (11.4%)	
Group 1: Personal factors				
Age	Incident cases Non-incident cases	Mean (SD)	48.6 (12.6) 46.2 (14.5)	p=0.156
Gender	Male Female	355 (54.5%) 296 (45.5%)	42 (11.8%) 32 (10.8%)	p=0.910
Ability	Mild Moderate Severe Profound	254 (39.0%) 141 (21.7%) 125 (19.2%) 131 (20.1%)	25 (9.8%) 25 (17.9%) 15 (11.9%) 9 (6.9%)	p=0.384
Down Syndrome	No Yes	517 (79.4%) 134 (20.6%)	65 (12.6%) 9 (6.7%)	p=0.023
Mental ill health in the past	No Yes	523 (80.3%) 128 (19.7%)	46 (8.8%) 28 (21.9%)	p<0.001
Family history of mental ill health	No Yes	609 (93.5%) 42 (6.5%)	69 (11.3%) 5 (11.9%)	p=0.952

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; mean (SD) reported for continuous characteristics in those with or without an incident episode during follow-up; p-values are from χ^2-test or t-test as appropriate.

Table 4.16.2 Relationship between individual past experiences factors at T1 & incident episodes of mental ill-health

		Whole cohort	Incident mental ill-health (excluding problem behaviour, dementia and delirium)	
		N=651	74 events (11.4%)	
Group 2: Past experiences				
Ex long-stay hospital resident	No Yes	540 (82.9%) 111 (17.1%)	57 (10.6%) 17 (15.3%)	p=0.124
Outwith family home in childhood	No Yes	487 (74.8%) 164 (25.2%)	54 (11.1%) 20 (12.2%)	p=0.603
Death of parent in childhood	No Yes	550 (84.5%) 101 (15.5%)	61 (11.1%) 13 (12.9%)	p=0.566
Divorce of parents in childhood	No Yes	615 (94.5%) 36 (5.5%)	70 (11.4%) 4 (11.1%)	p=0.922
Abuse / adversity in childhood	No Yes	428 (65.7%) 223 (34.3%)	43 (10.0%) 31 (13.9%)	p=0.126
Abuse / adversity in adulthood	No Yes	571 (87.7%) 80 (12.3%)	60 (10.5%) 14 (17.5%)	p=0.017

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; p-values are from χ^2-test.

Table 4.16.3 Relationship between individual lifestyle and supports factors at T1 & incident episodes of mental ill-health

		Whole cohort	Incident mental ill-health (excluding problem behaviour, dementia and delirium)	
		N=651	74 events (11.4%)	
Group 3: Lifestyle and supports				
Accommodation / support	Family carer Independent Paid carer Congregate	258 (39.7%) 51 (7.8%) 297 (45.7%) 44 (6.8%)	14 (5.4%) 9 (17.6%) 43 (14.5%) 8 (18.2%)	p=0.001
No daytime job / occupation	Has job No job	499 (76.8%) 151 (23.2%)	59 (11.8%) 15 (9.9%)	p=0.735
Deprivation quintile	Most affluent 2 3 4 Most deprived	107 (16.4%) 54 (8.3%) 56 (8.6%) 72 (11.1%) 362 (55.6%)	12 (11.2%) 3 (5.6%) 6 (10.7%) 11 (15.3%) 42 (11.6%)	p=0.629
Marital status	Married / partner No live-in partner	84 (13.0%) 563 (87.0%)	11 (13.1%) 63 (11.2%)	p=0.548
Smoker	No Yes	581 (89.7%) 67 (10.3%)	63 (10.8%) 11 (16.4%)	p=0.077
Life events in previous 12 months	Incident cases Non-incident cases	Mean (SD)	1.3 (1.2) 1.0 (1.0)	p=0.028

Notes; percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; mean (SD) reported for continuous characteristics in those with or without an incident episode during follow-up; p-values are from χ^2-test or t-test as appropriate.

Table 4.16.4 Relationship between individual health & disabilities factors at T1 & incident episodes of mental ill-health

		Whole cohort	Incident mental ill-health (excluding problem behaviour, dementia and delirium)	
		N=651	74 events (11.4%)	
Group 4: Health and disabilities				
Visual impairment	No Yes	349 (53.6%) 302 (46.4%)	43 (12.3%) 31 (10.3%)	p=0.410
Hearing impairment	No Yes	457 (70.2%) 194 (29.8%)	47 (10.3%) 27 (13.9%)	p=0.175
Bowel incontinence	No Yes	499 (76.8%) 151 (23.2%)	59 (11.8%) 15 (9.9%)	p=0.735
Urinary incontinence	No Yes	436 (67.1%) 214 (32.9%)	45 (10.3%) 29 (13.6%)	p=0.182
Impaired mobility	No Yes	508 (78.2%) 142 (21.8%)	66 (13.0%) 8 (5.6%)	p=0.012
Severe physical disability	No Yes	619 (95.1%) 31 (4.8%)	73 (11.8%) 1 (3.2%)	p=0.135
Epilepsy	No Yes	424 (66.6%) 213 (33.4%)	44 (10.4%) 30 (14.1%)	p=0.225
Special communication needs	No Yes	334 (51.3%) 311 (47.8%)	38 (11.4%) 35 (11.3%)	p=0.963

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; p-values are from χ^2-test.

The group specific regression analyses identified seven factors:

- level of ability
- Down's syndrome
- mental ill-health in the past
- abuse/adversity in adulthood
- type of accommodation
- urinary incontinence and mobility

These factors were then entered into the global regression model. Results of the group specific and global model regression analyses are detailed in table 4.17.

Table 4.17 Logistic regression results: incident mental ill-health

		Incident mental ill-health (excl. problem behaviour, dementia and delirium)			
		Group-specific models		**Global model**	
		Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value
Group 1: Personal factors					
Ability (vs. Mild ID)	Moderate ID	1.84 (0.98–3.42)		2.24 (1.15-4.39)	
	Severe ID	1.03 (0.51-2.10)	0.047	1.26 (0.58-2.74)	0.033
	Profound ID	0.61 (0.27-1.37)		0.73 (0.29-1.88)	
Down syndrome		0.47 (0.22-0.98)	0.031		
Mental ill-health in the past		3.40 (1.97-5.86)	<0.001	2.41 (1.36-4.28)	0.003
Group 2: Past experiences					
Abuse/adversity in adulthood		2.18 (1.14-4.21)	0.026	2.17 (1.07-4.43)	0.040
Group 3: Lifestyle and supports					
Accommodation/ support (vs. Family carer)	Independent	4.13 (1.66-10.3)		4.19 (1.57-11.14)	
	Paid carer	3.13 (1.66-5.89)	<0.001	2.82 (1.44-5.52)	0.003
	Congregate	3.91 (1.52-10.07)		3.38 (1.24-9.26)	
Group 4: Health and disabilities					
Urinary incontinence		2.19 (1.26-3.78)	0.006	1.85 (1.02-3.38)	0.047
Impaired mobility		0.27 (0.12-0.60)	<0.001	0.37 (0.16-0.87)	0.015

For the global model, the Hosmer-Lemeshow statistic was Chi square=1.86, d.f.=6, P=0.93, giving no indication of lack of fit.

Factors at time 1 that were related to an incident episode of mental ill-health (excluding problem behaviour, dementia and delirium) being identified at time 2 were having severe rather than mild intellectual disabilities (Odds Ratio 2.24, 95% CI 1.15-4.39), having a past psychiatric history (Odds Ratio 2.41, 95% CI 1.36-4.28), the experience of abuse, neglect or exploitation during adult life (Odds Ratio 2.17, 95% CI 1.07-4.43), not living with a family carer (Odds Ratio 4.19, 95% CI 1.57-11.14), urinary incontinence (Odds Ratio 1.85, 95% CI 1.02-3.38) and not having impaired mobility (Odds Ratio 2.7, 95% CI 1.15-6.25).

4.20 Factors related to the incidence of problem behaviour

Results from the initial univariate analysis, exploring the relationship of each individual variable of interest with the incidence of problem behaviour are detailed in Tables 4.18.1-4.18.4. At the second stage of analysis (group specific models), 1 participant had an incomplete data set (but did not have incident problem behaviour) for personal factors, there was no incomplete data set for past experiences, 5 participants had incomplete data sets for lifestyle/supports, none of whom had incident problem behaviour and 16 had incomplete data sets for health/disabilities but did not have incident problem behaviours. Type of accommodation/support was dichotomised to living with a family carer or not, and ability level was dichotomised to mild intellectual disabilities or moderate-profound intellectual disabilities, in view of numbers being too small to sub-categorise. At the third stage of the analysis (the global model) three participants had incomplete data-sets, none of whom had any incident episodes. Results of the logistic regression analysis are detailed in table 4.19.

Factors at time 1 that were independently related to an incident episode of problem behaviour being identified at time 2 were having severe rather than mild intellectual disabilities (Odds Ratio 4.57, 95% CI 1.74-11.96), having experienced divorce of parents in childhood (Odds Ratio 9.93, 95% CI 3.11-31.76), not living with a family carer (Odds Ratio 5.70, 95% CI 1.99-16.32) and a higher number of life events in the preceding 12 month period (Odds Ratio 1.52, 95% CI 1.11-2.07).

Table 4.18.1 Relationship between individual personal factors at T1 & incident problem behaviour.

		Whole cohort	Incident problem behaviour	
		N=651	30 events (4.6%)	
Group 1: Personal factors				
Age	Incident cases Non-incident cases	Mean (SD)	41.9 (9.9) 46.5 (14.1)	p=0.022
Gender	Male Female	355 (54.5%) 296 (45.5%)	19 (5.4%) 11 (3.7%)	p=0.366
Ability	Mild Moderate Severe Profound	254 (39.0%) 140 (21.5%) 126 (19.4%) 131 (20.1%)	9 (3.5%) 9 (6.4%) 4 (3.2%) 8 (6.1%)	p=0.005
Down Syndrome	No Yes	517 (79.4%) 134 (20.6%)	25 (4.8%) 5 (3.7%)	p=0.340
Mental ill health in the past	No Yes	523 (80.3%) 128 (19.7%)	23 (4.4%) 7 (5.5%)	p=0.378
Family history of mental ill-health	No Yes	609 (93.5%) 42 (6.5%)	29 (4.8%) 1 (2.4%)	p=0.518

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; mean (SD) reported for continuous characteristics in those with or without an incident episode during follow-up; p-values are from χ^2-test or t-test as appropriate.

Table 4.18.2 Relationship between individual past experiences factors at T1 & incident problem behaviour.

		Whole cohort	Incident problem behaviour	
		N=651	30 events (4.6%)	
Group 2: Past experiences				
Ex long-stay hospital resident	No Yes	540 (82.9%) 111 (17.1%)	22 (4.1%) 8 (7.2%)	p=0.046
Outwith family home in childhood	No Yes	487 (74.8%) 164 (25.2%)	19 (3.9%) 11 (6.7%)	p=0.060
Death of parent in childhood	No Yes	550 (84.5%) 101 (15.5%)	27 (4.9%) 3 (3.0%)	p=0.424
Divorce of parents in childhood	No Yes	615 (94.5%) 36 (5.5%)	24 (3.9%) 6 (16.7%)	p<0.001
Abuse / adversity in childhood	No Yes	428 (65.7%) 223 (34.3%)	20 (4.7%) 10 (4.5%)	p=0.877
Abuse / adversity in adulthood	No Yes	571 (87.7%) 80 (12.3%)	29 (5.1%) 1 (1.3%)	p=0.140

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; p-values are from χ^2-test.

Table 4.18.3 Relationship between individual lifestyle & supports factors at T1 & incident problem behaviour.

		Whole cohort	Incident problem behaviour	
		N=651	30 events (4.6%)	
Group 3: Lifestyle and supports				
Accommodation / support	Family carer Independent Paid carer Congregate	258 (39.7%) 51 (7.8%) 297 (45.7%) 44 (6.8%)	5 (1.9%) 3 (5.9%) 18 (2.7%) 4 (9.1%)	p=0.004
No daytime job / occupation	Has job No job	499 (76.8%) 151 (23.2%)	24 (4.8%) 6 (4.0%)	p=0.731
Deprivation quintile	Most affluent 2 3 4 Most deprived	107 (16.4%) 54 (8.3%) 56 (8.6%) 72 (11.1%) 362 (55.6%)	6 (5.6%) 2 (3.7%) 1 (1.8%) 4 (5.6%) 17 (4.7%)	p=0.724
Marital status	Married / partner No live-in partner	84 (13.0%) 563 (87.0%)	7 (8.3%) 23 (4.1%)	p=0.108
Smoker	No Yes	581 (89.7%) 67 (10.3%)	29 (5.0%) 1 (1.5%)	p=0.190
Life events in previous 12 months	Incident cases Non-incident cases	Mean (SD)	1.5 (1.5) 1.0 (1.1)	p=0.016

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; mean (SD) reported for continuous characteristics in those with or without an incident episode during follow-up; p-values are from χ^2-test or t-test as appropriate.

Table 4.18.4 Relationship between individual health & disabilities factors at T1 & incident problem behaviour.

		Whole cohort	Incident problem behaviour	
		N=651	30 events (4.6%)	
Group 4: Health and disabilities				
Visual impairment	No Yes	349 (53.6%) 302 (46.4%)	19 (5.4%) 11 (3.6%)	p=0.402
Hearing impairment	No Yes	457 (70.2%) 194 (29.8%)	20 (4.4%) 10 (5.2%)	p=0.586
Bowel incontinence	No Yes	499 (76.8%) 151 (23.2%)	24 (4.8%) 6 (4.0%)	p=0.773
Urinary incontinence	No Yes	436 (67.1%) 214 (32.9%)	19 (4.1%) 11 (5.1%)	p=0.244
Impaired mobility	No Yes	508 (78.2%) 142 (21.8%)	24 (4.7%) 6 (4.2%)	p=0.978
Severe physical disability	No Yes	619 (95.1%) 31 (4.8%)	29 (4.7%) 1 (3.2%)	p=0.593
Epilepsy	No Yes	424 (66.6%) 213 (33.4%)	22 (5.2%) 8 (3.8%)	p=0.592
Special communication needs	No Yes	334 (51.3%) 311 (47.8%)	12 (3.6%) 18 (5.8%)	p=0.083

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; p-values are from χ^2-test.

Table 4.19 Logistic regression results: incident problem behaviour

		Incident problem behaviour			
		Group-specific models		Global model	
		Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value
Group 1: Personal factors					
Ability (vs. Mild ID)	Moderate ID				
	Severe ID	2.73 (1.15-6.49)*	0.015	4.57 (1.74-11.96)	0.001
	Profound ID				
Group 2: Past experiences					
Divorce of parents in childhood		5.98 (2.16-16.52)	0.002	9.93 (3.11-31.76)	<0.001
Ex- long-stay hospital resident		2.82 (1.17-6.80)	0.030		
Group 3: Lifestyle and supports					
Accommodation/ support (vs. Family carer)	Independent				
	Paid carer	4.67 (1.74-12.51)*	<0.001	5.70 (1.99-16.32)	<0.001
	Congregate				
Life events in previous 12 months		1.42 (1.07-1.88)	0.022	1.52 (1.11-2.07)	0.010

*For analysis of incident problem behaviour, smaller numbers of events required the combination of the Moderate, Severe and Profound ID groups (OR expressed relative to Mild ID group) and the Independent of care, Paid carer and Congregate care groups (OR expressed relative to Family carer group)

For the global model the Hosmer-Lemeshow statistic was Chi squared =1.11, d.f.=3, P=0.77 giving no indication of lack of fit.

4.21 Factors related to the incidence of unipolar clinician depression

For participants with incidence of episodes of unipolar depression (n= 42), the initial analyses identified 4 factors (mental ill-health in the past, type of accommodation/support, preceding life events and problem behaviours) which were then entered into the global regression. These results are reported in Tables 4.20.1-4.20.4. One participant had an incomplete data set and did not have incident depression. Type of accommodation/support was dichotomised to living with a family carer or not and level of ability into mild versus moderate-

profound, in view of numbers being too small to sub-categorise. Results of the Logistic Regression are displayed in Table 4.21.

Table 4.20.1 Relationship between individual personal factors at T1 & incident unipolar depression (clinician diagnosis)

		Whole cohort	Incident unipolar clinical depression	
		N=651	42 events (6.5%)	
Group 1: Personal factors				
Age	Incident cases Non-incident cases	Mean (SD)	46.79 (13.51 43.62 (14.18)	p=0.134
Gender	Male Female	355 (54.5%) 296 (45.5%)	22 (6.2%) 20 (6.8%)	p=0.772
Ability	Mild Moderate Severe Profound	254 (39.0%) 141 (21.7%) 125 (19.2%) 131 (20.1%)	14 (7.1%) 15 (8.6%) 6 (4.0%) 7 (5.3%)	p=0.435 (mild vs mod-prof)
Down Syndrome	No Yes	517 (79.4%) 134 (20.6%)	35 (6.8%) 7 (5.2%)	p=0.516
Mental ill health in the past	No Yes	523 (80.3%) 128 (19.7%)	26 (5.0%) 16 (12.5%)	p=0.002
Family history of mental ill health	No Yes	609 (93.5%) 42 (6.5%)	41(6.7%) 1(2.4%)	p=0.267

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; mean (SD) reported for continuous characteristics in those with or without an incident episode during follow-up; p-values are from χ^2-test or t-test as appropriate.

Table 4.20.2 Relationship between individual past experience factors at T1 & incident unipolar depression (clinician diagnosis)

		Whole cohort	Incident unipolar clinical depression	
		N=651	42 events (6.5%)	
Group 2: Past experiences				
Ex long stay hospital resident	No Yes	540 (82.9%) 111 (17.1%)	35 (6.5%) 7 (6.3%)	p=0.945
Out with family home in childhood	No Yes	487 (74.8%) 164 (25.2%)	32 (6.6%) 10 (6.1)	p=0.831
Death of parent in childhood	No Yes	550 (84.5%) 101 (15.5%)	37 (6.7%) 5 (4.9%)	p=0.504
Divorce of parents in childhood	No Yes	615 (94.5%) 36 (5.5%)	40 (6.5%) 2 (5.6%)	p=0.822
Abuse/adversity in childhood	No Yes	428 (65.7%) 223 (34.3%)	26 (6.1%) 16 (7.2%)	p=0.588
Abuse/adversity in adulthood	No Yes	571 (87.7%) 80 (12.3%)	34 (6.0) 8 (10.0%)	p=0.168

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; p-values are from χ^2-test.

.

Table 4.20.3 Relationship between individual lifestyle & support factors at T1 & incident unipolar depression (clinician diagnosis)

		Whole cohort	Incident unipolar clinical depression	
		N=651	42 events (6.5%)	
Group 3: Lifestyle and supports				
Accommodation / support	Family carer Independent Paid carer Congregate	258 (39.6%) 51 (7.8%) 298 (45.8%) 44 (6.8%)	9 (3.4%) 5 (9.8%) 23 (7.7%) 5 (11.4%)	p=0.012 (family carer vs non-family carer)
No daytime job / occupation	Has job No job	499 (76.8%) 151 (23.2%)	33 (6.6%) 9 (6.0%)	p=0.775
Deprivation quintile	Most affluent 2 3 4 Most deprived	107 (16.4%) 54 (8.3%) 56 (8.6%) 72 (11.1%) 362 (55.6%)	7 (6.5%) 1 (1.9%) 3 (5.4%) 7 (9.7%) 24 (6.6%)	p=0.509
Marital status	Married / partner No live-in partner	84 (13.0%) 563 (87.0%)	5 (6.0%) 37 (6.6%)	p=0.830
Smoker	No Yes	581 (89.7%) 67 (10.3%)	37 (6.4%) 5 (7.4%)	p=0.730
Life events in previous 12 months		Mean=1.01 (SD=1.1)	Mean=1.43 (SD=1.2)	p=0.024

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; mean (SD) reported for continuous characteristics in those with or without an incident episode during follow-up; p-values are from χ^2-test or t-test as appropriate.

Table 4.20.4 Relationship between individual health & disabilities factors at T1 & incident unipolar depression (clinician diagnosis)

		Whole cohort	Incident unipolar clinical depression	
		N=651	42 events (6.5%)	
Group 4: Health and disabilities				
Visual impairment	No Yes	349 (53.6%) 302 (46.4%)	24 (6.9%) 18 (6.0%)	p=0.635
Hearing impairment	No Yes	457 (70.2%) 194 (29.8%)	27 (5.9%) 15 (7.7%)	p=0.386
Bowel incontinence	No Yes	499 (76.7%) 151 (23.2%)	33 (6.6%) 9 (6.0%)	P=0.775
Urinary incontinence	No Yes	436 (67.1%) 214 (32.9%)	24 (5.5%) 18 (8.4%)	p=0.157
Impaired mobility	No Yes	508 (78.2%) 142 (21.8%)	36 (7.1%) 6 (4.3%)	p=0.220
Severe physical disability	No Yes	619 (95.1%) 31 (4.8%)	41(6.6%) 1(3.2%)	p=0.453
Epilepsy	No Yes	424 (66.6%) 213 (33.4%)	26 (6.1%) 16 (7.5%)	p=0.508
Special communication needs	No Yes	334 (51.3%) 311 (47.8%)	22 (6.6%) 19 (6.1%)	p=0.804
Problem Behaviour	No Yes	506 (77.7%) 145 (22.3%)	26 (5.1%) 16 (11.0%)	p=0.011

Notes: percentages for Whole Cohort indicate prevalence of characteristic at T1; other percentages indicate prevalence of incident ill-health; p-values are from χ^2-test.

Factors at T1 that predicted an incident episode of unipolar depression being identified at T2 were mental ill-health in the past (Odds Ratio 2.48, 95% CI 1.27-4.83), problem behaviours (Odds Ratio 2.04, 95% CI 1.05-4.00) and preceding life events (Odds Ratio 1.30, 95% CI 1.02-1.65).

For the global model, the Hosmer and Lemeshow statistic was Chi squared = 4.32, on 5 d.f., P= 0.51 giving no indication of lack of fit.

Table 4.21 Logistic regression results: incident unipolar depression

		Incident unipolar depression			
		Group-specific models		Global model	
		Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value
Group1: Personal factors					
Mental ill-health in the past		2.73 (1.42-5.26)	0.004	2.48 (1.27-4.83)	0.010
Group 3: Lifestyle and supports					
Accommodation/ support (vs. Family carer)	Independent				
	Paid carer	2.49 (1.17-5.31)	0.011		
	Congregate				
Life events in previous 12 months		1.30 (1.02-1.65)	0.044	1.30 (1.02-1.65)	0.046
Group 4: Health and disabilities					
Problem behaviour		2.29 (1.19-4.40)	0.016	2.04 (1.05-4.00)	0.042

*For analysis of incident depression, smaller numbers of events required the combination of the Moderate, Severe and Profound ID groups (OR expressed relative to Mild ID group) and the Independent of care, Paid carer and Congregate care groups (OR expressed relative to Family carer group)

4. 22 Summary of factors associated with incident mental ill-health, problem behaviour and depression

Table 4.22 summarises the logistic regression results for the group specific and global models for incident episodes of mental ill-health (excluding problem behaviour, dementia and delirium), incident problem behaviour and incident unipolar depression.

Table 4.22 Summary of factors associated with incident episodes of mental ill-health, problem behaviour & depression

*For analysis of incident problem behaviour and incident depression, smaller numbers of events required the combination of the Moderate, Severe and Profound ID groups (OR expressed relative to Mild ID group) and the Independent of care, Paid carer and Congregate care groups (OR expressed relative to Family carer group)

		Incident mental ill-health (excl. problem behaviour, dementia and delirium)				Incident problem behaviour				Incident depression			
		Group-specific models		Global model		Group-specific models		Global model		Group-specific models		Global model	
		Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value
Group 1: Personal factors													
Ability (vs. Mild ID)	Moderate ID	1.84 (0.98–3.42)		2.24 (1.15-4.39)									
	Severe ID	1.03 (0.51-2.10)	0.047	1.26 (0.58-2.74)	0.033	2.73 (1.15-6.49)*	0.015	4.57 (1.74-11.96)	0.001				
	Profound ID	0.61 (0.27-1.37)		0.73 (0.29-1.88)									
Down syndrome		0.47 (0.22-0.98)	0.031	-	-								
Mental ill health in the past		3.40 (1.97-5.86)	<0.001	2.41 (1.36-4.28)	0.003					2.73 (1.42-5.26)	0.004	2.48 (1.27-4.83)	0.010
Group 2: Past experiences													
Divorce of parents in childhood						5.98 (2.16-16.52)	0.002	9.93 (3.11-31.76)	<0.001				
Abuse/adversity in adulthood		2.18 (1.14-4.21)	0.026	2.17 (1.07-4.43)	0.040								
Ex- long-stay hospital resident						2.82 (1.17-6.80)	0.030	-	-				
Group 3: Lifestyle and supports													
Accommodation/ support (vs. Family carer)	Independent	4.13 (1.66-10.3)		4.19 (1.57-11.14)									
	Paid carer	3.13 (1.66-5.89)	<0.001	2.82 (1.44-5.52)	0.003	4.67 (1.74-12.51)*	<0.001	5.70 (1.99-16.32)	<0.001	2.49 (1.17-5.31)	0.011	-	-
	Congregate	3.91 (1.52-10.07)		3.38 (1.24-9.26)									
Life events in previous 12 months						1.42 (1.07-1.88)	0.022	1.52 (1.11-2.07)	0.010	1.30 (1.02-1.65)	0.044	1.30 (1.02-1.65)	0.046
Group 4: Health and disabilities													
Urinary incontinence		2.19 (1.26-3.78)	0.006	1.85 (1.02-3.38)	0.047								
Impaired mobility		0.27 (0.12-0.60)	<0.001	0.37 (0.16-0.87)	0.015								
Problem behaviour										2.29 (1.19-4.40)	0.016	2.04 (1.05-4.00)	0.042

4.23 Enduring mental ill-health

At T1, 114 participants had mental ill-health (excluding problem behaviours, bipolar affective disorder in remission, psychosis of any type in remission, recurrent depressive disorder in remission, dementia, delirium, autism, personality disorders and specific phobias). These exclusions were made because recovery from dementia, autism and personality disorders is not expected, delirium has a clear organic aetiology and the rate of specific phobias was not adequately ascertained.

Of the 20 participants with non-affective psychosis at T1, 17 (85.0%) were still unwell at T2. Of the 38 with any manic or depressive episode at T1, 10 (26.3%) were still in an affective episode at T2. Of the 35 with depression (unipolar or bipolar) at T1, 9 (25.7%) were still depressed at T2. Of the 27 participants with an anxiety disorder at T1, 24 (88.9%) were still unwell with an anxiety disorder at T2. Recovery from affective disorder was much more likely than recovery from psychosis or anxiety disorders. This data is displayed in Figure 4.3. In total, 77 (67.5%) of the 114 participants who had mental ill-health (with exclusions) at T1 still had mental ill-health at T2 and 37 (32.5%) had recovered. These two groups were not compared in view of the small numbers rendering such analysis as underpowered, instead, the analysis compared the mental ill-health endurance group with the rest of the cohort. Factors related to the endurance of mental ill-health (with exclusions), comparing those with endurance of mental ill-health throughout the 2 year follow up period with the rest of the cohort, are detailed in Tables 4.23.1-4.23.4. No participants had an incomplete data set.

For analysis, small numbers of events required the combination of moderate-severe-profound groups (Odds Ratio expressed relative to mild group), independent, paid carer and congregate care groups (Odds Ratio expressed relative to family carer group) and deprivation categories 1-4 and deprivation categories 5-7 (Odds Ratio expressed relative to deprivation categories group 1-4).

Figure 4.3 **Number of participants with mental ill-health at T1, number of these participants still ill at T2 and number of these participants recovered by T2**

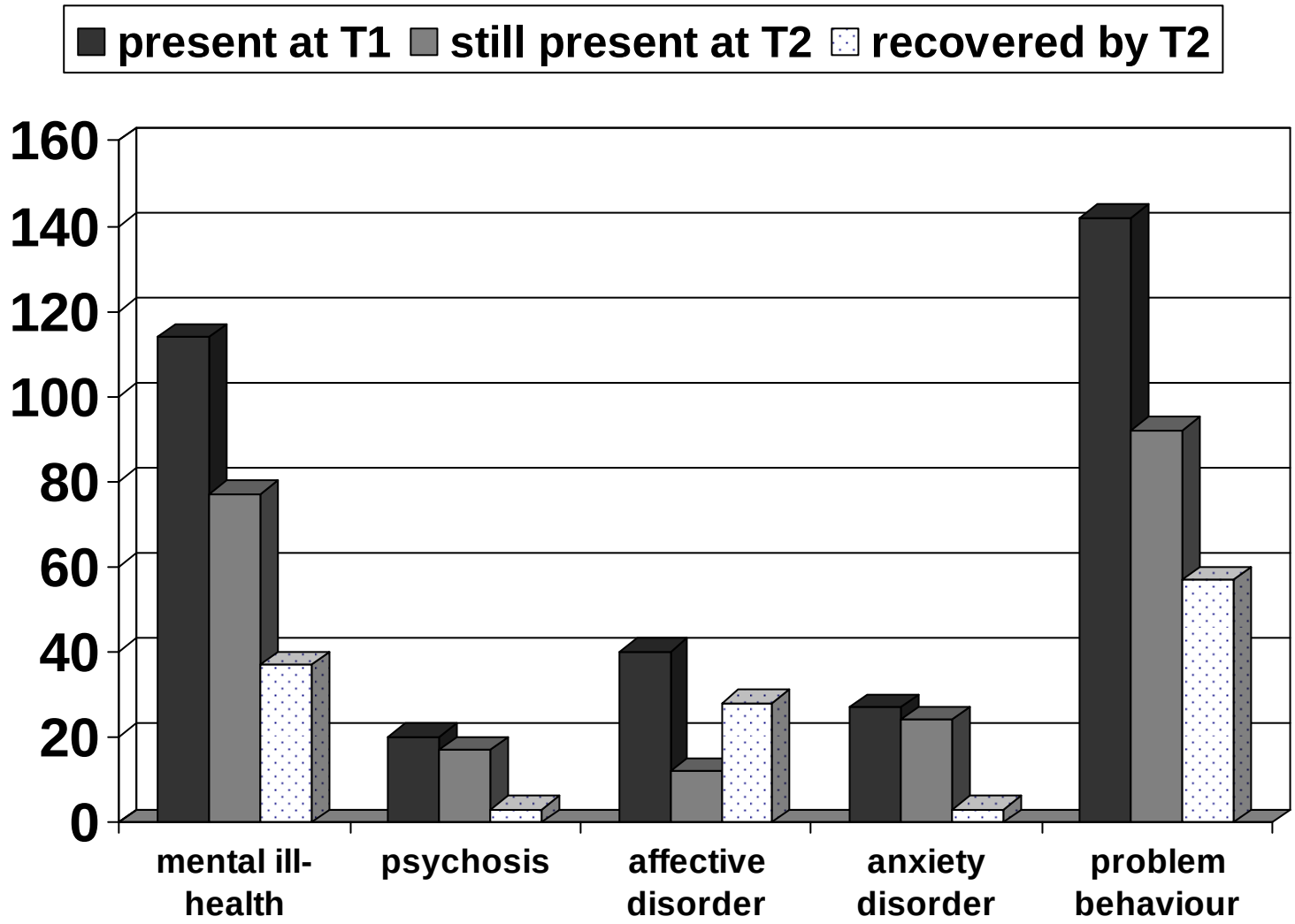


Table 4.23.1 Relationship between personal factors & endurance of mental-ill health

		Whole Cohort	Enduring Mental Ill-Health	
		N=651	N=77 (11.8%)	
Group 1: Personal factors				
Age	Mean (SD)	Mean= 43.6 (SD=14.2)	Mean=44.3 (SD=12.6)	P=0.103
Gender	Male Female	355 (54.5%) 296 (45.5%)	41 (11.6%) 36 (12.2%)	P=0.809
Ability	Mild Moderate Severe Profound	254 (39.0%) 140 (21.5%) 126 (19.4%) 131 (20.1%)	27 (10.7%) 16 (11.4%) 17 (13.5%) 17 (13.0%)	P=0.449
Down Syndrome	No Yes	517 (79.4%) 134 (20.6%)	72 (14.0%) 5 (3.7%)	P=0.001
Mental ill-health in the past	No Yes	523 (80.3%) 128 (19.7%)	25 (4.8%) 52 (40.6%)	P=0.003
Family history of mental ill-health	No Yes	609 (93.5%) 42 (6.5%)	70 (11.5%) 7 (16.7%)	P=0.315

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring mental ill-health group, percentages refer to the proportion with enduring mental ill-health out of the whole cohort with that characteristic; p-values are from χ^2-test or t-test as appropriate

Table 4.23.2 Relationship between past experiences factors and endurance of mental-ill health

		Whole Cohort	Enduring Mental Ill-Health	
		N=651	N=77 (11.8%)	
Group 2: Past experiences				
Ex long-stay hospital resident	No Yes	540 (82.9%) 111 (17.1%)	59 (10.9%) 18 (16.2%)	P=0.116
Outwith family home in childhood	No Yes	487 (74.8%) 164 (25.2%)	55 (11.3%) 22 (13.4%)	P=0.467
Death of parent in childhood	No Yes	550 (84.5%) 101 (15.5%)	65 (11.8%) 12 (11.8%)	P=0.986
Divorce of parents in childhood	No Yes	615 (94.5%) 36 (5.5%)	73 (11.9%) 4 (11.1%)	P=0.891
Abuse / adversity in childhood	No Yes	428 (65.7%) 223 (34.3%)	48 (11.2%) 29 (13.0%)	P=0.502
Abuse / adversity in adulthood	No Yes	571 (87.7%) 80 (12.3%)	60 (10.5%) 17 (21.2%)	P=0.005

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring mental ill health group, percentages refer to the proportion with enduring mental ill health out of the whole cohort with that characteristic; p-values are from χ^2-test

Table 4.23.3 Relationship between lifestyle & supports factors and endurance of mental-ill health

		Whole Cohort	Enduring Mental Ill-Health	
		N=651	N=77 (11.8%)	
Group 3: Lifestyle and supports				
Accommodation / support	Family carer Independent Paid carer Congregate	258 (39.7%) 51 (7.8%) 297 (45.7%) 44 (6.8%)	24 (9.3%) 7 (13.7%) 41 (13.8%) 5 (11.4%)	P=0.101
No daytime job / occupation	Has job No job	499 (76.8%) 151 (23.2%)	54 (10.8%) 23 (15.2%)	P=0.142
Deprivation quintile	Most affluent 2 3 4 Most deprived	107 (16.4%) 54 (8.3%) 56 (8.6%) 72 (11.1%) 362 (55.6%)	16 (14.5%) 9 (16.7%) 7 (12.5%) 6 (8.3%) 39 (10.8%)	P=0.110
Marital status	Married / partner No live-in partner	10 (1.5%) 641 (98.5%)	2 (20.0%) 75 (11.7%)	P=0.420
Smoker	No Yes	581 (89.7%) 67 (10.3%)	61 (10.5%) 15 (22.4%)	P=0.004
Life events in previous 12 months	Mean (SD)	1.0 (1.1)	1.23 (1.2)	P=0.012

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring mental ill health group, percentages refer to the proportion with enduring mental ill health out of the whole cohort with that characteristic; p-values are from χ^2-test or t-test as appropriate

Table 4.23.4 Relationship between health and disabilities factors and endurance of mental-ill health

		Whole Cohort	Enduring Mental Ill-Health	
		N=651	N=77 (11.8%)	
Group 4: Health and disabilities				
Visual impairment	No Yes	349 (53.6%) 302 (46.4%)	40 (11.5%) 37 (12.3%)	P=0.755
Hearing impairment	No Yes	457 (70.2%) 194 (29.8%)	54 (11.8%) 23 (11.9%)	P=0.989
Bowel incontinence	No Yes	499 (76.8%) 151 (23.2%)	53 (10.6%) 24 (15.9%)	P=0.079
Urinary incontinence	No Yes	436 (67.1%) 214 (32.9%)	46 (10.6%) 31 (14.5%)	P=0.145
Impaired mobility	No Yes	508 (78.2%) 142 (21.8%)	68 (13.4%) 9 (6.3%)	P=0.022
Severe physical disability	No Yes	619 (95.1%) 31 (4.8%)	75 (12.1%) 2 (6.5%)	P=0.341
Epilepsy	No Yes	424 (66.6%) 213 (33.4%)	54 (12.7%) 22 (10.3%0	P=0.377
Special communication needs	No Yes	334 (51.3%) 311 (47.8%)	40 (12.0%) 36 (11.6%)	P=0.875
Problem Behaviour	No Yes	506 (77.7%) 145 (22.3%)	44 (8.7%) 33 (22.8%)	P=<0.001

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring mental ill health group, percentages refer to the proportion with enduring mental ill health out of the whole cohort with that characteristic; p-values are from χ^2-test

For this comparison, not having Down's syndrome, past psychiatric history, adult adversity or abuse, smoking, number of life events, not having immobility and having additional problem behaviour at T1 were significantly associated with the endurance of mental ill-health. These 7 factors were then entered into the regression model. Not having Down's syndrome (Odds Ratio 3.32, 95% CI 1.28-8.59, p=0.005), smoking (Odds Ratio 2.24, 95% CI 1.15-4.36, p=0.023), not having immobility (Odds Ratio 3.00, 95% CI 1.42-6.30, p=0.001), and having additional problem behaviour (Odds Ratio 3.45, 95% CI 2.06-5.79, p=<0.001) were retained within the backwards stepwise logistic regression model as independently associated with the endurance of mental ill-health. Hosmer & Lemeshow Chi-square =0.25, d.f.=5, p=0.999 giving no indication of lack of fit. Results of the logistic regression analysis are detailed in Table 4.24.

Table 4.24 Logistic regression results for enduring mental ill-health

	Enduring mental ill-health (excl. problem behaviour, dementia and delirium)			
	Group-specific models		**Global model**	
	Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value
Group 1: Personal factors				
Down syndrome	0.257 (0.10-0.6.5)	0.001	0.30 (0.12-0.78)	0.005
Mental ill health in the past	2.021 (1.19-3.43)	0.011	-	-
Group 2: Past experiences				
Abuse/adversity in adulthood	2.30 (1.26-4.18)	0.010	-	-
Group 3: Lifestyle and supports				
Smoking	2.46 (1.31-4.63)	0.009	2.24 (1.15-4.36)	0.023
Life events in previous 12 months	1.14 (0.93-1.39)	0.214	-	-
Group 4: Health and disabilities				
Impaired mobility	0.36 (0.17-0.75)	0.003	0.33 (0.16-0.70)	0.001
Problem behaviour	3.720 (2.25-6.15)	<0.001	3.45 (2.06-5.79)	<0.001

4.24 Enduring problem behaviour

At T1, 149 participants had problem behaviours of whom 92 (61.7%) had enduring problem behaviours and 57 (38.3%) had recovered by T2 (See Figure 4.3). Again because of the small numbers the group with enduring problem behaviour was compared with the rest of the cohort. Results from the initial univariate analysis are reported in Tables 4.25.1-4.25.4. For analysis, small numbers of events required the combination of moderate-severe-profound groups (Odds Ratio expressed relative to mild group), independent, paid carer and congregate care groups (Odds Ratio expressed relative to family carer group) and deprivation categories 1-4 and deprivation categories 5-7 (Odds Ratio expressed relative to deprivation categories 5-7 group).

Table 4.25.1 Relationships between personal factors & enduring problem behaviour

		Whole Cohort	Enduring Problem behaviour	
		N=651	N=92 (14.1%)	
Group 1: Personal factors				
Age	Mean (SD)	Mean=43.6 (SD =14.2)	Mean =44.9 (SD=13.9)	P=0.687
Gender	Male Female	355 (54.5%) 296 (45.5%)	59 (16.6%) 33 (11.1%)	P=0.046
Ability	Mild Moderate Severe Profound	254 (39.0%) 140 (21.5%) 126 (19.4%) 131 (20.1%)	18 (7.1%) 17 (12.1%) 19 (15.1%) 38 (29.0%)	P=<0.001
Down Syndrome	No Yes	517 (79.4%) 134 (20.6%)	89 (17.2%) 3 (2.2%)	P=<0.001
Mental ill health in the past	No Yes	523 (80.3%) 128 (19.7%)	68 (13.0%) 24 (18.8%)	P=0.094
Family history of mental ill health	No Yes	609 (93.5%) 42 (6.5%)	82 (13.5%) 10 (23.8%)	P=0.063

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring problem behaviour group, percentages refer to the proportion with enduring problem behaviour out of the whole cohort with that characteristic; p-values are from χ^2-test or t-test as appropriate

Table 4.25.2 Relationships between past experiences factors & enduring problem behaviour

		Whole Cohort	Enduring Problem behaviour	
		N=651	N=92 (14.1%)	
Group 2: Past experiences				
Ex long-stay hospital resident	No Yes	540 (82.9%) 111 (17.1%)	56 (10.4%) 36 (32.4%)	P=<0.001
Outwith family home in childhood	No Yes	487 (74.8%) 164 (25.2%)	35 (7.2%) 57 (34.8%)	P=0.002
Death of parent in childhood	No Yes	550 (84.5%) 101 (15.5%)	75 (13.6%) 17 (16.8%)	P=0.397
Divorce of parents in childhood	No Yes	615 (94.5%) 36 (5.5%)	86 (14.0%) 6 (16.7%)	P=0.653
Abuse / adversity in childhood	No Yes	428 (65.7%) 223 (34.3%)	54 (12.6%) 38 (17.0%)	P=0.124
Abuse / adversity in adulthood	No Yes	571 (87.7%) 80 (12.3%)	80 (14.0%) 12 (15.0%)	P=0.812

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring problem behaviour group, percentages refer to the proportion with enduring problem behaviour out of the whole cohort with that characteristic; p-values are from χ^2-test

Table 4.25.3 Relationships between lifestyle & supports factors & enduring problem behaviour

		Whole Cohort	Enduring Problem behaviour	
		N=651	N=92 (14.1%)	
Group 3: Lifestyle and supports				
Accommodation / support	Family carer Independent Paid carer Congregate	258 (39.7%) 51 (7.8%) 297 (45.7%) 44 (6.8%)	20 (7.8%) 3 (5.9%) 58 (19.5%) 11 (25.0%)	P=<0.001
No daytime job / occupation	Has job No job	499 (76.8%) 151 (23.2%)	66 (13.2%) 26 (17.2%)	P=0.218
Deprivation quintile	Most affluent 2 3 4 Most deprived	107 (16.4%) 54 (8.3%) 56 (8.6%) 72 (11.1%) 362 (55.6%)	24 (22.4%) 9 (16.7%) 5 (8.9%) 12 (16.7%) 42 (11.6%)	P=0.042
Marital status	Married / partner No live-in partner	10 (1.5%) 641 (98.5%)	1 (10.0%) 91 (14.2%)	P=0.705
Smoker	No Yes	581 (89.7%) 67 (10.3%)	84 (14.5%) 8 (11.9%0	P=0.576
Life events in previous 12 months	Mean (SD)	1.0 (1.1)	1.13 (1.2)	P=0.276

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring problem behaviour group, percentages refer to the proportion with enduring problem behaviour out of the whole cohort with that characteristic; p-values are from χ^2-test or t-test as appropriate

Table 4.25.4 Relationships between health & disabilities factors & enduring problem behaviour

		Whole Cohort	Enduring Problem behaviour	
		N=651	N=92 (14.1%)	
Group 4: Health and disabilities				
Visual impairment	No Yes	349 (53.6%) 302 (46.4%)	41 (11.7%) 51 (16.9%)	P=0.060
Hearing impairment	No Yes	457 (70.2%) 194 (29.8%)	63 (13.8%) 29 (14.9%)	P=0.697
Bowel incontinence	No Yes	499 (76.8%) 151 (23.2%)	56 (11.2%) 36 (23.8%)	P=<0.001
Urinary incontinence	No Yes	436 (67.1%) 214 (32.9%)	42 (9.6%) 50 (23.4%)	P=<0.001
Impaired mobility	No Yes	508 (78.2%) 142 (21.8%)	67 (13.1%) 25 (17.6%0	P=0.182
Severe physical disability	No Yes	619 (95.1%) 31 (4.8%)	90 (14.5%) 2 (6.5%)	P=0.207
Epilepsy	No Yes	424 (66.6%) 213 (33.4%)	51 (12.0%) 39 (18.3%)	P=0.032
Special communication needs	No Yes	334 (51.3%) 311 (47.8%)	31 (9.3%) 61 (19.6%)	P=<0.001

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring problem behaviour group, percentages refer to the proportion with enduring problem behaviour out of the whole cohort with that characteristic; p-values are from χ^2-test

When the group with enduring problem behaviour was compared to the rest of the cohort, male gender, more severe intellectual disabilities, not having Down's syndrome, ex-long stay hospital residence, living out with the family home as a child, not living with a family carer, less deprivation, bowel incontinence, urinary incontinence, epilepsy and special communication needs were all found to be significantly associated with the endurance of problem behaviour. These factors were entered into the Global Model.

Male gender (Odds Ratio 1.77, 95% CI 1.04-3.00, p=0.032), more severe intellectual disabilities (Odds Ratio 2.27, 95% CI 1.23-4.20, p=0.007), not having Down's syndrome (Odds Ratio 6.23, 95% CI 1.89-20.55, p= <0.001), not living with a family carer (Odds Ratio 2.34, 95% CI 1.31-4.17, p=0.003), less deprivation (Odds Ratio=1.86, 95% CI 1.13-3.07, p=0.015) and urinary incontinence (Odds Ratio 2.33, 95% CI 1.35-4.00, p=0.002) were retained as independently related to the endurance of problem behaviour. Hosmer and Lemeshow Chi square= 4.21, d.f. =8, p=0.838, giving no indication of lack of fit. At the second and third stage of the analysis no participants had an incomplete data set. Results of logistic regression analysis are reported in Table 4.26.

Table 4.26 Logistic regression results for enduring problem behaviour

	Enduring problem behaviour			
	Group-specific models		Global model	
	Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value
Group 1: Personal factors				
Male Gender	1.44 (0.90-2.31)	0.123	1.77 (1.04-3.00)	0.032
More severe intellectual disabilities (vs. Mild ID)	3.00 (1.74-5.20)	<0.001	2.27 (1.23-4.20)	0.007
Not having Down's syndrome	9.07 (2.81-29.24)	<0.001	6.23 (1.89-20.55)	<0.001
Group 2: Past experiences				
Ex-long stay hospital resident	4.15 (2.60-6.73)	<0.001	-	-
Outwith family home in childhood	1.34 (0.80-2.24)	0.273	-	-
Group 3: Lifestyle and supports				
Not living with Family carer(vs. Family carer)	2.70 (1.57-4.63)	<0.001	2.34 (1.31-4.17)	0.003
Less Deprivation	1.83 (1.15-2.92)	0.011	1.86 (1.13-3.07)	0.015
Group 4: Health and disabilities				
Bowel incontinence	1.03 (0.82-1.30)	0.799	-	-
Urinary incontinence	2.46 (1.53-3.94)	<0.001	2.33 (1.35-4.00)	0.002
Special communication needs	1.92 (1.18-3.13)	0.008	-	-
Epilepsy	1.25 (0.78-2.01)	0.363	-	-

4.25 Enduring unipolar depression

4.25.1 Participants with unipolar clinician depression at T1

Thirty two (4.9%) of the cohort were depressed at T1. Seven were still in the same episode of depression at T2, 25 had recovered from the T1 depressive episode but of these 2 became depressed again, 1 of whom was still depressed at T2, and one of whom had recovered from the second episode of depression

by T2. Recovery rate from an episode of unipolar depression at T1 by T2 (2 years later) was 78%.

Dates of the onset and date of recovery (if within the two year follow up period) of the T1 episodes of depression were available for 20 participants. Seven cases were still in episode and 5 cases had a missing date of recovery but were known to have recovered by T2. For these 20 subjects the mean duration of episode of T1 depression was 16.4 months (SD=14.3), the median was 12 months.

Eleven out of the 27 participants (41%) with recovery data available, recovered from the episode of depression present at T1, within 1 year of the onset of the depressive episode. Sixteen (59%) were known to have taken longer than 1 year to recover. For 11 participants (41%) the duration of the T1 identified depressive episode was more than 2 years.

4.25.2 Participants with incidence of unipolar clinical depression occurring within 1 year of T1

There were 19 episodes of unipolar clinical depression that occurred within 1 year of T1 and hence could then also be categorised into recovery within 1 year or not. Combining these 19 participants with the 27 participants with an episode of depression at T1 (with onset/recovery data available) gave a total of 45 participants with an episode of depression that was known to have recovered or not within 1 year of onset. One participant had T1 depression and another episode of depression occurring within 1 year of T1 hence the sample of 45 rather than 46. Analysis within this group was not undertaken due to the small numbers rendering such an analysis underpowered. However, the group of 21 participants with an episode of depression with duration > 1 year was compared with the rest of the cohort to ascertain significant associations. Results of the initial univariate analysis are detailed in Tables 4.27.1- 4.27.4. For analysis, small numbers of events required the combination of moderate-severe-profound groups (Odds Ratio expressed relative to mild group), independent, paid carer and congregate care groups (Odds Ratio expressed relative to family carer

group) and deprivation categories 1-4 and deprivation categories 5-7 (Odds Ratio expressed relative to deprivation categories 5-7 group).

Table 4.27.1 Relationships between personal factors & depression duration >1 year

		Whole Cohort	Depression > 1year	
		N=651	N=21(3.2%)	
Group 1: Personal factors				
Age	Mean (SD)	Mean= 43.6 (SD=14.2)	Mean= 44.6 (SD=13.7)	P=0.734
Gender	Male Female	355 (54.5%) 296 (45.5%)	8 (2.3%) 13 (4.4%)	P=0.124
Ability Vs mild	Mild Moderate Severe Profound	254 (39.0%) 140 (21.5%) 126 (19.4%) 131 (20.1%)	14 (5.5%) 4 (2.9%) 2 (1.6%) 1 (0.8%)	P=0.008
Down Syndrome	No Yes	517 (79.4%) 134 (20.6%)	20 (3.9%) 1 (0.8%)	P=0.068
Mental ill-health in the past	No Yes	523 (80.3%) 128 (19.7%)	9 (1.7%) 12 (9.4%)	P=<0.001
Family history of mental ill-health	No Yes	609 (93.5%) 42 (6.5%)	21 (3.4%) 0 (0%)	P=0.221

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring depression group, percentages refer to the proportion with enduring depression out of the whole cohort with that characteristic; p-values are from χ^2-test or t-test as appropriate

Table 4.27.2 Relationships between past experiences factors & depression duration >1 year

		Whole Cohort	Depression > 1year	
		N=651	N=21(3.2%)	
Group 2: Past experiences				
Ex long-stay hospital resident	No Yes	540 (82.9%) 111 (17.1%)	20 (3.7%) 1 (0.9%)	P=0.128
Outwith family home in childhood	No Yes	487 (74.8%) 164 (25.2%)	18 (3.7%) 3 (2.3%)	P=0.242
Death of parent in childhood	No Yes	550 (84.5%) 101 (15.5%)	17 (3.1%) 4 (4.0%)	P=0.649
Divorce of parents in childhood	No Yes	615 (94.5%) 36 (5.5%)	19 (3.1%) 2 (5.6%)	P=0.416
Abuse / adversity in childhood	No Yes	428 (65.7%) 223 (34.3%)	11 (2.6%) 10 (4.5%)	P=0.190
Abuse / adversity in adulthood	No Yes	571 (87.7%) 80 (12.3%)	16 (2.8%) 5 (6.3%)	P=0.102

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring depression group, percentages refer to the proportion with enduring depression out of the whole cohort with that characteristic; p-values are from χ^2-test

Table 4.27.3 Relationships between lifestyle & supports factors & depression duration >1 year

		Whole Cohort	Depression > 1year	
		N=651	N=21(3.2%)	
Group 3: Lifestyle and supports				
Accommodation / support	Family carer Independent Paid carer Congregate	258 (39.7%) 51 (7.8%) 297 (45.7%) 44 (6.8%)	8 (3.1%) 5 (9.8%) 7 (2.4%) 1 (2.3%)	P=0.875
No daytime job / occupation	Has job No job	499 (76.8%) 151 (23.2%)	8 (1.6%) 13 (8.6%)	P=<0.001
Deprivation quintile	Most affluent 2 3 4 Most deprived	107 (16.4%) 54 (8.3%) 56 (8.6%) 72 (11.1%) 362 (55.6%)	3 (2.8%) 2 (3.7%) 3 (5.4%) 3 (4.2%) 11 (3.0%)	P=0.857
Marital status	Married / partner No live-in partner	10 (1.5%) 641 (98.5%)	3 (30.0%) 18 (2.8%)	P=<0.001
Smoker	No Yes	581 (89.7%) 67 (10.3%)	17 (2.9%) 4 (6.0%)	P=0.183
Life events in previous 12 months	Mean (SD)	1.0 (1.1)	1.81 (1. 6)	P=0.039

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring depression group, percentages refer to the proportion with enduring depression out of the whole cohort with that characteristic; p-values are from χ^2-test or t-test as appropriate

Table 4.27.4 Relationships between health & disabilities factors & depression duration >1 year

		Whole Cohort	Depression > 1year	
		N=651	N=21(3.2%)	
Group 4: Health and disabilities				
Visual impairment	No Yes	349 (53.6%) 302 (46.4%)	17 94.9%) 4 (1.3%)	P=0.011
Hearing impairment	No Yes	457 (70.2%) 194 (29.8%)	14 (3.1%) 7 (3.6%)	P=0.719
Bowel incontinence	No Yes	499 (76.8%) 151 (23.2%)	17 (3.4%) 4 (2.6%)	P=0.644
Urinary incontinence	No Yes	436 (67.1%) 214 (32.9%)	16 (3.1%) 5(2.3%)	P=0.366
Impaired mobility	No Yes	508 (78.2%) 142 (21.8%)	16 (3.1%) 5 (3.5%)	P=0.825
Severe physical disability	No Yes	619 (95.1%) 31 (4.8%)	19 (3.1%) 2 (6.5%)	P=0.299
Epilepsy	No Yes	424 (66.6%) 213 (33.4%)	16 (3.8%) 5 (2.3%)	P=0.342
Special communication needs	No Yes	334 (51.3%) 311 (47.8%)	15 (4.5%) 6 (1.9%)	P=0.067
Problem Behaviour	No Yes	506 (77.7%) 145 (22.3%)	16 (3.2%) 5 (3.4%)	P=0.863

Notes: for the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the enduring depression group, percentages refer to the proportion with enduring depression out of the whole cohort with that characteristic; p-values are from χ^2-test

When the endurance depression group (depression duration > 1year) was compared with the rest of the cohort, mild intellectual disabilities (Odds Ratio 3.43, 95% CI 1.35-8.76, p=0.007), mental ill-health in the past (Odds Ratio 6.16, 95% CI 2.51-15.09, p=<0.001), being married or having a live in partner (Odds Ratio 9.22, 95% CI 1.96-43.43, p=0.013), no daytime occupation or job (Odds Ratio=5.22, 95% CI 2.03-13.42, p=0.001) having more life events (Odds Ratio 1.65, 95% CI 1.22-2.23, p=0.003) and not having visual impairment (Odds Ratio 3.82, 95% CI 1.27-11.46, p=0.008) were significantly associated with the endurance of depression.

All of these factors except mild intellectual disabilities were retained in the global regression model, the results of which are reported in Table 4.28. The Hosmer-Lemeshow statistic was Chi square= 9.71, d.f.=8, p=0.286 giving no indication of lack of fit.

Table 4.28 Logistic regression results for depression duration > 1 year

	Depression duration > 1year			
	Group-specific models		**Global model**	
	Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value
Group 1: Personal factors				
Mild Intellectual Disabilities (vs. mod-profound)	3.43 (1.35-8.76)	0.007	-	-
Mental ill-health in the past	6.16 (2.51-15.09)	<0.001	6.68 (2.53-17.67)	<0.001
Group 3: Lifestyle and supports				
Married/live in partner	9.22 (1.96-43.43)	0.013	6.95 (1.16-41.53)	0.045
No daytime job/occupation	5.22 (2.03-13.42)	0.001	5.19 (1.91-14.07)	0.001
Life events in previous 12 months	1.65 (1.22-2.23)	0.003	1.68 (1.22-2.32)	0.003
Group 4: Health and disabilities				
No Visual impairment	3.82 (1.27-11.46)	0.008	4.42 (1.36-14.39)	0.006

As the depression endurance group included participants with T1 depression, and day time occupation or employment was measured at T1 and hence could be a consequence of the depressive episode rather than a predictor of endurance, the univariate analysis for this variable was repeated for only those with incident depression i.e. occurring post T1. Not having daytime occupation or employment remained significantly associated with the endurance of depression (p= 0.007).

4.26 Summary of significant independent associations with mental ill-health, problem behaviour and depression

A summary of the factors found to be significantly and independently related to the prevalence, incidence and endurance of mental ill-health, problem behaviour and depression are detailed in Tables 4.29- 4.31 respectively. Table 4.32 presents all factors found to be significantly and independently related to the prevalence, incidence and endurance of mental ill-health, problem behaviour and depression in one Table. Figures for the factors found to be significantly and independently associated with the prevalence of the various types of mental ill-health are taken from the results of the prevalence study, Cooper et al (2007).

Table 4.29 Summary of significant independent associations with mental ill-health

Factor significantly independently related	Prevalence of mental ill-health	Incidence of mental ill-health	Enduring mental ill-health
Female gender	+		
Severe intellectual disabilities	+	+	
Not having Down's syndrome			+
Past psychiatric history	+	+	
Abuse/adversity in adulthood		+	
Not living with a family carer	+	+	
Smoker	+		+
Number of life events in preceding year	+		
Urinary incontinence	+	+	
Not having visual impairment			
Not having immobility at T1	+	+	+
Not having severe physical disability/quadriplegia	+		
Problem behaviour			+

Table 4.30 Summary of significant independent associations with problem behaviour

Factor significantly independently related	Prevalence of problem behaviour	Incidence of problem behaviour	Enduring problem behaviour
Female	+		
Male			+
Severe intellectual disabilities	+	+	+
Not having Down's syndrome	+		+
Divorce of parents in childhood		+	
Former long stay hospital resident			+
Not living with a family carer	+	+	+
Living in less deprived area			+
Number of life events in preceding year		+	
Visual impairment	+		
Urinary incontinence	+		+
Not having severe physical disability/quadriplegia	+		

Table 4.31 Summary of significant independent associations with depression

Factor significantly independently related	Prevalence of depression	Incidence of depression	Enduring depression (duration >1yr)
Female	+		
Past psychiatric history		+	+
Not living with a family carer			
No job or daytime occupation			+
Married or living with partner			+
Smoker	+		
Number of life events in preceding year	+	+	+
Not having hearing impairment	+		
Not having visual impairment			+
Problem behaviour		+	

Table 4.32 Summary of significant independent associations with mental ill-health, problem behaviour and depression

Factor (significantly independently related to)	Prevalence			Incidence			Enduring		
	Mental ill-health	Problem Behaviour	Depression	Mental ill-health	Problem Behaviour	Depression	Mental ill-health	Problem behaviour	Depression duration >1yr
Personal Factors									
Female gender	+	+	+						
Male gender								+	
Severe intellectual disabilities	+	+		+	+			+	
Not having Down's syndrome		+					+	+	
Past psychiatric history	+			+		+			+
Past experiences									
Divorce of parents in childhood					+				
Abuse/adversity in adulthood				+					
Lifestyles and supports									
Not living with family carer	+	+		+	+			+	
No job or day time occupation									+
Living in less deprived area								+	
Married or living with partner									+
Smoker	+		+				+		
Number of life events in preceding year	+		+		+	+			+
Health and Disabilities									
Visual impairment		+							
Not having visual impairment									+
Not having hearing impairment			+						
Urinary incontinence	+	+		+				+	
Not having immobility at T1	+			+			+		
Not having severe physical disability/quadriplegia	+	+							
Problem behaviour						+	+		

Chapter 5 DISCUSSION

5.1 Incidence of mental ill-health

The two year incidence rate for any type of mental ill-health (excluding specific phobia) in adults with mild-profound intellectual disabilities was found to be 16.3% i.e. almost one in six adults experienced at least one episode of mental-ill health during the two year follow up period. This is a significant amount of illness that persons themselves, carers and services have to manage. There are no other studies that have measured the overall incidence of mental-ill health in adults with intellectual disabilities to compare this finding with.

Comparison of this finding with the reported incidence rates for the general population is hampered by the fact that some of the mental ill-health that occurs in the intellectual disabilities population does not present in the general population. Problem behaviours make up a significant proportion of the overall incidence of mental ill-health in the intellectual disabilities population but are hardly reported in the general population. When the incidence rate for the intellectual disabilities population is restricted to disorders that are also seen in the general population, the overall incidence rate is less. However, if the additional disorders seen only in the intellectual disabilities population are included, the overall incidence rate is almost the same as that in the general population. This suggests that the overall rate of onset of mental ill-health in the intellectual disabilities population is at least as high as it is in the general population and the difficulties in identifying and diagnosing mental ill-health in this population means it might be higher.

When comparing incidence rates for individual types of mental ill-health, there were some very clear differences in the incidence rates in the intellectual disabilities population compared to the general population.

5.1.1 Incidence of non-affective psychosis

The incidence rate for non-affective psychosis, (despite the difficulties in diagnosing this in non-verbal patients) is approximately ten times (standardised incident ratio = 9.93) that seen in the general population even though the rate of drug and alcohol use in this population is negligible. There are a number of potential reasons for this. It has been demonstrated that both intellectual disabilities and psychosis can arise from a common cause such as genetic disorders e.g. Prader Willi Syndrome (Beardsmore et al, 1998), Velocardiofacial Syndrome (Murphy & Owen, 2001) and possibly central nervous system injuries e.g. meningitis and pregnancy and birth complications (O'Dwyer, 1997; Sanderson et al, 2001). There is also the Kraepelinian concept of pfropfschizophrenie, which was re examined by Doody et al (1998) with the conclusion that a severe form of schizophrenia may occur where schizophrenia and intellectual disabilities arise together from a common genetic aetiology. The slight excess of males in the intellectual disabilities population, combined with the higher rate of psychosis in males (Murray & van OS, 1998), is also likely to have contributed to the increased incidence of non-affective psychosis in intellectual disabilities. Quite a few studies in the general population have suggested that being raised in an urban environment is a direct or at least indirect risk factor for schizophrenia (Eaton et al, 2000; Haukka et al, 2001) and the increased incidence of psychosis found in this study could be related to this. However, although the study population was predominantly urban it did include a fair proportion of suburban areas and was probably not that different in this respect from the study population in the general population study (Kirkbride et al, 2006) used to calculate the standardised incidence ratio for non-affective psychosis. Thus, it is unlikely that the raised incidence of non-affective psychosis found in this study is due to the urban/rural factor. In conclusion, it seems most likely that the increased incidence of non-affective psychosis in the intellectual disabilities population is due to a combination of the predominance of males, the increased rate of genetic disorders and the increased rate of central nervous system injuries in the intellectually disabled population – but of course it is also very likely that there are other, as yet unidentified factors at play here and the individual contribution and interaction of these factors is unknown.

5.1.2 Incidence of first episode mania/bipolar affective disorder

The incidence rates for first episode mania and new onset bipolar affective disorder are also significantly higher with standardised incident ratios of 100.2 and 52.4 respectively. Could this be due to the mis-diagnosis of mania in adults with intellectual disabilities? Non-verbal patients with acute physical ill-health can present with irritability, over activity, disturbed sleep, reduced concentration and distractibility. In these patients, the underlying physical ill-health can go undetected for several months, hence there is the possibility of them meeting diagnostic criteria for a manic episode. In view of this possibility, all episodes of mania were reviewed a second time by the research psychiatrist (ES), several months after completion of the study. No cases required re-categorisation and therefore it is unlikely that mis-diagnosis has contributed to the very high incidence rate of mania/bipolar affective disorder found in this study. The incidence of bipolar affective disorder is thought to be higher in the urban compared to the rural population (Blazer et al, 1985) but for the same reasons as stated in the paragraph above, this factor is not likely to have contributed. Most studies in the general population have found no gender difference in the prevalence of bipolar affective disorder so the excess of males in the intellectual disabilities population will not have contributed to the increased incidence. Such a higher rate of mania/bipolar affective disorder is especially unexpected given the high rate of use of mood stabilising drugs in this population. At T1, 26% of the sample were taking mood stabilising drugs, the very large majority of which were for the treatment of epilepsy. The most likely possible explanations for the very much higher incidence of first episode mania/bipolar affective disorder are (as for non-affective psychosis) the increased rate of genetic disorders and nervous system injuries in people with intellectual disabilities. This adds some weight to the ongoing debate surrounding the Kraepelinian dichotomy which has been challenged, with the suggestion that there may not be any point of uncommonness between the clinical features of schizophrenia and bipolar disorder; rather that there is a continuum, with some shared aetiology, and some aetiology distinct to either schizophrenia or bipolar disorder (Craddock & Owen, 2005).

5.1.3 Incidence of Depression

The incidence rate of depression in intellectual disabilities does not differ significantly from that in the general population. Is this what we would expect? Studies in the general population have consistently shown an increased risk for depression in women, at almost twice that for men (Weissman & Klerman, 1985). Is it possible that the excess of men in the intellectual disabilities population has reduced the overall rate of depression in this cohort? This is not the case as the incidence rate of depression in men with intellectual disabilities was not found to be significantly different from the rate in women with intellectual disabilities. Prior psychiatric history, low socioeconomic status and unemployment are thought to be risk factors for depression and each is very prevalent in adults with intellectual disabilities. In contrast, marriage, which is thought to be a protective factor (Bland et al, 1988) is rare. Considering this, and the fact that many adults with intellectual disabilities experience ridicule, rejection, exploitation and abuse and have poor social support it is surprising that the incidence of depression found in this cohort was not higher than that reported for the general population. However, there is the difficulty in diagnosing depression in patients with more severe intellectual disabilities and the trend of higher incidence rates in those with mild and moderate levels of intellectual disabilities suggests that this is relevant. Adults with intellectual disabilities may not be able to recognise or report symptoms such as low mood, loss of self esteem, anhedonia, feelings of guilt or suicidal ideas and sleep and appetite disturbance, even when present, may not be recognised by carers. Thus it is possible that only more severe cases of depression in this cohort were detected (despite the use of diagnostic criteria appropriate for adults with intellectual disabilities) and that mild episodes of depression were missed, hence the lower than expected incidence of depression.

5.1.4 Incidence of Anxiety

The incidence rate of anxiety disorders was very much lower than that reported for the general population. This may be due to difficulties in identifying and diagnosing these disorders in the intellectual disabilities population and the fact

that participants with only specific phobia were not progressed to full psychiatric assessment, and hence precise data for specific phobias is not available.

Is there any reason to expect that adults with intellectual disabilities have a significantly lower incidence rate of anxiety disorders? They are exposed to at least as many life events and probably more, their coping skills tend to be less well developed, they are more likely to experience abuse and rejection, they have less well developed linguistic skills (leading to greater difficulties in discussing or dismissing fears and resulting in over generalisation) and they tend to have a smaller number of supportive relationships (Rosen & Burchard, 1990). Some studies have found a high prevalence rate of anxiety disorders in adults with intellectual disabilities. Hassiotis et al (2008), Cooper (1997) and Deb et al (2001a) all found a prevalence rate of anxiety disorders in adults with intellectual disabilities higher than that in the general population and Emerson (2003) found a higher prevalence rate of anxiety disorder in children with intellectual disabilities compared to children without intellectual disabilities. But these reported high prevalence rates of anxiety could be due to a longer duration of anxiety disorders rather than a high incidence.

The rate of panic disorder has been found to be two fold in women compared to men (Eaton et al, 1994). The excess of men in the intellectual disabilities population would result in a slightly lower overall rate for intellectual disabilities but not to the degree found in this study. Anxiety disorders are especially difficult to diagnose in adults with intellectual disabilities due to the reliance on subjective report of symptomatology and this is likely to have contributed to the lower rate. This study did not accurately measure the incidence of specific phobia and the rate for this is very likely to be lower than the true rate. Specific phobia accounts for a significant proportion of the incidence of anxiety disorders in the general population, so this goes someway to explaining the significantly lower rate found in this study. It is also very likely that anxiety disorders are diagnosed as behavioural problems in adults with intellectual disabilities. On the other hand, epilepsy has been associated with increased rates of anxiety (Titlic et al, 2009). Other possible explanations for the lower incidence of anxiety disorders found in this study include the widespread use of antipsychotic medication for treating behavioural problems which may also reduce anxiety

symptoms (23.2% of the sample were on antipsychotic preparations, 49.6% on any kind of psychotropic, including anticonvulsants, at T1) and the speculation that adults with intellectual disabilities are reliant on others and so have less to worry about (although having less control over one's life may act in the other direction). In addition the lower levels of responsibility people with intellectual disabilities generally have, the developmental effect of not being aware of certain anxiety provoking situations and the possibility that having some form of care acts as a buffer against anxiety could also contribute. Then again, we know that adults with intellectual disabilities experience as many and possibly more traumatic events than others and that these are associated with neurotic symptoms (Hastings et al, 2004).

In conclusion, it may be that the incidence rate of anxiety disorders found in this study is an underestimate of the true incidence as a result of methodological flaws, particularly the inadequate measurement of specific phobias. However, it is also possible, that the reported high prevalence of anxiety disorders in adults with intellectual disabilities is due to a higher chronicity of anxiety disorders rather than a higher incidence and that the lower incidence finding in this study is accurate. Further research examining the incidence and recovery rates of anxiety disorders in more detail in this population would help clarify this.

5.1.5 Incidence of substance misuse

The incidence of substance misuse in adults with intellectual disabilities is very much lower than that reported for the general population. This is to be expected as most adults with intellectual disabilities are not exposed to or have the opportunity to obtain illicit drugs or alcohol. There is also the developmental issue with most adults with intellectual disabilities never reaching the developmental level at which people would normally become interested in experimenting with drug and alcohol use. What little occurs is in the more able group who receive only part time support.

5.1.6 Incidence of dementia

The incidence of early onset dementia was found to be very much higher than in the general population with a standardised incident ratio of 66.67 (95% CI 18.16-170.69). This was entirely accounted for by adults with Down's syndrome developing early onset Alzheimer's disease. A high incidence of early onset Alzheimer's disease in people with Down's syndrome has already been reported by Holland et al (2000). Holland et al (2000) found an incidence rate of 15.9% over an 18 month period for all types of dementia in a population based sample of 44 adults aged over 40 years with Down's syndrome. This gives an incidence rate of 106.13 per 1000 person years. The equivalent incidence rate for early onset dementia in adults with Down's syndrome aged over 40 yrs in this study was 36.6 per 1000 person years which is very much higher than that reported for the general population but lower than that found by Holland et al (2000) presumably due to the differing methodology (all participants in the Holland et al study received a specific dementia assessment that included neuropsychological testing). This increased risk of early onset Alzheimer's disease in adults with Down's syndrome is thought to be associated with the over expression of the amyloid precursor protein gene although it is unlikely that this is the sole factor and other congenital and environmental factors may also contribute.

The Incidence of all types of dementia in persons over 65 yrs is generally accepted to be around 15-20 per 1000 person years (Mathews & Brayne, 2005). In this study, the incidence rate was 11 per 1000 person years, a lower, but not significantly lower rate. This finding is in keeping with that reported by Zigman et al (2004) who also found an incidence rate of all types of dementia in adults with intellectual disabilities aged over 65 years similar to the general population rate. However, Zigman's study was limited by not being population based and population based prevalence studies such as Strydom et al (2007), Cooper (1997), Lund (1985a) and Patel et al (1993) have all reported prevalence rates of dementia in adults with intellectual disabilities not due to Down's syndrome well above the general population rate. The lower incidence rate of dementia in adults with intellectual disabilities aged over 65 yrs found in this study may be because the screening interview missed cases of dementia,

patients with dementia were overrepresented in those who were not able to take part in the study or refused consent or it may be a true finding. The rate of dementia in adults with intellectual disabilities over 65 years of age could be less than that in the non-intellectual disabled population due to the reduced rate of smoking and alcohol use in the intellectual disabilities population, differential mortality and reduced rate of hypertension, but it is more likely that this study has simply failed to identify all cases of dementia or the finding is a Type II error due to the small number of adults aged over 65 yrs in the sample. The increased rate of brain injury, lack of 'reserve' in brain functioning, high prevalence of epilepsy and genetic disorders in the intellectual disabilities population makes it more likely that there is in fact a high incidence of dementia in adults with intellectual disabilities not due to Down's syndrome and that the lower incidence rate found in this study is a result of methodological limitations. Measurement of the incidence of dementia in adults with intellectual disabilities aged over 65 years of age was not the primary aim of this study.

5.2 Factors predictive of episodes of mental-ill health

(excluding problem behaviour, dementia and delirium)

No previous studies have examined factors predictive of mental ill-health in this population to allow comparison. Studies in the general population examining factors predictive of mental illness have focused on specific illnesses, rather than the overall rate of mental ill-health. Factors that were found to be predictive of the onset of mental ill-health (excluding problem behaviours) were more severe intellectual disabilities, past psychiatric history, abuse/adversity in adulthood, urinary incontinence, not having immobility and not living with a family carer. However, a factor that is found to be predictive of the onset of illness is not necessarily a causal factor. Susser (1973) has suggested the use of five criteria to aid in establishing a causal relationship. The suggested five criteria are:

1. **Temporal sequence of variables – i.e. it has to be shown that the cause happened before the effect**
2. **Consistency of associations on replication**
3. **Strength of the association**
4. **Specificity of association (discriminant validity)**

5. **Coherency of the explanation of the association – does it fit with pre-existing theory and evidence?**

Taking each of the identified predictive factors for the onset of mental ill-health in turn, I will discuss these criteria in more detail.

5.2.1 Severe intellectual disabilities as a predictive factor for episodes of mental ill-health (excluding problem behaviour, dementia and delirium)

This meets the first criteria of temporal sequence. In this study the level of intellectual disabilities was assessed at time point one, before the period during which the onset of mental illness was identified. Participants may have had mental illness prior to time point one which might have a led to a decline in functioning and thus made them more likely to have severe intellectual disabilities but as the categorisation of level of intellectual disabilities at time point 1 included making allowances for decline in functioning due to significant mental illness (such as dementia or chronic schizophrenia) this is not likely to of had any impact. No other studies have examined factors related to the incidence of mental illness in adults with intellectual disabilities but a few have examined factors associated with the prevalence of mental illness. Some prevalence studies have shown an increased rate in more severe intellectual disabilities (Bailey, 2008; Cooper et al, 2007; Lund, 1985a), others have shown a reduced rate (Iverson & Fox, 1989; Borthwick-Duffy & Eyman, 1990) and Corbett (1979) found a similar rate. It is therefore not possible to meet criterion 2. The strength of the association is moderate though, with an odds ratio of 2.24 (95% CI 1.15-4.39). The association is not specific and was also identified as predictive of problem behaviour. However, it is not an unexpected result and fits with our current theories of mental illness. Adults with more severe intellectual disabilities will have more severe brain dysfunction and thus it makes sense that they will experience more mental health problems. I think we can safely assume from this finding that patients with more severe intellectual disabilities are more likely to develop mental ill-health but this does not add to our understanding of why adults with more severe intellectual disabilities are more likely to experience mental ill-health.

5.2.2 **Past psychiatric history as a predictive factor for episodes of mental ill-health** (excluding problem behaviour, dementia and delirium)

This study counted any episode of mental ill-health occurring within the two year follow up period, whether or not it was a first ever episode. Thus, it is not surprising that having a past psychiatric history was predictive of the onset of an episode of mental ill-health as at least some of these episodes will have been recurrent episodes of affective or psychotic disorders. This could be examined in more detail by counting only first ever episodes of illness but would lead to significantly less power as the numbers would reduce substantially and introduce significant error. It is very difficult to ascertain whether or not an adult with intellectual disabilities has had any previous episodes of illness as these are often missed or the history is lost as carers change over time. Further examination of this predictive factor was not done in this study for these reasons. The strength of the association is moderate with an odds ratio of 2.41 (95% CI 1.36-4.28) but the association is not specific. Past psychiatric history also predicts the onset of problem behaviour. However, past psychiatric history predicting future mental ill-health makes sense and is in keeping with current evidence for the general population.

5.2.3 **Abuse/adversity in adulthood as a predictive factor for episodes of mental ill-health** (excluding problem behaviour, dementia and delirium)

Information about abuse/adversity in adulthood was collected at time point 2 and therefore does not meet the first criterion of the temporal relationship. Abuse/adversity in adulthood measured in this way could have occurred before, during or after the episode of mental ill-health and thus could be either cause or effect. This is a significant limitation and negates any conclusion that adversity or abuse in adulthood is a cause of mental ill-health in adults with intellectual disabilities. However, this is a finding that has been suggested by others. Sequeira & Hollins (2003) conducted a systematic review of the literature on the clinical effects of sexual abuse in adults with intellectual disabilities and found several studies suggesting that a range of psychopathology may follow sexual

abuse. Hastings et al (2004) examined a large population based sample of adults with intellectual disabilities and found that one or more life events in the preceding year was significantly associated with a score above threshold on the affective/neurotic sub-scale of the PAS-ADD checklist. A significant association between life events in the preceding two years and emotional and behavioural problems measured by the Developmental Behaviour Checklist for Adults was found by Hamilton et al (2005). Esbensen and Benson (2006) also found that life events were associated with problem behaviour and depressive symptoms but then went on to repeat the measures 4 months later and found that life events in the preceding 4 months predicted problem behaviours and depression even when controlling for past levels of depressive symptoms and behavioural problems. Several studies in the general population have also linked traumatic experiences in adulthood with the onset of mental illness (Bebbington et al, 1993) with the proposed theory that exposure to stress makes one vulnerable to hypothalamic-pituitary-adrenal axis dysregulation and that repeated exposure to traumatic events leads to the development of hostile attributions of others intentions. There is no reason to suppose that this would not also be applicable to adults with intellectual disabilities. The strength of the association found in this study was moderate with an odds ratio of 2.17 (95% CI 1.07-4.43).

5.2.4 **Urinary incontinence as a predictive factor for episodes of mental ill-health** (excluding problem behaviour, dementia and delirium)

Urinary incontinence was measured at time point 1 and therefore before the onset of mental illness. No other studies in the intellectual disabilities population have examined urinary incontinence as a risk factor for the onset of mental ill-health and so there are no other studies to compare this finding with. However, it is a finding that has been reported in the general population. A strong association between depression and urinary incontinence has been established for the general population (Vigod & Stewart, 2006; Zorn et al, 1999) but the direction of this relationship is less clear. Perry et al (2006) report that incident cases of urge incontinence were predicted by anxiety at baseline and incident cases of anxiety and depression by urge incontinence at baseline. Persons with urinary incontinence may be more likely to experience stigmatizing behaviour

and rejection from carers and peers, which could result in the development of lower self esteem, poor confidence and social isolation, leading to increased vulnerability for mental ill-health. Zorn et al (1999) suggest that a reduction in serotonergic function predisposes to depression and contributes to bladder overactivity and hence the efficacy of serotonergic based antidepressants in the treatment of urge incontinence and depression. It seems likely that mental ill-health and urinary incontinence interact and exacerbate each other and most likely that this is via serotonergic and noradrenergic pathways both of which have been implicated in mental disorders and urinary incontinence. The association of urinary incontinence with the onset of mental illness in this study was small with an odds ratio of 1.85 (95% CI 1.02-3.38).

5.2.5 **Not having immobility as a predictive factor for episodes of mental ill-health** (excluding problem behaviour, dementia and delirium)

Immobility was found to be a protective factor for the onset of mental ill-health. Those without immobility were more likely to become unwell. Immobility was measured at time point 1 and was therefore present before the onset of any episode of illness and unlikely to be due to the effects of mental illness. This relationship has been examined in community based samples of adults with intellectual disabilities with conflicting results. Deb et al (2001a) found a statistically significant relationship of physical disability with the prevalence of psychiatric illness but Moss et al (1993a) failed to demonstrate any such relationship. A relationship between chronic physical disability and the incidence of mental ill-health in the general population has been established (Singleton & Lewis, 2003) and one would expect there to be a similar finding in the intellectual disabilities population. But perhaps the impact of a physical disability in someone whose lifestyle is already limited by their intellectual disabilities is less significant. Or, conceivably the regular one to one interaction and physical touch necessitated by a person's immobility is a protective factor for adults with intellectual disabilities, many of whom have no intimate relationship. There is also the possibility that having immobility precludes circumstances and experiences that might be adversive to mental health. The association found was moderate with an odds ratio of 2.7 (95% CI 1.15-6.25). This was an

unexpected finding and not in keeping with other findings so could be a spurious result. Further investigation of this as a potential risk factor is required before any sound conclusions can be drawn.

5.2.6 Not living with a family carer as a predictive factor for episodes of mental ill-health (excluding problem behaviour, dementia and delirium)

Not living with a family carer was measured at time point one and therefore was present before the onset of any episode of mental illness but was not necessarily present before the onset of any mental illness and therefore the temporal relationship is weak. However, the fact that this risk factor was independent of past psychiatric history and remained significantly predictive of mental ill-health even when only first ever cases were counted, adds some support to the likelihood that not living with a family carer is a causal factor in the onset of mental ill-health in adults with intellectual disabilities. Other studies have identified living out with the family home as a factor associated with mental ill-health in this population (Deb et al, 2001b, Borthwick-Duffy & Eyman 1990), but these studies have examined prevalence rather than incidence and thus do not add any support to the direction of the relationship. This study is the first to be able to suggest that not living in the family home might be a causal factor rather than just the effect of mental ill-health. The strength of the association found in this cohort was moderate with an odds ratio of 2.82 (95% CI 1.44-5.52).

Not living with a family carer is not a risk factor that has been examined in the general population for obvious reasons but the quality of housing and mental health has been. Thomas et al (2007) measured psychiatric symptoms using the General Health Questionnaire in a cross sectional sample of 1058 adults in Wales, UK and found little evidence that residential quality or accessibility were associated with symptoms and concluded that the psychosocial environment is more important than the physical environment in relation to common mental disorder. This is an interesting idea and might explain, at least in part, our finding that not living with a family carer is a risk factor for the onset of mental ill-health. One could postulate that living in a group home is a less favourable

psychosocial environment than living at home with family, but of course this very much depends on the nature of the family and group home in question. The average size of group homes in the geographically defined area of the sample population was 3-4 persons. It is therefore very likely that at least one or two residents in each group home will have had some kind of mental ill-health at any one point in time and as a consequence residents in group homes are possibly exposed to a less favourable psychosocial environment. There is also the issue of the number of care givers (group homes typically have a care staff team of 4-10) and consequent number of different interaction styles and higher likelihood of temporary carers. Of course there is the issue of the trauma of the removal from the family home, and associated possible loss of family and local community contacts all of which are also likely mechanisms of action for this increased vulnerability. Finally, it may be that paid carers are less tolerant of psychopathology and are more likely to report issues as a health problem in comparison to family carers who are conceivably more likely to make allowances for a loved one. As all participants with possible mental ill-health were seen by a psychiatrist, the issue of over reporting seems unlikely but the possibility of underreporting by family carers remains. Further examination of this factor is merited to clarify the nature and direction of this relationship and to inform the development of possible preventative measures.

5.2.7 Living in more deprived area

Living in a more deprived area is predictive of mental ill-health in the general population (Lorant et al, 2003) but was not found to be predictive of mental-ill health in the intellectual disabilities population. The reason for this difference is not clear. Approximately half of the sample were living out with the family home in their own or shared tenancies or residential homes. Many of these placements will have been determined by professionals on the basis of existing vacancies rather than by the individual or their family, and made at short notice owing to the death of a family member or the breakdown of an existing support package. This differs from the general population who make choices for themselves in their own time regarding when to move and where to live. In addition, it is possible that adults with intellectual disabilities do not take on the lifestyle characteristics of the area they are living in and are more influenced by

the views and actions of their family relatives and area of origin. The very large majority of adults with intellectual disabilities are reliant on state benefits for their sole income and so could be considered as living in relative poverty regardless of where they live. Finally, it is also possible that living in a more deprived area is predictive of mental ill-health in adults with intellectual disabilities but was not significant in this study due to the sample size.

5.2.8 Not having daytime occupation

Not having any daytime occupation was not found to be predictive of mental ill-health, which is in contrast to the general population (Singleton & Lewis, 2003) where unemployment is a potent risk factor. In this sample, 76.8% had some form of daytime activity or employment. This included such activities as attendance at a day centre for adults with intellectual disabilities, college courses and structured leisure activities. Only a very small minority of participants with daytime occupation were actually in employment. This difference in the categorisation i.e. not having daytime occupation rather than unemployment, might explain why this was not found to be predictive of mental ill-health in the intellectually disabled population. The type of daytime occupation for adults with intellectual disabilities may not be as protective as paid employment is for the general population. Some of the daytime occupation for adults with intellectual disabilities will not involve any sense of responsibility, reward or career development and they may not get the same colleague support that exists for the general population.

5.2.9 Marital status

Marital status has been associated with depression in the general population, with married and never married having a significantly lower risk compared to those who are separated or divorced but no statistically significant association between marital status and the onset of common mental disorders was found by Singleton & Lewis (2003). In this study, there was a trend for being married to be associated with the onset of mental ill-health in adults with intellectual disabilities, but it was not statistically significant, hence conclusions cannot be drawn regarding it. Very few of the sample were married or had live in partners.

5.2.10 Epilepsy

Epilepsy was not found to be a risk factor for the onset of mental ill-health. Studies examining epilepsy and the prevalence of mental ill-health in the intellectual disabilities population have produced conflicting results. Lund (1985b) found a rate of 52% for psychiatric diagnosis in people who had had seizures within the previous year compared with 26% in those without seizures, and Corbett (1979) found a rate of 60.8% in those with epilepsy and 40% in those without. Deb & Joyce (1998), however, found no increased rate of problem behaviour or psychiatric illness in intellectually disabled people with epilepsy. Espie et al (2003) found a prevalence rate of psychiatric disorder according to the PAS-ADD checklist in a sample of adults with epilepsy and intellectual disabilities to be no higher than that reported for a community based sample of adults with intellectual disabilities and concluded that epilepsy itself was not a risk factor for psychiatric disorder.

It is widely accepted that in the general population epilepsy confers an increased risk for mental health disorder. Depression, anxiety and psychosis are all common in people with epilepsy. Considering the direct negative impact of some epilepsy drugs on mood and cognition, the social and psychological effects of a chronic illness and the effects on neurotransmission evoked by seizures, one would expect epilepsy to be a risk factor for the onset of mental ill-health in this population, particularly since this population is already more susceptible to such effects as a consequence of their intellectual disabilities. It is possible that any effect of epilepsy in this study was lessened by the categorisation procedure. Any history of epilepsy was compared against no history of epilepsy. Thus some participants included in the epilepsy category may have had only a few seizures in childhood and none in adulthood or could have had epilepsy that was very well controlled and been seizure free for multiple years. Comparing active epilepsy against in-active or no history of epilepsy might have produced a different result.

5.2.11 Communication impairment

Special communication needs was not found to be independently associated with the onset of mental ill-health. Although, communication impairment has been reported as a factor significantly associated with the prevalence of problem behaviour (McClintock et al, 2003) the two population based studies to date that have examined its relationship with the prevalence of mental ill-health (Cooper et al 2007, Deb at al 2001a) both failed to demonstrate any significant association and hence this finding is in keeping with previous findings.

5.3 Examination of factors predictive of specific types of mental ill-health

Examination of factors predictive of the onset of specific types of mental ill-health in this study was limited by the small number of episodes of the different types of mental ill-health. Only problem behaviour and depression had sufficient numbers to allow this.

5.4 Factors predictive of episodes of problem behaviour

Severe intellectual disabilities, divorce of parents in childhood, not living with a family carer and life events were found to be predictive of the onset of problem behaviour.

5.4.1 Severe intellectual disabilities as a predictive factor for episodes of problem behaviour

An association between more severe intellectual disabilities and the prevalence of problem behaviour has been reported by a number of researchers, although most did not take into account the overlap of factors investigated (McLintock et al, 2003) and therefore could not conclude that more severe intellectual disabilities was independently associated i.e. separate from autism and communication impairment. However, Tyrer et al (2006) did examine independent associations with the prevalence of aggressive behaviour and also found that more severe intellectual disabilities was independently associated with aggressive behaviour. The temporal relationship is strong but it is not

specific at all. The strength of the association is strong with an odds ratio of 4.57 (95% CI 1.74-11.96). Given that more severe intellectual disabilities correlates with more severe brain dysfunction and more severe intellectual disabilities makes it more likely that any psychopathology identified is in the form of behaviour change (as they are less able to recognise and report their own psychopathology) it is an association that has a theoretical base.

5.4.2 Divorce of parents in childhood as a predictive factor for episodes of problem behaviour

Information about the divorce of parents in childhood was collected at time point 2 but as it refers to an event in childhood and this study included only adults it is an event that will have occurred before any episode of incident problem behaviour in the follow up period. However, as problem behaviours can be, and often are an enduring or relapsing/remitting condition (Keirnan et al, 1997; Reid & Ballinger, 1995), it is entirely possible that many of the participants with onset of problem behaviour during the follow up period also had problem behaviour at some point in childhood and thus divorce of a parent in childhood could be cause or effect. Stress levels in families with a child with intellectual disabilities are known to be high, and especially so if the child has complex needs. The strength of this association was very high with an odds ratio of 9.93 (95% CI 3.11-31.76).

5.4.3 Not living with a family carer as a predictive factor for episodes of problem behaviour

Not living with a family carer is an association with problem behaviour that has already been reported. Deb et al (2001b) and Tyrer et al (2006) both found that living with paid carers was associated with the prevalence of problem behaviour. Again, as moving out of the family home could have been as much cause as effect (because of the known relapsing remitting nature of problem behaviour and counting of episodes of problem behaviour rather than first ever episodes of problem behaviour) this factor cannot be assumed to be anything other than an association with the onset of an episode of problem behaviour. This finding does not inform our understanding of the direction of this

relationship. The strength of the relationship was high with an odds ratio of 5.7 (95% CI = 1.99-16.32).

5.4.4 Life events as a predictive factor for episodes of problem behaviour

Esbensen & Benson (2006) found that life events were associated with problem behaviour but then went on to repeat the measures 4 months later and found that life events in the preceding 4 months predicted problem behaviours even when controlling for past levels of depressive symptoms and behavioural problems. This supports the findings of this study that more life events in the preceding 12 months predicts the onset of problem behaviour. Number of life events is not a predictive factor specific to problem behaviour, it also predicts depression, which adds some weight to the theories that problem behaviours are depressive equivalents in those with more severe intellectual disabilities. For the same reasons as above, the direction of this relationship remains unclear. The association was small with an odds ratio of 1.52 (95% CI = 1.11-2.07).

5.5 Factors predictive of episodes of depression

Past psychiatric history, problem behaviour and life events were found to be predictive of the onset of depression.

5.5.1 Past psychiatric history as a predictive factor for episodes of depression

As already discussed, it is expected that past psychiatric history is predictive of incident depression as depression tends to be a relapsing and remitting condition and many of the incident episodes will have been part of a recurrent depressive disorder. This issue could be clarified by including only first ever episodes but was not possible due to small numbers and the inaccuracy of knowing whether or not identified episodes truly are first ever episodes. Past psychiatric history has been established as a risk factor for depression in the

general population (Horwarth et al, 1992). The strength of this association was moderate with an odds ratio of 2.54 (95% CI 1.28-5.01).

5.5.2 Problem behaviour as a predictive factor for episodes of depression

The presence of problem behaviour at time point 1 was found to be predictive of the onset of a depressive episode during the two year follow up period. Of note is that this finding was independent of past psychiatric history. As onset of and change in problem behaviour can occur as a feature of depression in this population (sometimes referred to as “behavioural equivalents”) it is possible that some problem behaviours identified at time point 1 were early symptoms of depression. However, as all participants with new onset or worsening of problem behaviour at time point 1 and all participants with an incident episode of depression underwent detailed psychiatric assessment this is an unlikely explanation for the association. Several cross-sectional studies have reported an association between problem behaviours and the prevalence of depression in this population, but have not been able to confirm the direction of this relationship due to the cross sectional design (Marston et al, 1997; Moss et al, 2000; Rojhann et al, 2004). The prospective cohort design of this study allows the conclusion that adults with pre-existing problem behaviour are at higher risk of depression. The strength of the association found was moderate with an odds ratio of 2.04 (1.05-4.00). This association may be due to problem behaviours and depression having similar aetiologies, or due to problem behaviours leading to stress, limiting people lives and affecting the quality of their relationships, making them more vulnerable to depression.

5.5.3 Life events as a predictive factor for episodes of depression

Life events were measured at T1. Any life events occurring in the previous 12 months were counted and conceivably could have occurred as much as 36 months before any incident episode. The temporal relationship here is thus fragile. However, it is an association that has been reported elsewhere for the intellectual disabilities population. Hastings et al (2004) examined a large population based sample of adults with intellectual disabilities and found that

one or more life events in the preceding year was significantly associated with a score above threshold on the affective/neurotic sub-scale of the PAS-ADD checklist. A signification association between life events in the preceding two years and emotional and behavioural problems measured by the Developmental Behaviour Checklist for Adults was found by Hamilton et al (2005). Esbensen and Benson (2006) also found that life events were associated with depressive symptoms but then went on to repeat the measures 4 months later and found that life events in the preceding 4 months predicted problem behaviours and depression even when controlling for past levels of depressive symptoms. Studies in the general population have also linked traumatic experiences in adulthood with the onset of depression and Kendler et al (1999) has suggested that there is a substantial causal relationship between stressful life events and the onset of episodes of major depression. However, Kendler et al (1999) also suggest that about one-third of the association between stressful life events and onsets of depression is non-causal, since individuals predisposed to major depression select themselves into high-risk environments. This seems an unlikely causal factor in those with severe intellectual disabilities who very much rely on others to control their environment but is a possible causal factor for those with mild and moderate intellectual disabilities. The association between life events and the onset of depression was small with an odds ratio of 1.34 (95% CI 1.04-1.72).

5.6 Endurance of mental ill-health

In a stable population with a stable disease rate (which we can assume is applicable to this study given that the time between the prevalence and incidence rate measurements was only 2 years), prevalence is proportional to the frequency of development of new cases multiplied by the average duration of the condition. Accordingly, if the overall incidence rate of mental ill-health in the intellectual disabilities population is no higher than that in the general population then, the higher point prevalence rate (Cooper et al, 2007) must be due to longer duration of illness.

The rate of recovery from mental ill-health present at T1 by T2, was low at just 32.5%. Recovery was defined as the time point when symptoms no longer met

DC-LD diagnostic criteria or (for those with illness at T1 according to clinician diagnosis but not DC-LD criteria) when the clinician managing the treatment recorded that recovery had occurred. This low rate of recovery is in keeping with the findings of Reid & Ballinger (1995), Eyman et al (1981) and Wallander et al (2006), all of whom also found a persistence of psychiatric symptoms over time in their longitudinal cohorts of people with intellectual disabilities. It is likely that this recovery rate is lower than that in the general population but finding suitable studies for comparison has been hampered by the tendency for researchers to measure outcomes for individual psychiatric disorders in the general population rather than for all psychiatric disorders.

Ram et al (1992) found that about one third of patients with first episode schizophrenia had a benign course while two thirds either relapsed or failed to recover or were re-admitted to hospital over a two year period. The rate of recovery from psychosis in this cohort was (6/41)14.3% (95% CI 5.6-29.2), lower than the 33% recovery rate reported by Ram et al (1992). However, these rates are not directly comparable as this study included all psychosis and not just first episode psychosis. Nonetheless, the findings suggest that the recovery rate from psychosis is lower for people with intellectual disabilities. This is as one would expect considering that poor premorbid functioning, cognitive dysfunction, frontal and soft neurological signs and structural brain abnormalities (Wong et al, 1997) have all been found to correlate with a poorer outcome in schizophrenia.

The rate of recovery from depression within the two year follow up period was 74.3%, which is lower than that reported for the general population by Spijker et al (2002). Spijker et al (2002) reported that approximately 80% of newly originated major depressive episodes in the general population had recovered by two years. This is not directly comparable, as in our study all cases of depression whether recurrent or first episode were counted and cases were recruited at differing times during the course of the disorder which will have led to lead time bias and consequent over representation of chronicity. However, bearing this in mind, it seems likely that the two year rate of recovery from depression in adults with intellectual disabilities is similar to that in the general population.

All cases of mental ill-health identified at T1 were referred to mental health services for further assessment and treatment but it is not known what treatment was offered or the level of compliance. However, it is reasonable to assume that the treatment received was of a standard at least as good as that offered elsewhere in the United Kingdom and as consequence that these results can be generalised. One could argue that as all cases were referred into specialist services and as this would not normally be the case for adults with intellectual disabilities with psychopathology, the recovery rate in this study may be higher than what would normally occur. However, many of the participants with mental ill-health identified at T1 had been unwell for sometime before T1, but were only then referred into mental health services as a result of the assessment at T1. Thus, the study sample contained a proportion of people with a long duration of illness prior to treatment which means that the reported recovery rate could be improved simply by ensuring that those with onset of mental ill-health are given treatment as early as possible. This could be achieved by providing training for carers, improving access to specialist mental health services and screening high risk groups.

This low recovery rate is not unexpected given the complexity of problems and high level of co-morbidity in the intellectual disabilities population but highlights the need for studies examining risk factors for the endurance of mental ill-health and the effectiveness of treatments for psychiatric disorder in this population.

5.7 Risk factors for endurance of mental ill-health

(excluding problem behaviours, bipolar affective disorder in remission, psychosis of any type in remission, recurrent depressive disorder in remission, dementia, delirium, autism, and personality disorders)

Problem behaviour was identified as a predictor of endurance of mental ill-health throughout the two year follow up period. Persistent problem behaviour can lead to exclusion from activities, social isolation, carer burnout and self esteem and physical health issues, so it is not surprising that it may delay recovery from mental illness. Another possibility is that problem behaviour is in fact a symptom of mental illness and signifies more severe mental illness,

hence the lowered recovery rate in this group. The strength of the association of problem behaviour with the endurance of mental ill-health was moderately strong with an odds ratio of 3.45 (95% CI 2.06-5.79).

Not having Down's syndrome was associated with the endurance of mental ill-health suggesting that Down's syndrome is in some way protective. This could be due to the different types of mental ill-health experienced by people with Down's syndrome compared to people with intellectual disabilities not due to Down's syndrome. It has been proposed that mania (Sovner et al, 1985; Cooper & Collacott, 1993) and schizophrenia (Collacott et al, 1992; Prasher, 1995) are uncommon in adults with Down's syndrome, and indeed, in this cohort, none of the adults with Down's syndrome had a psychotic disorder or mania at T1. There is no reason to suspect that people with Down's syndrome receive or have preferential lifestyle and supports or health needs and disabilities compared to other adults with intellectual disabilities, although one cannot be certain of this. It is possible that having Down's syndrome is protective against the endurance of mental ill-health via a biologically rather than environmentally determined route. The strength of the association of not having Down's syndrome with the endurance of mental ill-health was moderately strong with an odds ratio of 3.32 (95% CI 1.28-8.59).

Being a smoker was significantly independently associated with the endurance of mental ill-health, which is an expected finding. The prevalence of smoking in adults with chronic mental ill-health is typically 2-4 times that in the general population with several studies suggesting that nicotine remediates some of the cognitive deficits associated with schizophrenia and other chronic mental illnesses (Sacco et al, 2004). The strength of this association was moderate with an odds ratio of 2.24 (95% CI 1.15-4.36).

Not having immobility was also significantly independently associated with the endurance of mental ill-health but this finding could be explained by its association with the prevalence of mental-ill health rather than being specifically related to endurance. The strength of this association was moderate with an odds ratio of 3.00 (95% CI 1.42-6.30).

5.8 Risk factors for endurance of problem behaviour

More severe intellectual disabilities, not having Down's syndrome, not living with a family carer and urinary incontinence were found to be associated with the endurance of problem behaviour throughout the two year follow up period. All of these factors were also found to be significantly associated with the prevalence of problem behaviour and so these findings could simply be associated with prevalence rather than endurance. However, male gender and living in a less deprived area, neither of which were found to be associated with the prevalence or incidence of problem behaviour, were also found to be significantly independently associated with the endurance of problem behaviour. The identified association of male gender with the endurance of problem behaviour could be due to a number of factors, including differing types of problem behaviour in men and women, differing thresholds for seeking treatment in men and women and differing responses to treatment in men and women. The association of male gender with the endurance of problem behaviour was small with an odds ratio of 1.77 (95% CI 1.04-3.00). The finding that living in a less deprived area is associated with the endurance of problem behaviour is not an expected result and could be a false positive, but could also be due to the placement of adults with more severe problem behaviour in more affluent areas with larger properties used for congregate care or with more space to allow safer management of problem behaviours. The association found was small with an odds ratio of 1.86 (95% CI 1.13-3.07).

5.9 Risk factors for endurance of depression

Not having daytime activity or employment and not having visual impairment were identified as significantly and independently associated with depressive episodes of duration more than one year. Not having any daytime activity or occupation is an expected risk factor and is in keeping with findings in the general population, but not having visual impairment was not and may be a spurious result. The strength of these relationships was strong with an odds ratios of 5.19 (95% CI 1.91-14.07) for not having any daytime activity or employment and 4.42 (95% CI 1.36-14.39) for not having visual impairment. Not having daytime occupation or activity may well be an effect rather than cause of

delayed recovery – prodromal symptoms may have resulted in cases withdrawing from activities well before symptoms were sufficient to meet clinical significance or diagnostic criteria so cannot be assumed to be a causal factor. Intervention studies measuring the effect of daytime occupation or activity on the duration of depressive episodes would improve our understanding of this.

Number of life events, a past psychiatric history and being married were also found to be significantly independently associated with depressive episodes of duration more than one year. The first two of these were also found to be associated with the incidence of depression, but being married was not, making it more likely that it is a factor influencing recovery from depression in intellectual disabilities. This finding is in contrast to that of Mueller et al (1996). Meuller et al found that in the general population, not living with a partner was predictive of a longer duration of depression. Is marriage or co-habitation harmful rather than protective against recovery from depression for people with intellectual disabilities? The strength of the association between being married or having a live in partner and an episode of depression lasting more than one year was strong with an odds ratio of 6.95 (95% CI 1.16-41.53). However, the number of participants who were married or co-habitating was very small at only 10, so this finding may be spurious.

5.10 Strengths of the study

The main strengths of this study were the longitudinal design, use of a population based sample, the sample size, the reasonable attrition rate, the comprehensiveness of the structured assessment and the use of appropriate diagnostic criteria.

5.10.1 Longitudinal design

The longitudinal design of this study allowed the examination of factors predictive of the onset of mental ill-health. However, the cross sectional design and counting of any episode of mental ill-health whether first ever or not, does not allow the drawing of any sound conclusions regarding the direction of the

relationships between these factors and the onset of episodes of mental ill-health.

5.10.2 Population based sample - *also discussed in limitations section.*

The population based nature of this sample and in particular the fact that it includes both urban and sub-urban areas means that the results are generalisable to adults with intellectual disabilities living in other areas of the UK and other developed countries. It also includes all levels of intellectual disabilities. Many previous epidemiological studies have included only those with mild or borderline intellectual disabilities or those with severe-profound intellectual disabilities. There was no difference between participants for whom consent was and was not gained to participate at T2, and I consider that these results are generalisable within other developed countries.

5.10.3 Comprehensive structured assessment

With the general population it is reasonable to suspect that most episodes of significant mental ill-health are presented to the health service or reported on questioning, and hence case identification is straight forward. However, this assumption cannot be made for the population with intellectual disabilities, as most do not hold down positions of responsibility or have partners, are subject to diagnostic overshadowing (where symptoms of ill-health are wrongly attributed to the person's underlying intellectual disabilities by paid carers and professionals), cannot report their own history or symptomatology and are known to have poor access to services for a range of reasons. Hence there is no easy short-cut to identifying the incidence of mental ill-health, unlike for the general population. The methodology has fully addressed these issues and is a major strength of the study. All participants were screened by a professional with experience in intellectual disabilities and those with possible mental ill-health were referred for detailed structured psychiatric assessment by a psychiatrist with specialist knowledge and skills in intellectual disabilities psychiatry – the "gold standard" of psychiatric assessment and diagnosis. As the screening process was intentionally designed to be over inclusive and resulted in a number of false positives, the probability that cases were missed

was minimised as far as possible. This could only have been reduced further by all participants undergoing psychiatric assessment. This is a task that would have been intensely time consuming and costly and would have necessitated a reduction in the sample size, severely limiting the capacity to measure the incidence of less common types of mental ill-health and identify any risk factors associated with the onset of mental ill-health.

5.10.4 Diagnostic criteria used

Assigning diagnoses to adults with intellectual disabilities is a very complex procedure with multiple different factors to be taken into consideration, such as physical ill-health, developmental level, effects of institutionalisation and polypharmacy. This study has benefited from a robust process for this. All potential cases were seen by an intellectual disabilities psychiatrist and discussed at case conferences with the other intellectual disabilities psychiatrists involved in the study to be assigned a consensus diagnosis. This improved both the reliability and validity of the diagnostic categorisations. In addition, all diagnoses were collected from the case notes and data entered by one research psychiatrist (ES) and adherence to diagnostic criteria and any dubious diagnoses were double checked through this process.

The use of operationalised standard diagnostic criteria, DC-LD, ICD-10-DCR and DSM-IV-TR without any modifications means that this study can be easily replicated by other researchers throughout the world.

Clinician diagnoses were also included as the “gold standard” and used in the risk factor analysis because consensus clinical diagnosis was felt to be the most representative of what intellectual disabilities psychiatrists in the UK are diagnosing in adults with intellectual disabilities and most likely to be the diagnostic categorisation with the highest sensitivity and specificity because of the complexity in assigning diagnoses of mental ill-health in this population. Although DC-LD is operationalised and field studies have demonstrated that it has good face validity it has not had its psychometric properties formally assessed, so its sensitivity and specificity is unknown. ICD-10-DCR and DSM-IV-TR have not had their psychometric properties assessed for use in the

intellectual disabilities population and because of their reliance on subjective report of symptomatology are not likely to be as sensitive as consensus clinical diagnosis. In addition, consensus clinical diagnosis was chosen as the “gold standard” as there are no diagnostic assessment tools for use in this population with a sensitivity and specificity likely to be higher than the comprehensive structured psychiatric assessment process used in this study.

DC-LD diagnostic criteria were specifically designed for use in the intellectual disabilities population and this study shows that the incident rate according to DC-LD is more similar to the clinical diagnoses rate than ICD-10-DCR or DSM-IV-TR supporting the view that DC-LD criteria is more appropriate for use in this population.

5.10.5 High reliability scores

Intra-rater reliability of the diagnoses of problem behaviours according to DC-LD criteria by the research psychiatrist (ES) reviewing every research interview was assessed and found to be high. Inter-rater reliability was also assessed and found to be high. This high reliability, although demonstrated for only one aspect of the assessment procedure, may also be representative of the reliability of other aspects of the assessment procedure as the same research psychiatrist supervised/reviewed all aspects of the assessment procedure.

5.10.6 Definition of caseness

In some prospective cohort studies, it can be difficult to be sure that all members of the cohort are truly disease free/accurately categorised at the outset but this was not a significant problem. In this study, all participants were screened for psychiatric disorder at T1 using a validated instrument and with the threshold for caseness reduced to ensure 100% sensitivity and any possible cases then underwent detail psychiatric assessment. In addition, the allocation of caseness at T1 did not take place until 1 year after the psychiatric assessment, therefore lessening the risk of bias due to misclassification at the outset. Misclassification bias may be present in the intellectual disabilities population because of the difficulties with diagnosis and tendency for other

problems such as physical ill-health or insufficient support levels to present with psychopathology but was successfully reduced in this study. Finally, standard and appropriate diagnostic criteria were use to classify caseness.

5.11 Other methodological problems with prospective cohorts

Other methodological problems with prospective cohort studies include the ageing of the cohort over time such that it may not be representable of younger cohorts in the population, changing knowledge of diseases that identify new risk factors not measured at baseline and changes in the definition of psychiatric disorders over time but none of these were an issue for this study due to the 2 year follow up period.

5.12 Limitations of the study

The main limitations of the study were the attrition rate, the reliance on participant/informant recall, and the use of some tools with unknown reliability and validity in the intellectual disabilities population – all of which are likely to have resulted in a downward bias of the incidence rate. In addition, multiplicity may have led to Type I errors.

5.12.1 Attrition

Attrition rates in longitudinal cohort studies can seriously bias the results. In this study 70% of the original cohort was followed up. Of the original sample of 1202, 54 died, 28 were unable to participate due to serious physical/terminal ill-health and 184 had to be excluded because it was not possible to obtain consent (i.e. they could not give consent and did not have a Welfare Guardian or traceable next of kin who could give consent on their behalf) due to the requirements of the Adults with Incapacity (Scotland) Act 2000 that had been enacted between T1 and T2. Has this biased the sample? It is likely that those without a Welfare Guardian or traceable next of kin were less likely to be living with a family carer and more likely to have been institutionalised at some point in their lives. The risk factor analysis suggests that this would lead to a downward bias of the overall incidence rate. Serious physical ill-health is known

to be a risk factor for mental ill-health in the general population, so the exclusion of these participants may also be responsible for a downward bias of the incidence rate.

Of the 946 who were eligible to participate, despite several moving out of the area, all were traced and no-one was lost to follow up due to individual mobility. 143 participants and 142 relatives refused consent at T2. It is possible that those that refused consent had a higher rate of psychiatric illness than those that consented and consequently that the results are an underestimate. However, the rate of psychiatric illness at T1 was not found to be significantly different for the participants and non-participants at T2.

70% is an acceptable follow up rate given the reported difficulties in retaining cohorts of the intellectual disabled population (Wadsworth et al, 1992, Maughan et al, 1999: Richards et al, 2001) and the difficulties in gaining consent inflicted by the introduction of the Adults with Incapacity Act (Scotland) 2000 between T1 and T2.

5.12.2 Case ascertainment

A database of adults with intellectual disabilities living in the Glasgow Health Board Area was used to identify the sample rather than screening the whole population for intellectual disabilities and so technically an administrative rather than a true population based sample was used. However, the database used had a reasonable ascertainment rate compared to other databases in Europe (McGrother et al, 2001; van Schrojenstein Lantman-de Valk et al, 2006) and the fact that GP's were paid a fee per patient with intellectual disabilities identified, makes it likely to be representative. Almost 100% of adults in Scotland are registered with a GP so it is improbable that a significant number of adults with intellectual disabilities were missed and extremely unlikely that any adults with moderate-profound intellectual disabilities were missed.

5.12.3 Recall bias

Recall bias is the error that occurs because of inaccuracies in the respondent or informant's memory of events. All follow up data was collected retrospectively during the research interview at T2. Thus a degree of recall bias was inevitable and may well have amounted to the under reporting of episodes of illness during the 2 year period. However, this was minimised by the research assistant giving multiple prompts to stimulate memories of episodes of illness/health contacts.

The two year follow up period was specifically chosen to ensure sufficient incident cases occurred during the follow up period to allow exploration of risk factors for the onset of mental ill-health but also to lessen the risk of attrition and recall bias. The longer the period of follow up the higher the attrition rate and lower the recall rate. Many adults with intellectual disabilities live in group homes with paid carers, many of whom are temporary workers and thus, unless communication systems are fail-safe, there is a high risk of information being lost when carers move on. This was minimised by the research assistants seeking an alternative informant if the first informant had known the participant for less than 2 years and using multiple prompts to identify all possible health contacts during the interview. Nonetheless, it is inevitable that some episodes of mental ill-health will have been forgotten about, resulting in a downward bias of incidence rates. Incompleteness of case note entries will also have contributed to this by limiting the amount of past psychiatric history available.

Some of the risk factor information was collected at T2 rather than at T1. This included the information about experience of adversity and family history of psychiatric illness, both of which could be effect rather than cause and are unlikely to be accurate due to the secrecy surrounding these issues.

Extending the follow up period would have given more patient years and thus more power to the risk factor analysis but this would have been at the cost of the attrition rate and level of recall bias.

5.12.4 Cumulative testing effects

Cumulative testing effects with the possibility of under reporting as a result of respondents learning that the more symptoms reported the longer the interview, and being less interested in the process second time round will also have led to a downward bias of the incidence rate.

5.12.5 Reliability and validity of the mental ill-health assessment procedure

Reliability is the extent to which a measurement instrument yields consistent, stable, and uniform results over repeated observations or measurements under the same conditions each time. Reliability is particularly difficult in studies of psychiatric illness because of the reliance on respondent and informant information and even more so in psychiatric studies in the intellectual disabilities population because of the disproportionate reliance on informant information, the quality of which can vary widely. Nonetheless, reliability can be improved by structuring and standardising the assessment procedure and training those carrying out the assessment, both of which occurred in this study. However, no reliability tests of the research interview procedure were carried out to formally assess this which is a noteworthy limitation of this study.

The PAS-ADD checklist and Vineland Adaptive Behaviour Scales have been shown to have adequate reliability in the intellectually disabled population but the use of ICD-10-DCR and DSM-IV-TR have only been shown to have reliability in the general population. DC-LD has been shown to have good face validity but has not had its reliability measured.

A modified version of the PAS-ADD checklist was used to screen for symptoms of psychiatric illness at T1 and T2 and to gather information on symptomatology experienced during any episode of illness occurring between T1 and T2. Although the PAS-ADD checklist has had its reliability and validity demonstrated, as some modifications were made to the checklist and it was never intended to be used retrospectively, it cannot be assumed that the psychometric properties still apply to its use in this study. However, as the

modifications included only additional questions and a change in the scoring method to make it more sensitive this is not likely to have had a significant impact on the psychometric properties.

Although inter and intra-rater reliability of the problem behaviour categorisation was examined and found to be high, no other tests of reliability were carried out and in particular no test of reliability of the research interviews or psychiatric diagnoses were carried out. Nonetheless, reliability/validity was enhanced by the research psychiatrist (ES) reviewing every research interview in detail and the psychiatric diagnoses being agreed by consensus.

The validity of the screening process was not examined and as a consequence it is unknown how much of an underestimate the findings may actually be. This could have been measured by a number of participants not identified as having mental ill-health during the two year period going on to have full psychiatric assessment. This was not carried out due to time/manpower constraints.

The tools use to aid identification of mental ill-health covered most psychopathology but did not specifically include eating disorders or sexual dysfunction and as a consequence the reported rates for these conditions are likely to be an underestimate. As specific phobia was not counted as a symptom in the PAS-ADD check list screening, a measure of the incidence of specific phobia cannot be reported.

Information about past psychiatric history was gathered from a number of sources but is unlikely to have been accurate because of the previously described difficulties in recognising mental ill-health in this population. Mental ill-health often only comes to the attention of services when there is a significant disturbance of behaviour and therefore it is quite likely that many less severe previous episodes of mental ill-health have not been identified.

The use of different methods to obtain empirical information on the same criterion increases the reliability of that information and thus contributes to the validity of the use of that empirical data to measure the concept of interest. In this study the use of a structured interview that included a screening tool with

demonstrated reliability and validity, supplemented by case note review and the gold standard clinical psychiatric assessment with diagnoses according to appropriate diagnostic criteria will have provided the most valid assessment achievable bar each and every participant undergoing psychiatric assessment.

5.12.6 Interview bias

All data collected at T1 was collected by Intellectual Disabilities Nurses, specifically employed and trained for this task, whereas all data at T2 was collected by research assistants, who were also specifically employed and trained for this task. Although the two groups received similar training and used the same assessment tools, they may have had different interviewing styles. However, this should not have had any real impact on the incidence rate as the incidence rate calculations were based largely on information collected at T2 and any possible cases were then seen by a psychiatrist and any T1 misclassifications identified were corrected accordingly. But this may have had an effect on the recovery rates measured. Participants with symptoms identified at T1 by a nurse may not have had symptoms deemed significant enough to record by the research assistant at T2 and/or the reverse of this could have occurred.

5.12.7 Sample size

Although this study was the largest population based longitudinal study in intellectual disabilities to date, the number of incident cases was small and limited the power of the risk factor analysis. Small numbers necessitated different types of illness being grouped together and did not allow examination of risk factors for individual types of mental ill-health other than depression and problem behaviour. As a consequence, risk factors identified for any type of mental ill-health may in fact be risk factors specific to one type of mental ill-health.

5.12.8 Standardised incident ratio calculations

It is important to note that although standardised incident ratios were calculated, the studies used for comparison differed in the method of assessment, tools used and diagnostic categories and so these need to be interpreted with some caution.

5.12.9 Investigation of multiple variables

The main aim of this project was to assess a broad range of factors that are potentially associated with the incidence of mental ill-health and thus a large number of variables were investigated and there were several sub-group analyses. Both of these methodological aspects of the project will have increased the probability of false-positive results (i.e. the probability that at least one result is significant at $p<0.05$ by chance). The Bonferroni correction can be used to account for such an inflated Type I error but was not made in this project because of the explorative nature of the study, the high likelihood that several of the factors investigated were interdependent, the tendency for the Bonferroni procedure to over-correct for multiple testing and thus inflate the rate of false negatives, and because all variables investigated were specifically selected based on current knowledge of likely aetiological factors/associated factors for mental ill-health in people with intellectual disabilities and/or people without intellectual disabilities. Nonetheless, some caution is required when interpreting the positive findings of this study.

5.12.10 Calculation of recovery rates

For the recovery rates from mental ill-health, depression and problem behaviour, it is known that some of the cases identified at T1 had been ill for a number of years but had not until then received any heath intervention. This will have led to an overrepresentation of chronic cases and a downward bias of the recovery rates but is still a generalisable result given that the difficulties this population has in accessing appropriate health services is thought to be widespread and not confined to Glasgow. Analysis of recovery rates from the incident cases would give a more accurate measurement of recovery rates for

patients that do receive health interventions as all cases were referred into services at some point during the two year follow up period. However, such cases, although referred into services, may not have received equitable treatment and no measurement of this was made.

5.13 Clinical significance of the findings

The findings of this study are of much clinical relevance. Knowing the incidence rate for episodes of mental ill-health in adults with intellectual disabilities will allow health boards to ensure that mental health services for this population match the level of need. It will allow more accurate prediction of the number and type of health professionals required to meet the mental health needs of this population. It will also usefully inform decisions about the nature and type of in-patient services required.

We now know that the incidence of psychosis is significantly higher in adults with intellectual disabilities than in the general population. Mental health services for adults with intellectual disabilities will need to ensure that they are adequately resourced and that health professionals and carers have the necessary skills to identify and manage this effectively. Most mental health services for the general adult population in the UK now have First Episode Psychosis Teams and some consideration should be given as to whether such teams would be of benefit to adults with intellectual disabilities. One could argue that a specialist team for managing psychosis in adults with intellectual disabilities would be of more benefit in this population because of the difficulties with diagnosis and poorer outcome of such conditions, but this may be negated by the overall numbers of cases, as although the incidence of psychosis is much higher in adults with intellectual disabilities, the actual numbers of cases with first episode psychosis is still small compared to the general population. In a population of 1 million adults you would expect approximately 232 adults without intellectual disabilities to develop psychosis each year but only 8 adults with intellectual disabilities to develop psychosis each year. It may be more sensible for intellectual disabilities services to work jointly with First Episode Psychosis teams or for neighbouring intellectual disabilities services to consider

working together to provide a more specialist and intensive service for adults with intellectual disabilities and psychosis.

A similar argument also applies to bipolar affective disorder, where the incidence is very much higher in adults with intellectual disabilities compared to the general population, but the actual numbers of new cases a service can expect each year is small.

For dementia, the very high rate of early onset dementia in adults with Down's syndrome has previously been reported and the results from this study confirm this. Health services can use this information to more usefully inform the development of services specifically for adults with Down's syndrome and dementia. Particular consideration should be given to screening programmes to ensure early detection and treatment. The incidence rates will allow health services to ascertain whether or not a memory clinic specific for adults with intellectual disabilities would be a useful resource. In a total population of 1 million adults you would expect approximately 26 adults with intellectual disabilities to develop early onset dementia each year. These findings are also of utility for social services in predicting the number and nature of social care services needed to support people with Down's syndrome and dementia. This is especially important considering the increasing life expectancy and consequent ageing population of adults with intellectual disabilities.

Episodes of problem behaviour accounted for a significant proportion of the overall incidence rate of mental ill-health in adults with intellectual disabilities. In addition, although for some people the problem behaviour remitted, for others, despite treatment, the problem behaviour was persistent during the two year follow up period. Managers and commissioners of services need to ensure that services have sufficient expertise and capacity to assess and manage problem behaviours, as well as develop more effective ways of treating problem behaviours in this population. Also, managers and commissioners of services need to ensure that services are able to provide support to people with problem behaviours over prolonged periods of time. Finally, social services and care providers need to be aware that although some problem behaviours will resolve, some will be persistent over time and ensure that individuals providing support

services to people with persistent problem behaviour have the necessary knowledge and expertise for this.

We now know that substance misuse is much less likely to occur in adults with intellectual disabilities and developing specialist substance misuse services for this group is probably not justified in most areas of the United Kingdom. In a total population of 1 million adults you would expect less than 3 new cases of substance misuse in adults with intellectual disabilities per year. It would be more appropriate for adults with intellectual disabilities and substance misuse problems to be supported to access the expertise in mainstream substance misuse services with support from intellectual disabilities services as appropriate.

The identification of factors predictive of mental ill-health means that high risk groups can be identified and targeted for interventions such as more support around the time of life events, professional input for urinary incontinence or screening for identification of illness at an early stage. It also allows training in the promotion of mental health, the identification of mental ill-health and the management of mental ill-health in adults with intellectual disabilities to be specifically targeted at staff working with the adults at greatest risk of developing mental ill-health, thus facilitating more efficient use of resources.

The demonstration that known risk factors for mental ill-health in the general population, such as smoking and level of deprivation, may not be applicable to people with intellectual disabilities means that public health strategies for improving mental health and minimising health inequality will not necessarily benefit people with intellectual disabilities, unless these differences are taken in to consideration. If public health intervention focuses only on areas of importance to the general population, it will fail to address the factors most relevant to adults with intellectual disabilities and the existing inequality gap is likely to widen.

The high level of endurance of mental ill-health over the two year follow up period highlights the need for planners, commissioners and managers of mental health services for adults with intellectual disabilities to assess the effectiveness

of treatments currently offered and to develop more effective treatments. The factors found to be associated with the endurance of mental ill-health will help direct clinicians in their assessment of prognosis as well as allow them to consider risk of endurance when deciding on the clinical prioritisation of patients. It also allows specific interventions to be targeted at high risk groups.

Finally, of note is the fact that many of the participants in the research project only received treatment for their mental ill-health problems when this was identified via their participation either at T1 or T2 and it is quite possible that they would have not received any such treatment unless they had participated in the research project. Planners, commissioners and managers of health and social services need to ensure that people working with or supporting adults with intellectual disabilities have a better understanding of mental ill-health and how it presents in this population and endeavour to improve access to and the effectiveness of mental health services for this population.

5.14 Implications for future research

The incidence rates found in this study need to be replicated before it can be assumed that they are accurate. Another large population based prospective cohort study using similar methodology and in particular, the same diagnostic criteria and definition of episodes of mental ill-health is necessary. This would also be required before we can assume that the identified risk factors are truly associated. More in depth study to investigate mechanisms underpinning the associations found is also indicated.

The identification of risk factors for the onset of mental ill-health means that hypothesis based studies, leading on to the development of interventions and then randomised controlled trials are now possible.

Further research examining the relationship between the risk factors of place of residence and having urinary incontinence would be prudent, especially as both these factors affect a significant proportion of adults with intellectual disabilities. Teasing out the direction of the relationship of these factors would then allow the development of preventative measures and potentially more effective

treatments. This would require a larger study or longer follow up period to allow sufficient numbers to analyse first ever episodes of mental illness and thus ensure a strong temporal relationship between the risk factor and onset of illness.

Further examination of the identified risk factor of not having immobility is merited, since this finding is out of keeping with other research findings and the postulated theories for a mechanism of action are weak.

Further examination of physical ill-health as a risk factor for the onset of mental ill-health is also indicated. Physical ill-health has been found to be a strong predictor of mental ill-health in the general population but, other than urinary incontinence, the physical health variables investigated in this study were not found to be associated with the onset of mental ill-health. However, this may have been because individual categories of physical health related to disability were investigated rather than overall physical health burden. Future cohort studies that include the use of a global measure of physical health burden are indicated and might produce a different result,

A larger longitudinal study is required to provide sufficient numbers to allow investigation of individual risk factors for psychosis, bipolar affective disorder and individual types of problem behaviour. However, the numbers required to achieve this would be considerable and will require collaboration between research centres across large geographical areas or significant extension of the follow up period such that recall bias and attrition would become significant issues. Using case-control studies to examine factors associated with specific disorders would be more realistic. More detailed examination of the risk factors for specific disorders would also have the potential to contribute to our understanding of the aetiology of such disorders in the general population.

More detailed analysis of epilepsy as a potential risk factor is also required before it can be discounted as not contributing to mental ill-health in this population. Active as opposed to inactive epilepsy or level of seizure control or type of seizures need to be examined as potential risk factors rather than any history of epilepsy as was investigated in this study.

The level of endurance of mental ill-health found in this study was high but as the aim of this study was not to measure effectiveness of treatment the reasons for this high-level of endurance remain unclear. Studies specifically examining the effectiveness of treatment and outcome of mental ill-health in adults with intellectual disabilities are necessary.

The risk factors for episodes of mental ill-health and the endurance of mental ill-health identified in this study will allow studies measuring the impact modifying these risk factors has on the incidence and endurance of mental health problems. Following a cohort of participants at high risk of mental ill-health and providing a proportion of the cohort with a specific intervention would allow the measurement of any effect the intervention has on the incidence of mental ill-health. Interventions with the potential for modifying the incidence of mental ill-health in this population would be the management of urinary incontinence, increased support around life events and the types of accommodation provided. Similarly, further studies (such as randomised controlled trials) examining the effect of modifying the risk factors identified for the endurance of mental ill-health, such as smoking or lack of daytime occupation are now possible, The risk factor results could also be used to identify high risk populations for targeted screening and early intervention studies.

Chapter 6 CONCLUSIONS

The two year incidence of episodes of mental ill-health in adults with intellectual disabilities according to clinical diagnosis was 16.3%. This incidence rate is similar to the incidence rate of mental disorders in the general population but the type and proportion of individual disorders that account for this rate is different. Approximately 20% of the incidence rate was accounted for by problem behaviour, a disorder not generally seen in the general population.

The incidence of non-affective psychosis was much higher in adults with intellectual disabilities compared to the general population with a standardised incident ratio of 9.93 (95% CI 2.05-29.02). The incidence of bipolar affective disorder was very much higher in adults with intellectual disabilities compared to the general population with a standardised incident ratio of 100.20 (95% CI 12.14-361.96). The incidence of early onset dementia was also much higher in adults with intellectual disabilities compared to the general population with a standardised incident ratio of 66.67 (95% CI 18.16-170.69) and this being accounted for by cases of early onset Alzheimer's disease in adults with Down' syndrome. The incidence of substance misuse disorders was very much lower in adults with intellectual disabilities compared to the general population with a standardised incident ratio of 0.04 (95% CI 0.00-0.24). The incidence of anxiety disorders might be lower in the intellectual disabilities population compared to the general population. Methodological limitations in this study prevent a firm conclusion regarding this.

Factors that were found to be predictive of episodes of mental ill-health (excluding problem behaviour, dementia, and delirium) in adults with intellectual disabilities were, in order of decreasing strength of association: not living with a family carer, not having immobility, mental ill-health in the past, more severe intellectual disabilities, abuse/adversity in adulthood, and urinary incontinence.

Not having immobility was an unexpected finding and requires further investigation before any firm conclusion can be drawn. In contrast to findings in the general population, higher levels of deprivation, smoking and not having

daytime occupation were not predictive of episodes of mental ill-health. This finding may have been due to lack of power and requires further examination.

Divorce of parents in childhood, not living with a family carer, more severe intellectual disabilities and life events in the preceding 12 months were found to be predictive of episodes of problem behaviour. Past psychiatric history, problem behaviour and life events in the preceding 12 months were found to be predictive of episodes of depression.

There was a high level of endurance of mental ill-health in adults with intellectual disabilities with a two year recovery rate of only 32.5%. Factors identified as associated with the endurance of mental ill-health (excluding problem behaviours) in adults with intellectual disabilities were, in decreasing order of strength of association: problem behaviour, not having Down's syndrome, not having immobility and smoking. Factors identified as associated with the endurance of problem behaviour in adults with intellectual disabilities were, in decreasing order of strength of association: not having Down's syndrome, not living with a family carer, urinary incontinence, more severe intellectual disabilities, living in a less deprived and male gender. Factors identified as predictive of the duration of a depressive episode more than 1 year were, in decreasing order of strength of association: being married or having a live in partner, mental ill-health in the past, not having daytime activity or occupation, not having visual impairment and number of life events.

Further studies to replicate these findings and explore in more detail the relationship of the identified risk factors are required. However, the identification of risk factors for episodes of mental ill-health now allows the identification of high risk groups and targeted screening/training. It also provides the opportunity to investigate if modifying these risk factors has any influence on the development or course of mental ill-health in adults with intellectual disabilities.

It appears that the high point prevalence of mental ill-health in adults with intellectual disabilities compared to the general population is accounted for more by a higher level of endurance of mental ill-health than by a higher incidence. The apparent high level of endurance of mental ill-health in this

population may be due to diagnostic limitations and the consequent failure to detect milder cases, or because current treatments and interventions are less effective in this population or because mental ill-health is more severe and enduring in this population. Alternatively, it could be due to a combination of all of these or other as yet unidentified factors. Further investigation of this is required.

The epidemiology of mental ill-health in adults with intellectual disabilities differs from the epidemiology of mental-ill health in the general population. Public health strategies and social and health care policies need to take account of these differences to avoid worsening the existing health inequalities experienced by adults with intellectual disabilities.

Planners, commissioners and managers of mental health and social services for adults with intellectual disabilities need to take the findings of this study into consideration when developing interventions and designing services. The identification of risk factors for the onset of mental-ill health, the high incidence of some types of mental ill-health and the high level of enduring mental ill-health found in this study have significant implications for health and social care services. Services should be modified and developed in response to these findings to ensure that the mental health needs of adults with intellectual disabilities are met in full. This will require the development of improved methods for the identification and treatment of mental ill-health in this population, strategies for screening and early intervention for people in high risk groups, evaluation of the effects of modifying identified risk factors and the allocation of health and social care resources in line with the incidence rates and high level of enduring mental ill-health in this population.

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APPENDICES

Appendix I	Ethical approval
Appendix II	T2 Research interview tools/interview pack
Appendix III	Glasgow UCEDD psychiatric assessment tools
Appendix IV	Case note review assessment tools

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

20 JUN 2003

NHS SCOTLAND

Professor Sally-Ann Cooper
Professor of Learning Disabilities
University of Glasgow
Psychological Medicine
Division of Community Based Sciences
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Date: 17 June 2003
Your Ref.:
Our Ref.: MREC/03/0/43

Enquiries to: Walter Hunter
Extension: 89026
Direct Line: 0131 536 9026
Email: walter.hunter@lhb.scot.nhs.uk

Dear Professor Cooper

MREC/03/0/43: The incidence of mental health and mental ill health in adults with learning disabilities.

The members of the Multi-Centre Research Ethics Committee for Scotland delegated to lead the review of this application have considered the changes submitted in response to the Committee's earlier review of your application on 24 April 2003 as set out in our letter dated 1 May 2003. The documents considered were as follows:

Letter of response dated 5 June 2003
Revised application form dated 5 June 2003
Study flow-chart
Study protocol dated 26/3/03
Letter of invitation to relative: version 1 dated 17.05.03
Relative information sheet: version 2 dated 17.05.03
Relative's consent form: version 2 dated 17.05.03
Letter of invitation to participant: version 2 dated 17.05.03
Participant information sheet: version 2 dated 17.05.03
Participant consent form: version 2 dated 17.05.03
Carers information sheet: version 2 dated 17.05.03
Consent/assent statement form: version 2 dated 17.05.03
GP letter: version 2 dated 17.05.03
Consultant letter: version 2 dated 17.05.03
Demographics and past two years needs form
Two year mental ill health form: version 1 dated 21.03.03

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Modified pas-add checklist (Glasgow version): 24/1/02
Pervasive developmental disorder questionnaire
The C21st health check (sampled): Glasgow UAP, 2001

The 'lead reviewers', acting under delegated authority, are satisfied that these accord with the decision of the Committee and have agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you the favourable opinion of the Committee on the understanding that you will follow the conditions of approval set out below. A full record of the review undertaken by the Committee is contained in the attached MREC Response Form. The project must be started within three years of the date of this letter.

Conditions of Approval

- You do not recruit any research subject within a research site unless favourable opinion has been obtained from the relevant local research ethics committee.
- You do not undertake this research in an NHS organisation until the relevant NHS management approval has been obtained as set out in the Framework for Research Governance for Health and Community Care (Research Governance for Health and Social Care in England).
- You do not deviate from, or make changes to, the protocol without prior written approval of the Committee, except where this is necessary to eliminate immediate hazards to research participants or when the change involves only logistical or administrative aspects of the research. In such cases the Committee should be informed within seven days of the implementation of the change.
- You complete and return the standard progress report form to the Committee one-year from the date of this letter and thereafter on an annual basis. This form should also be used to notify the Committee when your research is completed. In this case the form should be sent to the Committee within three months of completion of the research.
- You must complete and return the standard progress report form to the Committee one year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the Committee when your research is completed.
- If you decide to terminate this research prematurely you must send a report to the Committee within 15 days, indicating the reason for the early termination.

NHS SCOTLAND

- You advise the Committee of any unusual or unexpected results that raise questions about the safety of the research.

Local Submissions

It is your responsibility to ensure that any local researcher seeks the approval of the relevant LREC before starting their research. To do this you should submit the appropriate number of copies of the following to the relevant LRECs:

- this letter
- the MREC Application Form (including copies of any questionnaires)
- the attached MREC response form
- Annex D of the Application Form
- one copy of the protocol
- the final approved version of the Patient Information Sheet and Consent Form

It is important to check with the respective LRECs the precise numbers of copies required as this will vary and failure to supply sufficient copies could lead to a delay. In addition, you should submit to LRECs only the revised paperwork reflecting the requirements of the Committee as referenced in the response form.

Local Sites

Whilst the Committee would like as much information as possible about local sites at the time you apply for ethical approval it is understood that this is not always possible. You are asked, however, to send details of local sites as soon as a researcher has been recruited. This is essential to enable the MREC to monitor the research it approves.

ICH GCP Compliance

The Committee is fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance were included on the

NHS SCOTLAND

computer disk containing the guidelines and application form and are available on request or on the Internet at www.corec.org.uk

Yours sincerely

Walter Hunter
MREC Administrator
cc: University of Glasgow
10 The Square
The University of Glasgow
Glasgow
G12 8QQ

Multi-Centre Research Ethics
Committee for Scotland

NHS SCOTLAND

RESPONSE FORM

DETAILS OF APPLICANT:

1. **Name and address of Principal Researcher:**

   Professor Sally-Ann Cooper
   Professor of Learning Disabilities
   University of Glasgow
   Psychological Medicine
   Division of Community Based Sciences
   Academic Centre
   Gartnavel Royal Hospital
   1055 Great Western Road
   Glasgow
   G12 0XH

2. **Title of project:**

   The incidence of mental health and mental ill health in adults with learning disabilities.

3. **Name and address of Sponsor:**

   University of Glasgow
   10 The Square
   The University of Glasgow
   Glasgow
   G12 8QQ

DETAILS OF MREC:

4. **MREC for Scotland**
   Deaconess House
   148 Pleasance
   Edinburgh
   EH8 9RS

5. **MREC Reference Number:** MREC/03/0/43

---

6. **Listed below is a complete record of the review undertaken by the Committee**

Chairman: Professor K Lees Vice-Chairman: Dr G Masterton

with the decisions made, dates of decisions and the requirements at each stage of the review:

Date of review: 24 April 2003

Committee members in attendance:

Professor K Lees (Consultant Physician/Clinical Pharmacologist)(Chairman)
Mrs F Brown (Nurse)
Mrs C Horne (Lay)
Ms R McInnes (Lay)
Dr G Masterton (Consultant Psychiatrist)
Professor E Matthews (Lay)
Mr L Moffat (Consultant Urologist)
Dr A Munro (General Practitioner)
Dr J Norman (Consultant Obstetrician/Gynaecologist)
Professor G Raab (Statistician)
Dr J Stansfield (Allied Health Professions)
Mrs M Sweetland (Statistician)
Mr A Walls (Consultant Surgeon)
Dr J Webster (Consultant Physician/Clinical Pharmacologist)

Outcome of review: Approved subject to change

Documents reviewed:

MREC application form dated 28 March 2003
Annexe E dated 28 March 2003
Study protocol dated 26/3/03
Participant letter of invitation: version 1 dated 31.3.03
Participant information sheet: version 1 dated 21.3.03
Carers information sheet: version 1 dated 26.3.03
Participant consent form: version 1 dated 26.3.03
Relative/carer assent form: version 1 dated 26.3.03
Consent/assent statement form: version 1 dated 26.3.03
GP letter: version 1 dated 26.3.03
Consultant letter: version 1 dated 26.3.03
Project Flow-chart
Demographics and past two years needs
The C21st health check: version 'The Glasgow UAP dated 2001
Modified PAS-ADD checklist: The Glasgow Version
Pervasive developmental disorder questionnaire
Adaptive Behaviour Scales (interview edition) survey form
Two-year mental ill health form: version 1 dated 21.03.03
Chief Scientist Office funding approval letter dated 14 February 2003
Curriculum Vitae

Changes/Information requested:

1. Provide more details on the storage of data bearing in mind the requirements of the Data Protection Act 1998.
2. Clarify whether the data would be anonymised; if so would they be anonymised with encryption.
3. Clarify whether explicit informed consent has been obtained to review the case records.
4. Ensure compliance with the research governance arrangements i.e. notifying the Trust's Data Protection Officer and NHS Glasgow's Caldicott Guardian - (and possibly also the Data Protection Officer for the University of Glasgow).
5. Concern that the one-hour interview may be insufficient to complete all the necessary instruments with this group of participants.
6. The consent arrangements for recruiting participants incapable of giving informed consent did not meet the requirements of the Adults with Incapacity (Scotland) Act 2000 i.e. it was inappropriate for the support worker to give consent and the necessary consent should be obtained from the welfare guardian or nearest/main caring relative.
7. The participant information sheet should:
    1. have sub-section headings for easier reading
    2. thank participants for taking time to read the information sheet
    3. clarify what medical notes would be accessed and how much the participant was consenting to release, to whom and for how long the access would be
    4. make it clear that only those parts of the participant's medical notes relevant to the study would be accessed
    5. mention that the participant would have an opportunity to agree or not agree to this part of the study.
8. The information sheet for carers should:
    1. be more invitational rather than asking carers to participate
    2. have sub-section headings for easier reading
    3. avoid the impression that the study may be able to help prevent or reduce the risk of mental ill health
    4. clarify what medical notes of the patient would be accessed and how much the they were consenting to release, to whom and for how long the access would be
    5. make it clear that only those parts of the patient's medical notes relevant to the study would be accessed
    6. mention that the carer would have an opportunity to agree or not agree to this part of the study.
9. The consent forms may:
    1. benefit from having tick boxes.

Documents reviewed by 'lead reviewers' (Dr G Masterton and Mrs F Brown):

Letter of response dated 5 June 2003
Revised application form dated 5 June 2003
Study flow-chart
Study protocol dated 26/3/03
Letter of invitation to relative: version 1 dated 17.05.03

Relative information sheet: version 2 dated 17.05.03
Relative's consent form: version 2 dated 17.05.03
Letter of invitation to participant: version 2 dated 17.05.03
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Consultant letter: version 2 dated 17.05.03
Demographics and past two years needs form
Two year mental ill health form: version 1 dated 21.03.03
Modified pas-add checklist (Glasgow version): 24/1/02
Pervasive developmental disorder questionnaire
The C21st health check (sampled): Glasgow UAP, 2001

Date approved by 'lead reviewers': 16 June 2003

7. THE FINAL DOCUMENTS AND ARRANGEMENTS APPROVED BY THE MREC

The Multi-Centre Research Ethics Committee for Scotland was satisfied that justification had been provided for the need to include incapacitated adults in this study.

The following items have also been approved by the Multi-Centre Research Ethics Committee for Scotland:

Study protocol dated 26/3/03
Study flow-chart
Letter of invitation to relative: version 1 dated 17.05.03
Relative information sheet: version 2 dated 17.05.03
Relative's consent form: version 2 dated 17.05.03
Letter of invitation to participant: version 2 dated 17.05.03
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Demographics and past two years needs form
Two year mental ill health form: version 1 dated 21.03.03
Modified pas-add checklist (Glasgow version): dated 24/1/02
Pervasive developmental disorder questionnaire
The C21st health check (sampled): Glasgow UAP, 2001
Adaptive Behaviour Scales (interview edition) survey form
Methods of initial recruitment to study
Compensation arrangements for subjects
Payments to researcher

Provision of expenses for subjects

Walter Hunter

Walter Hunter
Administrator
Multi-Centre Research Ethics Committee for Scotland
Date: 17 June 2003

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January 2005 version ***Project number [ ][ ][ ][ ] IP***

MENTAL HEALTH

Is the person known to have any **mental health needs**, emotional or psychological problems, dementia or other psychiatric illness, now or at any time in the last 2 years? [ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

If **YES**, specify the type of problem, illness or need, and any support the person receives
.....
.....

If **YES, PAST EPISODE**, estimate the dates and total number of months when it occurred
.....
.....

Has the person had any **possible mental health problems** in the last 2 years
Yes = 1; No = 2; No, for the lesser time period the carer has known the participant = 3; don't know = 8 [ ]

If **YES**, please describe.....
.....

Project number [ ][ ][ ][ ]IP

MODIFIED PAS-ADD CHECKLIST - The Glasgow VERSION

SECTION 1: LIFE EVENTS

Has the person had any of these experiences *in the last year*?

Death of a parent, child, partner, brother or sister	[ ]
Death of a close family friend, carer or other relative	[ ]
Serious illness or injury	[ ]
Serious illness of a close relative, friend or carer	[ ]
Moved home	[ ]
Break up of a steady relationship	[ ]
Separation or divorce	[ ]
Start of a new relationship	[ ]
Serious problem with a close friend, carer, neighbour or relative	[ ]
End of paid employment	[ ]
Change in day centre / day opportunities	[ ]
Start of paid employment	[ ]
Change in key worker	[ ]
A problem due to a change in support package	[ ]
Bullied or harassed	[ ]
Other traumatic or hurtful experience	[ ]
Something valuable lost or stolen	[ ]
Problems with the police or other authority	[ ]
Major financial problem	[ ]
Some other event (please describe)	[ ]
.....	
None of these events has been experienced in the last year	[ ]

Project number [ ][ ][ ][ ]IP

SECTION 2: HEALTH PROBLEMS

Each question asks about problems the person may have had **IN THE PAST FOUR WEEKS**. Some questions may seem similar to others, but **please answer all the questions.** Read each question carefully and put a tick in the column which gives the best answer to the question.

	If you cannot answer a question, then PUT A LINE THROUGH THE QUESTION and write the reason. For example, if the person does not speak well enough for you to know if they have strange beliefs, cross out that question and write that reason. Ignore the numbers in the columns.	Has not happened in the past 4 weeks	Has occurred for the person in the past 4 weeks	Has been a serious problem for the person in the past 4 weeks
1	**Loss of** energy, has become tired much of the time (if **known** to be due to exertion or physical illness, tick the first column)	0	2	2
2	**Loss of** interests, enjoyment or motivation, such as spending less time doing things that the person usually likes to do	0	2	2
3	Sad or "down" (noticed for at least 3 days in the past 4 weeks)	0	2	2
4	Sudden intense fear, anxiety or panic triggered by **situations** or **things,** such as being in crowds, social situations, alone, thunder, spiders etc. Also, please specify the feared thing.....	0	2	2
5	Fearful, anxious or panicky (**not** triggered by situations or things)	0	2	2
6	**Repeated** actions, such as checking over and over that a door has been locked, or having to do things in a particular order	0	2	2
7	**Too** happy or "high" (noticed for at least 3 days in the past 4 weeks)	0	2	2
8	**Increased** lability of mood; mood rapidly alternating between misery and elation			
9	Excessive talking, singing or laughing, **more** so than usual for the person			
10	**Loss of** usual social inhibitions, indiscretion, or inappropriate social behaviour e.g. talking to strangers, overfamiliarity which is out of keeping with usual behaviour			
11	**Increased** interest in sex, or sexual indiscretions which are out of keeping with usual behaviour			
12	Attempts suicide or talks about suicide	0	1	1
13	**Loss** of appetite and/or enjoyment of food (if this is **known** to be due to dieting or bodily illness, tick the first column)	0	1	1
14	**Increased** appetite, over-eating	0	1	1
15	**Change** of weight, enough to make clothing fit less well (if **known** to be due to dieting or bodily illness, tick the first column)	0	0	0
16	Startled by sudden sounds or movements	0	1	1
17	**Loss** of confidence, or repeatedly seeking reassurance	0	1	1

Modified PAS-ADD Checklist

Project number [ ][ ][ ][ ]IP

	If you cannot answer a question, then PUT A LINE THROUGH THE QUESTION and write the reason. For example, if the person does not speak well enough for you to know if they have strange beliefs, cross out that question and write that reason. Ignore the numbers in the columns.	Has not happened in the past 4 weeks	Has occurred for the person in the past 4 weeks	Has been a serious problem for the person in the past 4 weeks
18	Suspicious, un-trusting, behaving as if someone is trying to get at or harm her/him or is talking about her/him	0	1	1
19	Avoids social contact **more than usual** for the person (socially withdrawn), or **reduced** speech / communication	0	1	1
20	**Loss** of self-esteem, feeling worthless	0	1	1
21	**More** tearful than usual			
22	Delay in falling asleep – at least one hour later than the person's usual time	0	1	1
23	Waking too early (at least one hour before the person's usual time) and **unable to sleep again**	0	1	1
24	**Broken** sleep, waking up for an hour or more, before falling back to sleep	0	1	1
25	**Less able** to concentrate on or pay attention to chosen activities such as watching television, reading, or other hobbies	0	1	1
26	Restless or pacing, unable to sit still; or **increased** over-activity	0	1	1
27	**More** irritable or bad tempered than usual; or **reduced** level of tolerance	0	1	1
28	**Less able**, or less willing to use self-care skills, such as dressing, bathing, using the toilet, and cooking (or requiring more prompting)	0	2	2
29	**More** forgetful or confused than usual, such as forgetting what has been said or getting lost in familiar places; or **more** forgetful of people's names; or **less** able to follow instructions	0	2	2
30	Strange experiences for which other people can see no cause, such as hearing voices or seeing things that other people do not	0	2	2
31	Strange or new beliefs for which other people can see no reason, such as the person believing someone or something is controlling her/his mind or that she/he has special powers	0	2	2
32	Concern that people or the television are referring to her/him, or giving her/him messages or instructions (when this is not the case)			
33	Odd gestures or mannerisms, which are unusual for the person	0	1	1
34	Odd or repetitive use of language, which is unusual for the person	0	1	1
35	Any other **change** from the person's usual behaviour. Pleases give details.....	0	0	0

How many ticks are there in the two right hand columns for Qs1-35? [ ][ ]
(Discuss referral with the research doctor if 2 or more)

Does the person have a positive score on any of the "at risk" Qs12, 18, 30, 31, or 32? [ ]
(If YES, discuss referral with the research doctor)

Appendix II - T2 Research interview tools

Past 2 years mental health history questionnaire

Project number [ ][ ][ ][ ]IP

Complete this item on return to base [ ]

If the person scores 2 or above, or has a positive score for the "at risk" questions, but, following discussion with the research doctor, a referral is not made, why not?

Symptoms are explained by physical illness = 1; Person already sees a psychiatrist = 2; Person declines referral = 3; Carer declines referral on person's behalf = 4; Other = 5 & specify.....

Has the person visited the GP for mental health problems in the last 2 years? [ ]

Yes = 1; No = 2; No for the lesser time period the carer has known the participant = 3; Don't know = 8

If **YES**, please describe the problem.....

.....

.....

If **YES**, please describe any treatments from the GP.....

.....

.....

Has the person seen a psychiatrist for mental health problems in the last 2 years? [ ]

Yes = 1; No = 2; No for the lesser time period the carer has known the participant = 3; Don't know = 8

If **YES**, please describe the problem.....

.....

.....

If **YES**, please describe any treatments from the psychiatrist.....

.....

.....

If **YES**, name of psychiatrist.....

Has the person seen a psychologist for mental health problems in the last 2 years? [ ]

Yes = 1; No = 2; No for the lesser time period the carer has known the participant = 3; Don't know = 8

If **YES**, please describe the problem.....

.....

.....

If **YES**, please describe any interventions from the psychologist.....

.....

.....

If **YES**, name of psychologist.....

Project number [ ][ ][ ][ ]IP

Has the person had any admissions to a psychiatric or learning disabilities hospital / unit in the last 2 years? [ ]

Yes = 1; No = 2; No for the lesser time period the carer has known the participant = 3; Don't know = 8

If **YES**, where? .....

If **YES**, give approximate dates.....

.....

.....

If **YES**, please describe any interventions or supports.....

.....

.....

If you have identified any **possible past episodes of mental ill-health** within the 2 year period which are not current / have resolved, please administer a **retrospective** *PAS-ADD Checklist – the Glasgow Version* for the identified period of time. Identify the 4 week period when symptoms were maximal, and administer the retrospective *PAS-ADD Checklist – the Glasgow Version for that period.*

What time period does this retrospective *PAS-ADD Checklist – the Glasgow Version* apply to?.....

.....

Indicate here if a retrospective *PAS-ADD Checklist – the Glasgow Version* is not indicated. [ ]

Retrospective completed = 1; Not required = 2

Did the person have any of these experiences in the *year prior to the onset of the episode*?

Death of a parent, child, partner, brother or sister	[ ]
Death of a close family friend, carer or other relative	[ ]
Serious illness or injury	[ ]
Serious illness of a close relative, friend or carer	[ ]
Moved home	[ ]
Break up of a steady relationship	[ ]
Separation or divorce	[ ]
Start of a new relationship	[ ]
Serious problem with a close friend, carer, neighbour or relative	[ ]
End of paid employment	[ ]

	Project number [ ][ ][ ][ ]IP
Change in day centre / day opportunities	[ ]
Start of paid employment	[ ]
Change in key worker	[ ]
A problem due to a change in support package	[ ]
Bullied or harassed	[ ]
Other traumatic or hurtful experience	[ ]
Something valuable lost or stolen	[ ]
Problems with the police or other authority	[ ]
Major financial problem	[ ]
Some other event (please describe)	[ ]
None of these events were been experienced in the year prior to the episode	[ ]

Appendix II - T2 Research interview tools

Retrospective Modified PAS-ADD Checklist

Project number [ ][ ][ ][ ]IP

Each question asks about problems the person may have experienced during the identified retrospective 4 week period.

	If you cannot answer a question, then PUT A LINE THROUGH THE QUESTION and write the reason. For example, if the person does not speak well enough for you to know if they have strange beliefs, cross out that question and write that reason. Ignore the numbers in the columns.	Has not happened in the identified 4 weeks	Has occurred for the person in the identified 4 weeks	Has been a serious problem for the person in the identified 4 weeks
1	**Loss of** energy, has become tired much of the time (if **known** to be due to exertion or physical illness, tick the first column)	0	2	2
2	**Loss of** interests, enjoyment or motivation, such as spending less time doing things that the person usually likes to do	0	2	2
3	Sad or "down" (noticed for at least 3 days in the past 4 weeks)	0	2	2
4	Sudden intense fear, anxiety or panic triggered by **situations** or **things,** such as being in crowds, social situations, alone, thunder, spiders etc. Also, please specify the feared thing.....	0	2	2
5	Fearful, anxious or panicky (**not** triggered by situations or things)	0	2	2
6	**Repeated** actions, such as checking over and over that a door has been locked, or having to do things in a particular order	0	2	2
7	**Too** happy or "high" (noticed for at least 3 days in the past 4 weeks)	0	2	2
8	**Increased** lability of mood; mood rapidly alternating between misery and elation			
9	Excessive talking, singing or laughing, **more** so than usual for the person			
10	**Loss of** usual social inhibitions, indiscretion, or inappropriate social behaviour e.g. talking to strangers, overfamiliarity which is out of keeping with usual behaviour			
11	**Increased** interest in sex, or sexual indiscretions which are out of keeping with usual behaviour			
12	Attempts suicide or talks about suicide	0	1	1
13	**Loss** of appetite and/or enjoyment of food (if this is **known** to be due to dieting or bodily illness, tick the first column)	0	1	1
14	**Increased** appetite, over-eating	0	1	1
15	**Change** of weight, enough to make clothing fit less well (if **known** to be due to dieting or bodily illness, tick the first column)	0	0	0
16	Startled by sudden sounds or movements	0	1	1
17	**Loss** of confidence, or repeatedly seeking reassurance	0	1	1
18	Suspicious, un-trusting, behaving as if someone is trying to get at or harm her/him or is talking about her/him	0	1	1
19	Avoids social contact **more than usual** for the person (socially withdrawn), or **reduced** speech / communication	0	1	1
20	**Loss** of self-esteem, feeling worthless	0	1	1
21	**More** tearful than usual			

Retrospective Modified PAS-ADD Checklist

Project number [ ][ ][ ][ ]IP

	If you cannot answer a question, then PUT A LINE THROUGH THE QUESTION and write the reason. For example, if the person does not speak well enough for you to know if they have strange beliefs, cross out that question and write that reason. Ignore the numbers in the columns.	Has not happened in the identified 4 weeks	Has occurred for the person in the identified 4 weeks	Has been a serious problem for the person in the identified 4 weeks
22	Delay in falling asleep – at least one hour later than the person's usual time	0	1	1
23	Waking too early (at least one hour before the person's usual time) and **unable to sleep again**	0	1	1
24	**Broken** sleep, waking up for an hour or more, before falling back to sleep	0	1	1
25	**Less able** to concentrate on or pay attention to chosen activities such as watching television, reading, or other hobbies	0	1	1
26	Restless or pacing, unable to sit still; or **increased** over-activity	0	1	1
27	**More** irritable or bad tempered than usual; or **reduced** level of tolerance	0	1	1
28	**Less able**, or less willing to use self-care skills, such as dressing, bathing, using the toilet, and cooking (or requiring more prompting)	0	2	2
29	**More** forgetful or confused than usual, such as forgetting what has been said or getting lost in familiar places; or **more** forgetful of people's names; or **less** able to follow instructions	0	2	2
30	Strange experiences for which other people can see no cause, such as hearing voices or seeing things that other people do not	0	2	2
31	Strange or new beliefs for which other people can see no reason, such as the person believing someone or something is controlling her/his mind or that she/he has special powers	0	2	2
32	Concern that people or the television are referring to her/him, or giving her/him messages or instructions (when this is not the case)			
33	Odd gestures or mannerisms, which are unusual for the person	0	1	1
34	Odd or repetitive use of language, which is unusual for the person	0	1	1
35	Any other **change** from the person's usual behaviour. Pleases give details.....	0	0	0

How many ticks are there in the two right hand columns for Qs1-35? [ ][ ]
(Discuss referral with the research doctor if 2 or more)

Does the person have a positive score on any of the "at risk" Qs12, 18, 30, 31, or 32? [ ]
(If YES, discuss referral with the research doctor)

Glossary of Symptoms for modified PAS-ADD checklist

Instructions for use

The PAS-ADD checklist is a psychiatric symptom checklist. It asks about problems that sometimes happen if a person has poor mental health. The checklist aims to help staff and carers to decide whether an assessment of an individual's mental health may be helpful.

- The person completing the checklist should have known the individual for **at least six months**, if possible.

- Most of the items on the checklist are to be completed on the basis of problems that have been present in the **past four weeks**, and have been observed to be a recent **change from normal**. This can cause some confusion where an individual is suffering from chronic mental illness and significant symptoms are present but have been present for so long that they are not a change from usual. In such cases, if a symptom is present and is thought to be **due to illness it should be rated.** However, if a symptom is present but is thought to be a **life-long trait** of the individual, rather than due to illness, it should **not** be rated.

- If a problem has been present during the four-week period, but is not present at the time of filling in the questionnaire, it should **still be rated as present.**

- A symptom should be rated as 'has not happened in the past four weeks' if the symptom has definitely **not** been present in the past month. A symptom should be rated as severe if **any** of the following apply;
  1. the symptom occurs with a high frequency and has been present for most of the time in the past four weeks
  2. the symptom is very severe and has caused considerable distress to the person you are rating or to others
  3. the symptom has significantly threatened the persons environment. E.g. exclusion from day centre, loss of relationships or has threatened the persons residential placement
  4. the symptom has caused serious danger to the person you are rating or to others.

Glossary Items

1. ***Loss of energy***

The person appears to be weary and lethargic compared to their normal self. They may take much longer than usual to do things.

2. ***Loss of interests***

A reduced interest or enthusiasm for hobbies or favourite objects and reduced participation in activities, which the person would usually find enjoyable – includes taking an interest in clothes, appearance etc. as well as activities.

3. ***Sad or down***

Applies to low mood that is persistent over significant periods of time and cannot be alleviated by events, which are generally perceived as pleasurable. Rate as severe if depressed mood is present for most of the day for at least two weeks in the past month. Rate as present even if there has been a significant life event such as bereavement.

4. ***Sudden intense fear or anxiety or panic triggered by certain situations***

A phobia is excessive and uncontrollable anxiety experienced in specific circumstances or when confronted by particular objects that wouldn't normally bother most people. Common phobias include fear of crowds, travelling, leaving home, being alone, eating in public, insects, heights, darkness, dogs. The specific circumstances triggering the fear should be noted.

5. ***Fearful anxious or panicky not triggered by certain situations***

This applies to people who experience anxiety, fear or apprehension without there being any specific circumstances. It is possible for people to experience both phobias and generalised anxiety symptoms together.

6. ***Repeated actions***

These are repetitive but senseless actions, which the person is compelled and anxious to perform. They may include checking, counting, having to touch things in a special way or dressing in a particular way.

7. ***Too happy or too high***

To be rated as present the mood must be elevated out of keeping with the individual's circumstances. Do not mark the symptom as present if the person has briefly been very happy due to appropriate circumstances.

8. ***Increased lability of mood***

Lability of mood occurs when mood is unstable and changes frequently and rapidly from misery to elation. Rate as present if this is a new problem for the person or if there has been recent worsening of longstanding mood lability.

9. ***Excessive talking, singing or laughing***

Rate as present only if more so than usual for the person and has been present for at least three days.

10. ***Loss of usual social inhibitions***

This includes behaviour that is out of character for the individual and inappropriate to the circumstances.

11. ***Increased sexual energy***

The person's sexual interest is heightened and they may show increased sexual activity. Rate only if there is a change from their usual sexual behaviour.

12. Attempts at suicide or talks about suicide

Any serious attempt at suicide should be rated as severe.

13. Loss of appetite

There is a definite loss of interest in food and pleasure in eating. In some case it may take much longer to eat food.

14. Increased appetite, over eating

15. Change of weight

16. Startled by sudden sounds or movements

17. Loss of confidence

Remember that people with learning disability are particularly susceptible to poor self-confidence, which can be a life-long trait. A life-long trait should not be rated here as a problem.

18. Suspicious, untrusting

It is important to consider when rating this item that people with learning disabilities are sometimes the object of ridicule or abuse or even physical attack. Only rate this symptom as present if there are no rational grounds for their thoughts and behaviour.

19. Avoids social contact more than usual or reduced speech

A noticeable reduction in a person's sociability compared to their usual. They may try to avoid people or stop taking part in social events.

20. Loss of self-esteem, feeling worthless

Individuals with this experience develop negative images about themselves and often let it be known that they dislike themselves and feel inferior to others.

21. More tearful then usual

22. Delay in falling asleep

The person finds it difficult to get off to sleep and may lie awake 'tossing and turning'. Rate only those episodes of sleep difficulty lasting more than one hour. Do not rate this symptom as present if it is due to physical illness or pain.

23. Waking too early

This applies only if the person has been wakening at least one hour before their usual time. If the individual eventually falls back to sleep again rate as broken sleep.

24. Broken sleep

The person wakes up during the night and has difficulty getting back to sleep. Rate only if person is awake for at least one hour.

25. Less able to concentrate

Concentration is poorer than usual. The person finds it more difficult than usual to take in information, to work, or give her/his full attention to activities that were previously absorbing. They may be more indecisive than usual.

26. Restless or pacing, or unable to sit still; or increased over-activity

Fidgeting of various parts of the body and an inability to sit still. This can range from plucking at fingers or clothing, or making restless movements with

her/his legs to pacing up and down, wandering about and being unable to sit down for very long.

27. More irritable or bad tempered than usual

The person with this symptom becomes easily annoyed so that tolerance over trivial annoyances and frustrations is reduced. The irritability is out of proportion to the circumstances. E.g. angry shouting, picking fights and quarrelling.

28. Less able or less willing to use self-care skills

This should be rated from the perspective of what the individual could previously do. They may no longer be able to dress themselves or toilet themselves appropriately or they require many more verbal prompts and reminders. This is often more evident in unfamiliar surroundings.

29. More forgetful or confused than usual

This should be rated from the perspective of what the individual could previously do. A person may increasingly forget appointments or where objects have recently been placed. In severe cases a person may be unable to remember previously learned information e.g. inability to recognise familiar people and places, difficulty finding their bedroom, inability to distinguish between day and night.

30. Strange experiences

If rating voices it is important to establish that they really are hallucinations (a false perception and not a sensory distortion) i.e. exclude such events as hearing the neighbours TV or radio through the wall.

31. Strange or new beliefs

Beliefs can be bizarre (e.g. that the Internet is controlling their thoughts) or quite plausible (e.g. that someone has stolen their purse) but the important quality is that they are false and the person is unresponsive to attempts at reasoning. Common strange beliefs include that someone or an organisation is trying to harm them or that other people know what they are thinking or that they are famous or have special powers.

32. Concern that people or the television are referring to him/her

Some people are convinced that a television programme or stories in the newspaper are referring directly to them or are about them. Also, other people believe they are receiving messages from the television or misinterpret gestures or actions made by other people as having a special significance for them when this is not the case.

33. Odd gestures, mannerisms

34. Odd or repetitive use of language

35. Any other change from the persons usual behaviour

Please give as much detail as is possible. Use the back of the checklist if extra space is needed.

ACKNOWLEDGEMENT

This glossary has been copied and modified from the Glossary Of Symptoms for the MINI PAS-ADD, Prosser et al, Hester Adrian Research Centre.

Project number [ ][ ][ ][ ]IP

Pervasive developmental disorder questionnaire

Does the person have autism, Asperger's syndrome or **autistic spectrum disorder**? [ ]

If **YES**, specify, and any support the person receives.....

.....

If **YES**, do not ask PDD questions.

If present, the following features will generally have had an onset within early childhood. Additionally, they will be present in some degree for most of the time. Put a tick in the column that gives the best answer to the question. Only tick the second column if the feature has been **present for at least 12 months**.

	If you cannot answer a question, then put a line through the question and write the reason	Has not happened in past 12 months	Has been present for most of the time in the past 12 months
1	Rarely uses eye-to-eye gaze, smiling or facial expression when interacting with others		
2	Rarely greets others spontaneously		
3	Rarely looks for or offers comfort or affection at times of distress		
4	Lacks feeling for others or shows abnormal response to other's emotions		
5	Does not share objects or food with others		
6	Does not share enjoyment or interests with others		
7	Does not respond in an appropriate way in social situations		
8	Compared to peers the person has difficulty in developing friendships and social relationships		
9	Has difficulty reciprocating in a conversation with others (according to verbal ability)		
10	Repeats the same phrase, word or sound over and over, out of context		
11	Misuse of subject pronouns e.g. uses 'you', 'he' or 'she', when 'I' is meant		
12	Has attachments to unusual objects		
13	Has hobbies or interests that seem odd to others		
14	Touches, smells or tastes objects inappropriately or with an unusual intensity		
15	Repetitive behaviour such as hand flapping, body rocking or spinning		
16	Has routines or rituals performed in a particular sequence		
17	Becomes distressed over changes in routine or surroundings		
18	Person has no verbal communication skills		

Office Use Only:

Score ASD1 (total score for Qs1-8) = [ ]
Score ASD2 (total score for Qs 9-11) = [ ]
Score ASD3 (total score for Qs 12-17) = [ ]

Threshold: person scores a minimum of 8 ticks with at least 3 in ASD1 & 2 in ASD3

Glossary of Symptoms for the Pervasive Developmental Disorder Questionnaire

The Pervasive Developmental Disorder Questionnaire is concerned with behaviours which have been longstanding. In most cases they will have had an onset in early childhood. However, there will often be circumstances where there is no parent to verify this. This does not preclude ratings being made, provided that informants are able to report that symptoms are generally persistent, and have occurred over **at least 12 months**.

1. This refers to a failure to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction. Some people with autism will use eye-to-eye contact but in an abnormal, non-reciprocal way – rate this item as positive if they do use eye-to-eye contact but in an abnormal way.

2. The person would not spontaneously greet visitors and/or would show no interest in any visitors or new people.

3. The person will rarely go to others when distressed or upset or feeling ill and/or will rarely make any attempt to comfort others.

4. The person shows a deviant or impaired response to other people's emotions.

5. Self evident.

6. The person shows a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, pointing out to other people objects of interest to the individual).

7. The person has difficulty modulating their behaviour according to social context.

8. Self evident.

9. The person experiences difficulty in holding a two way conversation with another person, e.g. the person may talk freely about their own interests but show little willingness to converse about subjects which are of interest to others. The person finds it difficult to follow with interest another person's conversation and build on that conversation in a social manner.

10. Self evident.

11. Self evident.

12. The person will have a specific object or objects that they are very attached to and will often insist that it goes with them wherever they go. They will tend to get very upset if someone else touches or takes their object away. The

attachment object should be unusual e.g. a comb, mirror or bag rather than a cuddly toy or blanket.

13. The person has a hobby or interest which is unusual both in its content and intensity, such as a compulsive interest in timetables, bus routes or traffic lights. The person rarely shares this interest with others.

14. This item applies to people who have an unusual interest in the sight, feel, sound, taste or smell of people or things, e.g. they may sniff objects or people inappropriately, peer at things intently for long periods of time, or touch things to their lips to see how they feel.

15. The person displays stereotyped behaviour, such as hand or finger flapping or twisting, rocking spinning, tip toe walking.

16. The person feels compelled to perform rituals or routines in a fixed order, e.g. having to place particular objects in exact positions or opening all doors at a particular angle or having to lay out cutlery and tableware in a particular order before eating or having to touch particular things before going on to do something else.

17. The person shows distress or unusual negative reactions to changes in small details in the environment, surroundings or daily routine, e.g. the re-arrangement of ornaments or furniture, or a change to their usual breakfast, may cause intense temper outbursts/aggression.

18. Self evident

This glossary has been copied and modified from the Glossary Of Symptoms for the MINI PAS-ADD, Prosser et al, Hester Adrian Research Centre.

January 2005 version ***Project number [ ][ ][ ][ ]IP***

THE C21st HEALTH CHECK – SAMPLED

INTERVIEW DETAILS

Name of **researcher** completing the interview.....

Date of interview (day/month/year) [ ][ ]/[ ][ ]/[ ][ ]

Name of person **supporting** the participant.....

Relationship of supporting person to participant.....[ ]
Next of kin = 1; Other relative = 2; Nurse = 3; Support worker = 4;
Other = 5 & specify.....

How long has the supporting person known the participant?.....

If **LESS THAN 2 YEARS**, take name, telephone and address details of a previous contact.....
.....
.....

HEALTH PROBLEMS IDENTIFIED BY PCLT HEALTH CHECK

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January 2005 version ***Project number [ ][ ][ ][ ]IP***

NEW KNOWN HEALTH PROBLEMS

Ask what **health problems** the person is known to have, or received treatment for (Refer to list on previous page for health problems identified by PCLT health check). Highlight below any new health problems identified in the last 2 years.

.....
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Any hearing problems?.....

Any vision problems? .....

CURRENT HEALTH CONCERNS

Ask if the person with learning disabilities or the person supporting her / him is aware of, or concerned about any health problems in particular, or any **new symptoms**.

.....
.....
.....
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.....
.....

January 2005 version ***Project number [ ][ ][ ][ ]IP***

MEDICATIONS

Ask to see all the **tablets**, medicines, inhalers, and injections the person is currently taking and list them. Ask why the person is prescribed each one. Include non-prescription medications such as those bought over the counter e.g. antihistamines and complementary medications.

Drug name	Dose and frequency	Reason for prescription

DEVELOPMENT

What is the **cause** of the person's **learning disabilities?** [ ]

Unknown = 1; Down's syndrome = 2; Tuberous sclerosis = 3;
Eclampsia / ante-partum haemorrhage / complications of pregnancy = 4;
'Birth injury' = 5; Meningitis / encephalitis = 6; Fragile X syndrome = 7;
Head injury = 8; Brain tumour = 9; Hydrocephalus = 10; Microcephaly = 11;
Phenylketonuria (PKU) = 12; Prader-Willi syndrom = 13; Smith-Magenis syndrome = 14;
Congenital rubella = 15; Rett syndrome = 16; Unclear if ever assessed = 88;
Other = 17 & specify .....

HEALTH PROMOTION

Number of **cigarettes** smoked per day / amount of tobacco smoked per day?.....

Number of units of **alcohol** drunk per week?.....

Does the person use **recreational drugs**? [ ]

Yes = 1; No =2

If **YES**, specify.....

January 2005 version) ***Project number [ ][ ][ ][ ] IP***

THE C21st HEALTH CHECK - SAMPLED: EXERCISE SUPPLEMENT

1. Does the person undertake any regular exercise at home, at work, or for leisure? (Please include housework and gardening).
Yes =1; No = 2 [ ]

If **yes**, please complete the table below.

What is the exercise activity? (Please specify e.g. swimming).				
What is the most vigorous (or energetic) thing that the person does when he/she is doing this exercise activity?				
How often does the person do this exercise activity? (E.g. weekly).				
How long does each session last (in minutes)?				
Does the person get sweaty or out of breath during this exercise activity?				
RA rating: Vigorous, Moderate, or Light				
RA rating: Number of 20-minute sessions in a 4-week period				

January 2005 version ***Project number [ ][ ][ ][ ]IP***

EPILEPSY

Has the person ever experienced **seizures, epilepsy or fits**? [ ]
Yes = 1; No = 2

[IF NO, SKIP TO THE NEXT SECTION]

Describe all the different type/s of seizure/s that the person experiences (for subsequent classification of seizure type/s with the research doctors).
If the person has a type of seizure, which sometimes occurs on its own and sometimes turns into another type of seizure (tonic-clonic), describe both of these types of seizures (i.e. list as two seizure types).
If the carer uses the medical term for the seizure, note this down, as well as taking a full description of the seizures.

Complex partial = 1; Simple partial = 2; Primary generalised tonic-clonic = 3; Absence = 4; Tonic = 5; Clonic = 6; Atonic = 7; Myoclonic = 8; Secondarily generalised tonic-clonic seizures = 9; Atypical = 10; Other = 11 & specify; Not sure = 88

Possible prompts:
Can you tell when she / he is going to have a seizure (and if so how)?
What is the first thing that happens when she / he has a seizure?
Does the person lose consciousness during the seizure?
Does she / he fall to the ground?
Can she / he still respond during the seizure?
Do some of her / his legs go stiff, twist and / or move (and if so, which ones)?
Does her / his head move?
Does her / his eyes deviate?
Does she / he have any repetitive or rhythmic movements during the seizure?
Has she / he ever been injured during a seizure?

i .....
.....
.....
.....[ ][ ]
ii .....
.....
.....
.....[ ][ ]
iii .....
.....
.....
.....[ ][ ]

iv .....
.....
.....
.....[ ][ ]

When was the person's last seizure?.....

If possible, record below the **number of seizures, for each type, per full calendar month**, for the last six months. If this is unknown, ask for an estimate of the number of seizures the person has e.g. how many seizures in the last week or month or year?

Month	Type i frequency	Type ii frequency	Type iii frequency	Type iv frequency
Estimate				

PROBLEM BEHAVIOURS

Does the person have any problem behaviours, challenging behaviour or special needs related to behaviour now, or at any time over the last 2 years?
Yes, current = 1; Yes, past episode = 2; No = 3;
No, for the lesser time period the carer has known the participant = 4 [ ]

If **YES**, specify the type of problem behaviour, and any support the person receives.....
.....
.....
.....
.....

If **YES**, for each type of problem behaviour, specify whether it occurred throughout the last 2 years, or if not, the estimated time period when it occurred (dates and total number of months).....
.....
.....
.....
.....

Some people need extra support because they have problems with their behaviour. I'd like to ask some routine questions about whether the person has any **specific types** of problem behaviours.

Appendix II - T2 Research interview tools

C21st Health Check Sampled - Problem behaviour Checklist

January 2005 version ***Project number [ ][ ][ ][ ]IP***

VERBAL AGGRESSION

Does the person have any problems with verbal aggression? E.g. shouting, screaming or swearing? Has she / he had problems with verbal aggression at any time in the last 2 years?
If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)
.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....
.....

A. If **YES**, How long does it / did it last when it occurs?.....
.....

A. If **YES**, How severe is it / was it?.....
.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....
.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?
.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....
.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....
.....
.....

C. If **YES**, does it / did it impact on another person's quality of life?.....
.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....
.....

Consensus rating by research team [ ]
Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

January 2005 version ***Project number [ ][ ][ ][ ]IP***

PHYSICAL AGGRESSION

Does the person have any problems with physical aggression? E.g. scratching, pinching, pulling hair, hitting, kicking, punching, throwing? Has she / he had problems with physical aggression at any time in the last 2 years?

If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)

.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....

.....

A. If **YES**, How long does it / did it last when it occurs?.....

.....

A. If **YES**, How severe is it / was it?.....

.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....

.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?

.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....

.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....

.....

.....

C. If **YES**, does it / did it impact on another person's quality of life?.....

.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....

.....

Consensus rating by research team [ ]

Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

January 2005 version ***Project number [ ][ ][ ][ ]IP***

DESTRUCTIVENESS TO PROPERTY
Does the person have any problems with destructiveness? E.g. throwing things, smashing things, ripping or shredding things, pulling things down, swiping things, punching or kicking things?
Has she / he had problems with destructiveness at any time in the last 2 years?
If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)
.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....
.....

A. If **YES**, How long does it / did it last when it occurs?.....
.....

A. If **YES**, How severe is it / was it?.....
.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....
.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?
.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....
.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....
.....
.....

C. If **YES**, does it / did it impact on another person's quality of life?.....
.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....
.....

Consensus rating by research team [ ]
Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

January 2005 version ***Project number [ ][ ][ ][ ]IP***

SELF-INJURY
Does the person have any problems with self-injury? E.g. scratching or pinching self, skin-picking, picking at wounds, pulling hair out, head banging, head or body punching, hitting or slapping, throwing self on floor, pulling out nails? Has she / he had problems with self-injury at any time in the last 2 years?
If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)
.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....
.....

A. If **YES**, How long does it / did it last when it occurs?.....
.....

A. If **YES**, How severe is it / was it?.....
.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....
.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?
.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....
.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....
.....
.....

C. If **YES**, does it / did it impact on another person's quality of life?.....
.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....
.....

Consensus rating by research team [ ]
Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

January 2005 version ***Project number [ ][ ][ ][ ]IP***

SEXUALLY INAPPROPRIATE BEHAVIOUR
Does the person have any sexual problems or committed any sexual offences? Does she / he understand not to masturbate in public, and not to strip or expose her / himself in public? Has she / he had any problems like this at any time in the last 2 years?
If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)
.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....
.....

A. If **YES**, How long does it / did it last when it occurs?.....
.....

A. If **YES**, How severe is it / was it?.....
.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....
.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?
.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....
.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....
.....
.....

C. If **YES**, does it / did it impact on another person's quality of life?.....
.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....
.....

Consensus rating by research team [ ]
Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

Appendix II - T2 Research interview tools

C21st Health Check Sampled - Problem behaviour Checklist

January 2005 version ***Project number [ ][ ][ ][ ]IP***

OPPOSITIONAL BEHAVIOUR

Does the person have any problems with being oppositional? E.g. deliberately not following requests, disagreeing with any community or household rules or regulations, not accepting responsibilities? Has she / he had problems with oppositional behaviour at any time in the last 2 years?

If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)

.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....

.....

A. If **YES**, How long does it / did it last when it occurs?.....

.....

A. If **YES**, How severe is it / was it?.....

.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....

.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?

.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....

.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....

.....

.....

C. If **YES**, does it / did it impact on another person's quality of life?.....

.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....

.....

Consensus rating by research team [ ]

Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

January 2005 version ***Project number [ ][ ][ ][ ]IP***

EXCESSIVELY DEMANDING

Does the person have any problems with being overly demanding? E.g. requiring continuous attention, much more so than the average person, unable to amuse self? Has she / he had problems with excessively demanding behaviour at any time in the last 2 years?

If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)

.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....

.....

A. If **YES**, How long does it / did it last when it occurs?.....

.....

A. If **YES**, How severe is it / was it?.....

.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....

.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?

.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....

.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....

.....

.....

C. If **YES**, does it / did it impact on another person's quality of life?.....

.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....

.....

Consensus rating by research team [ ]

Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

January 2005 version ***Project number [ ][ ][ ][ ]IP***

WANDERING

Does the person have any problems with wandering? E.g. walking off or going missing? Has she / he had problems with wandering at any time in the last 2 years?

If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)

.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....

.....

A. If **YES**, How long does it / did it last when it occurs?.....

.....

A. If **YES**, How severe is it / was it?.....

.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....

.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?

.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....

.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....

.....

.....

C. If **YES**, does it / did it impact on another person's quality of life?.....

.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....

.....

Consensus rating by research team [ ]

Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

January 2005 version ***Project number [ ][ ][ ][ ]IP***

FAECAL SMEARING
Does the person have any problems with soiling or smearing or playing with faeces? E.g.?
Has she / he had problems with this at any time in the last 2 years?
If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)
.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....
.....

A. If **YES**, How long does it / did it last when it occurs?.....
.....

A. If **YES**, How severe is it / was it?.....
.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....
.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?
.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....
.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....
.....
.....

C. If **YES**, does it / did it impact on another person's quality of life?.....
.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....
.....

Consensus rating by research team [ ]
Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

January 2005 version ***Project number [ ][ ][ ][ ]IP***

PICA

Does the person have any problems with pica – eating things that are not usually considered to be food? E.g. dirt or soil, frozen food that hasn't been defrosted, cigarette butts, coffee grounds, or clothes or materials? Has she / he had problems with pica at any time in the last 2 years?
If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)
.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....
.....

A. If **YES**, How long does it / did it last when it occurs?.....
.....

A. If **YES**, How severe is it / was it?.....
.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....
.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?
.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....
.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....
.....
.....

C. If **YES**, does it / did it impact on another person's quality of life?.....
.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....
.....

Consensus rating by research team [ ]
Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

January 2005 version ***Project number [ ][ ][ ][ ]IP***

OTHER PROBLEM BEHAVIOUR

Does the person have any other problem behaviours? Has she / he had any other problem behaviours at any time in the last 2 years?

If **YES**, is it a problem now? (Specify how long it has been a problem for the person). Or was it a problem at some other period during the last 2 years? (Specify when and for how long)

.....[ ]

Yes, current = 1; Yes, past episode = 2; No = 3; No, for the lesser time period the carer has known the participant = 4

A. If **YES**, How often does it / did it occur?.....

.....

A. If **YES**, How long does it / did it last when it occurs?.....

.....

A. If **YES**, How severe is it / was it?.....

.....

D. If **YES**, where does it / did it occur? (i.e. check it is not just in one setting – that it occurs across a range of personal and social situations, although it may be more severe or distressing in certain identified settings).....

.....

B. If **YES**, does it / did it only occur when the person is known to have a physical illness?

.....

B. If **YES**, does it / did it only occur when the person is known to have some other psychiatric illness? (Do not include autism i.e. do not assume any identified problem behaviours are due to autism).....

.....

C. If **YES**, does it / did it have a negative impact on the person's life? E.g. restriction of lifestyle, social opportunities, independence, community integration, access to services, or restriction of choices, or skills or use of skills.....

.....

.....

C. If **YES**, does it / did it impact on another person's quality of life?.....

.....

C. If **YES**, does it / did it put at risk the person's health & / or safety, or another person's health or safety?.....

.....

Consensus rating by research team [ ]

Current DC-LD problem behaviour = 1; Past episode of DC-LD problem behaviour = 2; No = 3

October 2004 version *Project Number [ ][ ][ ][ ]IP*

DEMOGRAPHICS

Date of birth (date / month / year) [ ][ ]/[ ][ ]/[ ][ ]

Gender [ ]
Male = 1; Female = 2

Marital status [ ]
Married / live-in partner = 1; Separated / divorced = 2; Single = 3; Widow/er = 4

Ethnicity [ ]
Indian = 1; Pakistani = 2; Bangladeshi = 3; Chinese = 4; Caucasian = 5; Black Caribbean = 6;
Black African = 7; Black other = 8; Other = 9 & specify.....

Post code, or address.....

SOCIAL SUPPORTS

Accommodation and support package

Who does the person live with? [ ]
Lives alone = 1; Lives with partner = 2; Lives with parent/s = 3; Lives with other family carer = 4;
Lives with other person / people = 5; Other = 6 & specify.....

Type of accommodation? [ ]
Parental home = 1; Other family carer home = 2; Lives independently = 3; Lives independently with
spouse / partner = 4; Supported group living = 5; Supported living - individual = 6; Residential care = 7;
Nursing home = 8; NHS accommodation = 9; Other = 10 & specify.....

How many adults live at the person's home (including her / himself; excluding support workers)? [ ]

How many children (under 16 years) live at the person's home? [ ]

If this is a family home, or supported living, ask: Is the flat / house privately owned or rented? [ ]
Owner occupied = 1; Privately rented = 2; Rented from housing association = 3

If this is not a family home (i.e. it is supported living), ask:
- How much paid support does the person receive? [ ]
  Part-time support (less than daily) = 1; Part-times support (daily) = 2;
  24 hour support, sleep-in nights = 3; 24 hours, waking night = 4; 24 hours, waking + sleep-in at night = 5
- If < 24 hour support, number of hours of paid support / week? [ ][ ][ ]
- Which organisation provides the support package.....
- How many whole time equivalents work here *or* how many hours of support per week in the home?.....

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- What bills does the person directly contribute to (i.e. *not* included in funding of support package?

Rent	[ ]
Gas	[ ]
Electricity	[ ]
Council tax / water	[ ]
Food / provisions	[ ]
Property maintenance	[ ]
Other & specify	[ ]

How long has the person lived here? If < 2 year, collect details of previous homes, and duration in each.

Employment

For everyone, ask:

- Has the person any regular arrangements for daytime activities or employment?
- Over the last 2 years, did the person have any regular daytime activities or employment in which she / he is no longer engaged?

Then ask about:

- The type of provider.
- The duration the arrangement was / has been in place (to identify its duration if less than 2 year).
- The person's usual pattern of days or hours / week, to estimate the number of hours / week.

Then calculate the estimated number of hours / week in each type of employment.
Then ask about each of the listed options, to see if it prompts identification of any other opportunities.

	Yes / No	Sector – NHS / SW / Private / Voluntary	Duration (if < 2 year)	Number of hours / week
Paid employment				
Paid employment, with support				
Voluntary work				
College course				
Day centre				
***1:1 support to access a day centre**				
***1:1 day opportunities support**				
Housewife / husband				
Retired				
Other & specify				

** Do not double count support – list 1:1 support here which is in addition to the care already listed above under "accommodation and support package" details.*

Tick here if the person has no employment in any of the above categories. [ ]

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Are there any employment activities or day opportunities that you think your relative/the person you support needs that he/she does not have at present?
Yes. Please specify .....[ ] No [ ] Don't know [ ]

If **yes**, are arrangements being made for this? Or, is there any reason why the person does not or cannot have these employment activities or day opportunities? Please state .....
.....

Short breaks from home

If the person lives in a family home, ask:
- Does the person have any regular arrangements for short breaks from home, or for respite care?
- Over the last 2 years, did the person have any regular arrangements for short breaks from home, or for respite care, which she / he no longer uses?

For everyone, ask:
- Does the person have any regular arrangements for breaks away from her / his usual home with family members or friends?
- Over the last 2 years, did the person have any regular arrangements for breaks away from her / his usual home with family members or friends, which she / he is no longer uses?

Then ask about:
- The type of provider.
- The duration the arrangement was / has been in place (to identify its duration if less than 2 year).
- The persons usual pattern of days or hours, to estimate number of days in last 2 years.

Then calculate the estimated number of days in the last 2 years, for each type.
Then ask about each of the listed options, to see if it prompts identification of any others breaks.

	Yes / No	Sector – NHS / SW / Private / Voluntary	Duration (if < 2 year)	Number of days in last 2 years
Breaks with other family member / friend				
Respite care unit				
***1:1 support**				
Other & specify				

* Do not double count support – list 1:1 support here which is in *addition* to the care already listed above under "accommodation and support package" and "employment" details.

Tick here if the person has no short breaks in any of the above categories [ ]

Are there any short breaks from home arrangements that you think your relative/the person you support needs that he/she does not have at present?
Yes. Please specify ..... [ ] No [ ] Don't know [ ]

If **yes**, are arrangements being made for this? Or, is there any reason why the person does not or cannot have these short breaks from home? Please state. .....
.....

Appendix II - T2 Research interview tools

Demographics and past 2 years needs questionnaire

October 2004 version *Project Number [ ][ ][ ][ ]IP*

AIDS AND ADAPTIONS

In the last two years, which of the following aids and adaptions have been purchased for the person? *For each aid or adaption purchased, ask*:

- Is/was this supplied through the NHS (*or* social work service)? If not, who is/was the supplier (eg charity or person pays/paid privately)

	Tick this box if the person received this in the last two yrs s	Who supplied it?	Tick this box if the person paid for it
Bath hoist			
Grab rails			
Electric wheelchair			
Moulded wheelchair			
Other wheelchair			
Special seating			
Walking frame			
Special footwear			
Brace/caliper			
Special helmet			
Hearing aid			
Other hearing device			
Glasses			
Dentures			
Other & specify			

Are there any aids or adaptions which you think your relative /the person you support needs that he/she does not have at present?
Yes. Please specify .....[ ] No [ ] Don't know [ ]

If **yes**, are arrangements being made for this? Or, is there any reason why the person does not or cannot have these aids or adaptions? Please state .....
.....

Appendix II - T2 Research interview tools

Demographics and past 2 years needs questionnaire

[redacted]

October 2004 version *Project Number [ ][ ][ ][ ]IP*

PROFESSIONAL SUPPORTS

In the last 2 yrs, which of the following professionals have been involved in the persons care? *Ask about:*
- Current involvement with each listed professional group.
- Previous involvement in the last 2 years, which has now ended.

For each professional the person has / had contact with, ask:
- Where does / did the person see her / him? At own home, or the GP practice, or at the hospital?
- Is / was this through the NHS (*or* social work service)? If not, who is / was the provider (eg charity, or person pays / paid privately)?
- How long does / did each appointment with the professional usually last?
- How long has (did) the person see her / him for (to identify duration if less than 2 years)?

Then calculate the estimated number of contacts during the last 2 year.
Then ask the following question:

Are there any professional supports which you think your relative/the person you support needs that he/she does not have at present?
Yes. Please specify .....[ ] No [ ] Don't know [ ]

If **yes**, are arrangements being made for this? Or, is there any reason why the person does not or cannot have these professional supports? Please state .....
.....

Appendix II - T2 Research interview tools

Demographics and past 2 years needs questionnaire

October 2004 version *Project Number [ ][ ][ ][ ] IIP*

	Yes / No	Domiciliary/ GP surgery/ Hospital	Sector – Public/ Private/Voluntary	Length of appointments	Frequency of appointments	Duration (if < 2 year)	Estimated contacts over last 2 years
Dietician							
S&LT							
Physiotherapist							
Occupational Therapist							
Psychologist							
Podiatrist							
Community LD Nurse							
Epilepsy Nurse							
Practice Nurse							
GP							
Other Doctor & specify ……							
Social worker							
Care manager -unspecified							
Advocate							
Dentist							
Optician							
Complementary therapist & specify……							
Other & specify ……							

October 2004 version *Project Number [ ][ ][ ][ ]IP*

UNPAID CARERS – ADDITIONAL INFORMATION

Only complete this section with unpaid (family) carers

Do you mind if I ask how old you are? [ ][ ]

Gender of carer [ ]
Male = 1; Female = 2

How would you describe your employment status? [ ]
Full time unpaid carer =1; Full time paid employment = 2; Part time paid employment = 3;
Unemployed = 4; Retired = 5; Voluntary work = 6; Student = 7; Housewife / husband = 9;
Other 8 & specify.....

How many hours of care / support do you provide in a typical week? [ ][ ][ ]

Do you have any other friends or relatives who regularly provide help (excluding those already listed in any of the categories above)? [ ]
Yes = 1; No = 2

If yes, in a typical week, how many hours of support do they provide? [ ][ ][ ]

Now administer the relative questionnaire

Updated 12 October 2004

Project number [ ][ ][ ][ ] IP

RELATIVE QUESTIONNAIRE

Today's date (date / month / year) [ ][ ]/[ ][ ]/[ ][ ]

FAMILY BACKGROUND – BIOLOGICAL AND ADOPTIVE

How many brothers and sisters does your relative have? [ ][ ]
(Include half siblings and step-siblings)

How old is your relative compared with her / his brothers and sisters? [ ]
Oldest = 1; Middle = 2; Youngest = 3; Only child = 4

Is her / his mother still alive? [ ]
Yes = 1; No = 2; Don't know = 8

If **NO,** how old was your relative when her / his mother died? [ ][ ]

Is her / his father still alive? [ ]
Yes = 1; No = 2; Don't know = 8

If **NO,** how old was your relative when her / his father died? [ ][ ]

Are your relative's parents married or living together as a couple? (Were your relative's parents married or living together as a couple before they passed away?) [ ]
Never together = 1; Together, then separated / divorced = 2; Married / living together = 3

If **SEPARATED / DIVORCED**, how old was your relative when they separated? [ ][ ]

When your relative was about 10 years old, what was the occupation of the head of household in their parents home? (select 1 parent only as the head of household)
Job title?.....
Name of employer?.....
.....
.....
.....

Currently, what is the occupation of the head of household in their parents home?
(select 1 parent only as the head of household, regardless of whether they currently live with parents)
Job title?.....
Name of employer?.....
.....
.....
.....

[redacted]

Project number [ ][ ][ ][ ]IP

How old was your relative's mother when she completed her education? Any qualifications? [ ]
Primary / secondary school, no qualifications = 1; Primary / secondary school, gained qualifications = 2;
Higher education = 3; University degree / equivalent professional qualification = 4

How old was your relative's father when he completed his education? Any qualifications? [ ]
Primary / secondary school, no qualifications = 1; Primary / secondary school, gained qualifications = 2;
Higher education = 3; University degree / equivalent professional qualification = 4

Has anyone in the family had any mental health problems? (If **YES**, ask who, biological or adoptive family, what sort of problem, and if they sought help from a doctor).....
.....
.....
.....
.....
.....

Yes, more than one relative = 1; Yes, parent = 2; Yes, sibling = 3; Yes, other biological = 4; [ ]
Yes, adoptive parent = 5; Yes, sibling through adoption = 6;
No = 9; No, but incomplete information = 10; Don't know = 8

(Omit if same as for participant) May I ask what your postcode is? (i.e. the participant's relative's post)
.....

ACCOMMODATION

Who did your relative live with / grow up with in childhood (0 – 16 years)? (Take a narrative) .....
.....
.....
.....
.....
.....
.....
.....

How many different homes was this in? [ ][ ]

Did your relative spend all her / his childhood with parent/s in the family home? [ ]
Yes = 1; No = 2; Don't know = 8

If **NO,** at what age did your relative leave the family home? (or at what ages was your relative outside the family home?).....

Project number [ ][ ][ ][ ] ***IP***

Did your relative spend any of her / his childhood living with other relatives or family friends? [ ]
Yes = 1; No = 2; Don't know = 8

If **YES,** for how long? (Code in months) [ ][ ][ ]

Did your relative spend any of her / his childhood living in a residential school? [ ]
Yes = 1; No = 2; Don't know = 8

If **YES,** for how long? (Code in months) [ ][ ][ ]

Did your relative spend any of her / his childhood living in foster care? [ ]
Yes = 1; No = 2; Don't know = 8

If **YES,** for how long? (Code in months) [ ][ ][ ]

Did your relative spend any of her / his childhood living in a children's home? [ ]
Yes = 1; No = 2; Don't know = 8

If **YES,** for how long? (Code in months) [ ][ ][ ]

Did your relative spend any of her / his childhood living in a hospital? [ ]
Yes = 1; No = 2; Don't know = 8

If **YES,** for how long? (Code in months) [ ][ ][ ]

(Omit if the person grew up in hospital care. Select the residence where the person lived for the longest amount of time in childhood)

When your relative was living at....., how many other children lived at that address? [ ][ ]
How many adults lived at that address? [ ][ ]
How many bedrooms were there at her / his home? [ ][ ]
Did she / he share a kitchen with another family? [ ][ ]
Did she he share a bathroom with another familly? [ ][ ]
Which area was this – do you remember the post code, or the address?.....
.....

For participants who had a significant "parental" figure in childhood other than a biological / adoptive parent, is this person still alive? [ ]
Yes = 1; No = 2; Don't know = 8

If **NO,** how old was your relative when this person died? [ ][ ]

If **YES,** what is / was the relationship of this significant person to your relative?.....
.....
.....

Project number [ ][ ][ ][ ] IP

EXPERIENCES

What type of school did your relative attend? [ ]
Mainstream, no support = 1; Mainstream with support for learning = 2; Special unit in mainstream school = 3; Started in mainstream, but moved to special school = 4; Special school = 5; Educated at home = 6; Not educated = 7; Don't know = 8, Other = 9 & specify.....

How old was your relative when she / he left school? [ ][ ]

How many years of schooling did your relative have in total? [ ][ ]

Did your relative have any long breaks during her / his education? [ ]
Yes = 1; No = 2; Don't know = 8

If **YES**, how long for? (In days) [ ][ ][ ]

How many admissions to hospital did your relative have due to illness in childhood? [ ]

If **1+**, how long was the longest admission? (In days) [ ][ ][ ]

Did your relative experience any significant deaths in childhood? [ ]
Yes = 1; No = 2; Don't know = 8

If **YES**, please describe.....
.....
.....
.....

Was your relative taken into social work care during childhood? (a looked after child)? [ ]
Yes = 1; No = 2; Don't know = 8

Did your relative experience any financial hardship during childhood? [ ]
Yes = 1; No = 2; Don't know = 8

If **YES**, please describe.....
.....
.....
.....

Did your relative experience any other traumatic or distressing events in childhood? [ ]
Yes = 1; No = 2; Don't know = 8

If **YES**, please describe.....
.....
.....
.....

Project number [ ][ ][ ][ ] IP

Some persons are disadvantaged by experiencing discrimination, negative attitudes, name-calling or bullying, harassment, neglect or abuse. [ ]
Has your relative been disadvantaged in this way in childhood or adult life?

Yes, childhood bullying = 1; Yes, adult bullying; = 3; Yes, childhood sexual abuse = 4;
Yes adult sexual abuse = 5; Yes, childhood physical abuse = 6; Yes, adult physical abuse = 7;
Yes, childhood emotional abuse = 9; Yes, adults emotional abuse = 10; Yes, childhood neglect = 11;
Yes, adult neglect = 12; Yes, childhood discrimination / negative attitudes = 13; Yes, adult discrimination / negative attitudes = 14; No = 2; Don't know = 8

If **YES**, please describe.....
.....
.....

Is there anything else you think is important from your relative's past which I haven't asked you about?
.....
.....
.....
.....

THANKYOU

When the study is completed, I will write to you to let you know the main findings, unless you prefer that I don't. [Tick the box if the person does not want a report.] [ ]

Appendix II - T2 Research interview tools

Glasgow UCEDD referral/case note review identification form

[ ] [ ] [ ] [ ]

Name: …….
Address : ……
Date of birth: …….

Date of MIHLD interview: [ ] [ ] / [ ] [ ] / [ ] [ ]
Date of PCLT interview: [ ] [ ] / [ ] [ ] / [ ] [ ]

1. Has the person scored positively on the **PAS-ADD**?
   [ ] Yes
   [ ] No (no further action unless in contact with psychiatry/psychology)

   Is the person currently in contact with psychiatry/psychology?
   [ ] Yes
   [ ] No (refer to UAP clinic for assessment) UAP ref [ ]

   Is the person on the UAP assessment list?
   [ ] Yes (refer to UAP clinic for assessment) UAP ref [ ]
   [ ] No (needs case note review)

2. Has the person scored positively on the **PDD**/are they known to have **autism**?
   [ ] Yes
   [ ] No (no further action)

   Is the person already in contact with psychiatry/psychology?
   [ ] Yes
   [ ] No (refer to UAP clinic for PDD assessment) UAP ref [ ]

   Is the person on the UAP assessment list?
   [ ] Yes (refer to UAP clinic) UAP ref [ ]
   [ ] No (needs case note review)

3. Has the person scored positively on the **Retrospective PAS-ADD**?
   [ ] Yes
   [ ] No (no further action)

   Was the person in contact with psychiatry/psychology at time of Retrospective PAS-ADD?
   [ ] Yes
   [ ] No (refer to UAP for retrospective assessment) UAP ref [ ]

   Is the person on the UAP assessment list?
   [ ] Yes (refer to UAP for retrospective assessment) UAP ref [ ]
   [ ] No (needs case note review)

4. **Epilepsy**? [ ]no [ ] yes ⟶ SAC / ES diagnosis [ ]

5. **Problem behaviour**? [ ]no [ ] yes ⟶ SAC / ES diagnosis [ ]

PSYCHIATRIC PRESENT STATE - LEARNING DISABILITIES

Dr. Sally-Ann Cooper

This is a purpose designed semi-structured interview, for the diagnosis of psychiatric disorders in adults with learning disabilities. It is used with subjects and/or informants. It is essential to evaluate 'change' when rating items, and to have received training in psychopathology. Specific examples should be sought to indicate change, before the rating can be made. •Rate trait items '7'.

•Rate unsure as '8'
•Rate not applicable as '9'

Participant number _ _ _

Date _ _/_ _/_ _

Interviewer _____

PPS-LD : DR. S-A. COOPER

I : ANXIETY DISORDERS

Worry/apprehension

Worries or feels apprehensive about everyday events and problems.

no=0; partial=1; yes=2; trait = 7 ___

Cfaverage

Compared to the average person, more likely to get anxious or nervous, less likely, or about the same?

less likely=0; the same=1; more likely=2. ___

Generalized anxiety (non-phobic)

Trouble with anxious or panicky feelings? Fearful? Racing heart beat, sweaty or shaking episodes? Difficulty breathing at times? When did this start? Describe, including frequency, duration and precipitants.

no=0; yes=2 (rate after completing the following checklist). ; trait = 7 ___

Which of the following occur whilst anxious?

- Difficulty breathing/ hyperventilation? ___
- Heart pounding/ palpitations? ___
- Dizzy/ unsteady? ___
- Chest pain? ___
- Dry mouth/ keeps getting drinks? ___
- Lump in throat/ repeated swallowing? ___
- Sweating/ hot or cold sweats? ___
- Flushing? ___
- Trembling/shaking? ___
- Churning stomach/ butterflies/ vomiting? ___
- * Marked startle response? ___

PPS-LD : DR. S-A. COOPER

* Increased restlessness? —
* Increased distractibility? —
* Increased irritability? —
* Initial insomnia, due to anxiety? —
Incontinent/ rush to toilet? —
Belief of dying? —
Belief of losing control? —

Panic

Meets the criteria for panic disorder?

no=0; yes=2. 4 panic attacks in 4 week period — - spontaneous and unpredictable - occurring not only in phobic situations - abrupt onset: maximum in a few minutes and lasts some minutes - includes fear + 4 of the symptoms listed above (except *)

Onsetanx

Age of onset of anxiety state? ——

trait=01.

Timeanx

Duration in months? ———

Agoraphobia must have fear + A.5 in at least 2 of these situations

Crowds? Going out? Public transport? Shops/ town centre/ Checkout? Theatre seat? Queues? Haircut? leaving home? Escape? Avoidance? Must have 2 autonomic symptoms from checklist above (except *)

no=0; yes=2. —

Animal phobia

(Animal phobia.) Must have 2 autonomic symptoms from checklist above (except *)

no=0; yes=2. —

PPS-LD : DR. S-A. COOPER

Social phobia eg. Eating in public; speaking in public; participation in a group or party; fear of being the focus of attention; fear they will behave in an embarrassing/humiliating way

(Social phobia.) Must have 2 autonomic symptoms from checklist (except *)

no=0; yes=2. Plus, one of:
- blushing or shaking
- fear of vomiting
or - urgency or fear of micturition or defaecation

Specific phobia

(Specific phobia.) Describe. Must have 2 autonomic symptoms from checklist (except *)

eg animals, birds, spiders, snakes, heights, thunder, enclosed spaces, blood, dentists, hospitals

no=0; yes=2.

Anxdep

Is the anxiety secondary to depression?

no=0; yes=2; unsure=8 (rate after completing section III).

PPS-LD : DR. S-A. COOPER

II : OBSESSIVE COMPULSIVE DISORDERS

Rituals

(Obsessional checking and repeating.) Does X have any personal routines or rituals. Things that s/he does over and over again. Like touching or counting things, or double checking things. Describe. How often? How long do the rituals take?

no=0; yes=2; with autistic spectrum disorder=4; trait=7. ___

Orderly

(Obsessional actions associated with excessive orderliness.) Does X tend to have a place for every thing and everything in its place? Does s/he always do things in a set way? Is s/he especially neat and tidy, too much so? Describe. How much time does this take?

no=0; yes=2; with autistic spectrum disorder=4; trait=7. ___

Cleanliness

(Obsessional cleanliness.) Does X spend time in repeated washing? Does s/he talk of germs/ dirt? Describe. How often and how long does this take?

no=0; yes=2; trait=7. ___

Thoughts

(Include all types of obsessional thoughts here.) Do you have thoughts that keep pushing into your mind? Do you try to keep them out? Do you think they are silly thoughts? Describe.

no=0; yes=2. ___

PPS-LD : DR. S-A. COOPER

Onsetobs

Age at onset of obsessional state?

Trait=01 __ __

Timeobs

Duration of obsessional state? (In months) ___ ___ ___

Obsdep

Is the obsessional state secondary to depression?

no=0; yes=2; unsure=8 (rate after completing section III). __

PPS-LD : DR. S-A. COOPER

III : MOOD DISORDERS AND DEMENTIA

Low Mood/ Misery

How is mood? Happy or sad? Has this changed? As cheerful as usual? ?Miserable

as usual=0; low=2; trait misery=7. ___

Labile mood

Is mood very changeable? Changes between happy and miserable within minutes or hours? Describe.

as usual=0; yes=2; trait=7. ___

Irritable

More irritable or interfering than usual? Do you get worked up over little things? Easily set on edge? Did you used to be like this?

no=0; yes=2; trait=7. ___

Withdrawn

How well does X mix with people? More socially withdrawn than usual?

no=0; yes=2; trait=7. ___

Anhedonia

What does X enjoy doing? Are there any things that can enjoy/ cooperate with? Ever interested in anything? Is there any change in the interest taken in things?

no=0; reduced interest=2; trait=7. ___

PPS-LD : DR. S-A. COOPER

Talkloss

(Reduced quantity of speech.) Has there been any change in speech? Describe.

no=0; reduced=2.

Talkgain

(Increased quantity of speech.)

no=0; overtalkative=2; trait=7.

Tears

More tearful than usual? Cry easily?

no=0; now and then=1; yes=2; trait=7.

Selfcare

Less able to care for himself now? Spending less time on his self care? Require more prompting now? Needing help with any tasks which he used to be able to do for self? Describe.

no=0; yes, a bit=1; yes=2.

Energy

Have energy levels changed? Doing as much as before? Moving around as much as usual?

no =0; less energy=2; ~~trait~~ overactive=7.

Energy gain

(Rate increased energy levels.) Charging around, rushing around. Full of excessive energy?

no =0; more energy/overactive=2; trait=7.

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

Cognitiveloss

Deteriorating in any way? Getting muddled and confused? Forgetful? Losing things more often? Different with increasing age/ Describe. (Cognitive decline).

no=0; yes=2. ___

Nameloss

Forgotten the names of people used to know?

no=0; yes=2. ___

Placeloss

Got lost in places where used to find way around, e.g. home, local streets?

no=0; yes=2. ___

Understanding

Able to follow instructions as well as in the past? Understands/comprehends surrounding events/ conversations as well as before? Take examples.

no change=0; deterioration=2. ___

Expansive

Does X claim to be especially good at something or everything? To have any special abilities? To have alot of money? To be very important? Has this changed? Probe for further manic symptoms in next section, if positive.

no=0; yes=2; trait=7. ___

CUT OFF FROM MOOD/DEMENTIA SCREEN IF NEGATIVE. COMPLETE ADDITIONAL SCHEDULES IF ANY ITEMS ARE POSITIVE.

PPS-LD

PPS-LD : DR. S-A. COOPER

Memory

Problem with memory? Is this a change? Forgotten things that would usually remember? e.g. birthday parties and Christmas?

no=0; yes=2. —

Recognition
No longer able to recognise previously familiar people

Timeloss no = 0, yes = 2 —

Mix up day and night? Up in the night, insistent it's morning? Used to do this?

no, or always did=0; yes, change=2. —

Literary skills loss

Read and write? Used to be able to?

no change=0; deterioration=2. —

Financial skills loss

Handle money/ change? Used to be able to?

no change=0; deterioration=2. —

Dysphasia

Get words mixed up more than used to? e.g. can't remember the names of things even though used to know?

no=0; yes, change=2. —

Personality

Personality changed? Same person that always used to be? Apathetic? Loss of self direction? Coarsening of existing personality traits? Describe.
or watering of social behaviour

no=0; yes=2. —

Agedementia

Age at which changes began? — —

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

Onsetdementia

Duration in months? ___

Describe changes, including clinical pattern (gradual/sudden onset, progression). Fits, faints, blackouts, strokes, behaviours?

Sleep

Has there been any change in sleep pattern? Describe Xs sleep patetern.

no=0; initial insomnia>1hour=1; mid-insomnia>1 hour=2; early morning wakening>1 hour=3; increased sleep, sleeping during the day=4; reversed sleep pattern =5; reduced need for sleep=6; trait sleep problem=7 .

A. __
B. __
C. __

Appetite

(Loss of appetite.) Any change in appetite?

no=0; reduced=2; trait poor appetite=7. __

Appetite gain

(Increased appetite)

no=0; increased=2. __

Weight loss

Any weight change?

no change=0; reduced=2. __

Quantify weight loss. in pounds. ___

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

Weight gain

no change=0; weight gain=2. ___

Quantify weight gain, in pounds. ___ ___ ___

DMV

At which time of the day better or worse in himself?

no DMV=0; worse in evening=1; worse in morning >1 hour=2; trait=7. ___

Concentration

How well does X concentrate? Any change in concentration/ ability to pay attention to things? More distractible? More impulsive?

no=0; worse=2; trait=7. ___

Verbals

Shout, swear or become verbal aggressive? Happening more often? Quantify.

no=0; more often=2; trait=7. ___

Verbal loss

(Reduced verbal aggression, compared to usual for X.)

no=0; less often=2. ___

Physicals

Physical aggression to other people/ violent at times? Hit or kick out? Any change in how often this occurs, or how severe? Quantify.

no=0; more often=2; trait=7. ___

Physical loss

(Reduced physical aggression to other people, compared to usual for X.)

no=0; less often=2. ___

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

Damages

(Physical aggression to property.) Does X ever damage belongings or property? Any change in frequency or severity? Describe.

no=0; more often=2; trait=7. —

Damage loss

(Reduction in frequency or severity of physical aggression to property.)

no=0; less often=2. —

Reassurance

Seeking more reassurance than usual? Following carer around? Checking things out with carer more often? Describe.

no=0; yes=2; trait=7. —

Selfharm

Tried to harm himself in anyway? Describe.

no=0; yes=2; trait=7. —

Somatic

More hypochondriacal than usual? Complaints of alot of aches and pains?

no=0; yes=2; trait=7. —

Libido

Any change in sexual behaviour? Describe.

no=0; inappropriate or increased=2; trait sexual problem=7. —

Sex loss

(Loss of interest in sex compared to usual.)

no=0; reduced=2. —

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

Other

Behaviours changed in any other way? Describe. Exaccerbations of maladaptive behaviours?. Reductions in behaviours?

no=0; yes=2. __

IF MANIC SYMPTOMS ON INITIAL SCREEN

Reckless

Overspending? Reckless? Irresponsible behaviour? Describe.

no=0; yes=2; trait=7. __

Indiscretion

Pathologically increased sociability, overfamiliar? Loss of social inhibitions? Describe.

no=0; yes=2; trait=7. __

IF SPEECH IS IN SENTENCES.

Guilt

Guilty about things? Expressing feelings of blame or responsible about things?

no=0; yes=2; trait=7. __

Morbid

Preoccupied with death? Talk about dying, being killed, or other people dying? Expects something terrible to happen? Expecting harm or destruction to occur?

no=0; yes=2; trait=7. __

PPS-LD : DR. S-A. COOPER

Esteem

Bad or wrong or inferior in some way? Describe. (Self esteem).

no=0; yes=2; trait=7. __

Hopeless

Says that he wants to die? No future? Hopeless?

no=0; yes=2; trait=7. __

Onset mood

Age at onset of this episode? __ __

Timemood

Duration in months of this episode? __ __ __

Past history

Any previous similar episodes?

no=0; unipolar depressed=2; bipolar=3; unipolar manic=4. __

Treatment response

If X has a past history of depression, did it respond to antidepressant drugs?

no, or not tried = 0; yes = 2 __

PPS-LD : DR. S-A. COOPER

IV : PSYCHOSIS ITEMS (IF SPEECH IS IN SENTENCES)

Complained of any strange or unusual experiences recently? Anything that was difficult to explain?

no=0; unsure=1; yes=2. ___

Complained of being picked on or got at? Complained of being followed or spied on? Complained of strangers in the house, or thefts? Suspicious of others?

no=0; unsure=1; yes=2. ___

Any new odd ideas or beliefs?

no=0; unsure=1; yes=2. ___

Conversations with imaginary people? Hear noises or voices when there is noone around to account for them?

no=0; unsure=1; yes=2. ___

Stopped watching the television? Why? TV is talking about him or people he knows? Is the TV hinting or giving messages? Voices coming from the TV, which other people don't hear?

no=0; unsure=1; yes=2. ___

People are talking about him behind his back? Describe.

no=0; unsure=1; yes=2. ___

People are talking about what he does? Or about what he thinks? Describe.

no=0; unsure=1; yes=2. ___

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

See things which aren't really there? See ghosts? Describe.

no=0; unsure=1; yes=2. —

Complain of his body being interfered with? Describe.

no=0; unsure=1; yes=2. —

Believe in mind-reading or telepathy? Think that people can mind read ?

no=0; unsure=1; yes=2. —

Complain of mind or thoughts being interfered with? Describe.

no=0; unsure=2; yes=2. —

Delusions

no=0; yes=2. —

Auditory hallucinations

no=0; yes , less than daily = 2; yes, daily = 3 —

Visual hallucinations

no=0; yes less than daily = 2; yes, daily = 3 —

Schneiderian first rank symptoms

list how many. —

Impossible (bizarre; fantastic) delusions

no=0; yes=2. —

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

Congruity

Mood congruent or not?

mood congruent=1; mood incongruent=2. —

Onsetschiz

Age at onset of this episode? — —

Timeschiz

Duration of this episode in months? — — —

Past history

Any previous psychotic episodes?

no=0; yes=2. —

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

V : POSITIVE MENTAL STATE ITEMS

Retardation of facial expression, gesticulation, bodily movement

no=0; yes=2. —

Agitation

no=0; yes=2. —

Distractible/ impaired concentration

no=0; yes=2. —

Overactive/ restless

no=0; yes=2. —

Catatonia

no=0; yes=2. —

"Negative" symptoms of schizophrenia. Describe.

no=0; yes=2. —

Hostile/ suspicious

no=0; yes=2. —

Motor tics

no=0; simple=1; complex=2; multiple=3. —

Vocal tics

no=0; simple=1; complex=2; multiple=3. —

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

Pressure of speech

no=0; yes=2. —

Flight of ideas

no=0; yes=2. —

Excessive laughter or singing

no=0; yes=2. —

Mute

no=0; yes=2. —

Slow/ retardation of thoughts

no=0; yes=2. —

Formal thought disorder

no=0; yes=2. —

Affect

euthymic=0; irritable=2; depressed=3; manic=4. —

Flat affect

no=0; yes=2. —

Incongruous affect

no=0; yes=2. —

Insight

yes=0; no insight=2; unassessable due to level of LD=8 —

Appendix III - Glasgow UCEDD psychiatric assessment tools

PPS-LD

PPS-LD : DR. S-A. COOPER

VI : MEDICAL ITEMS

Vision?

good=1; good with glasses=2; poor with glasses=3; poor=4; blind=5. ___

Hearing?

good=1; good with aid=2; poor with aid=3; poor=4; deaf=5. ___

Mobility?

full mobility=1; independent but poor=2; uses stick or frame=3; needs wheelchair when outside=4; needs wheelchair inside=5; cannot weightbear'immobile=6. ___

Hand use?

full use=1; unilateral=2; limited=3; no use=4. ___

Epilepsy?

no=0; yes, well controlled (<1 seizure/month)=1; yes, poor control=2. ___

Incontinence?

-urine. continent=0; occasional accidents=1; incontinent at night=2; incontinent=3. ___
-bowels. continent=0; occasional accidents=1; incontinent at night=2; incontinent=3. ___

INTERVIEW WAS CONDUCTED WITH:

subject=1; informant=2; both=3. ___

COOPERATIVE WITH INTERVIEW?

yes=0; partial=1; no=2. ___

project number [ ] [ ] [ ][ ]

Research Clinic - PROBLEM BEHAVIOUR CHECKLIST

Name:……

d.o.b:……. Date:…….

DC-LD general diagnostic criteria for problem behaviours

A The problem behaviour is of significant frequency, severity or chronicity to require clinical assessment and special interventions/support

B The problem behaviour must not be a direct consequence of other psychiatric disorders (e.g. pervasive developmental disorders non-affective psychotic disorders, depressive episode, generalised anxiety, obsessive compulsive disorder, personality disorders), drugs or physical disorders.

C One of the following must be present:
1. The problem results in a significant negative impact on the person's quality of life or the quality of life of others. This may be owing to restriction of his lifestyle or social opportunities, independence, community integration, service access or choices, or adaptive functioning
2. The problem behaviour presents significant risks to the health and/or safety of the person and/or others.

D The problem behaviour is persistent and pervasive. It is present across a wide range of personal and social situations, although may be more severe in certain identified settings.

Fill in the table below, ticking each box that applies.

	Behaviour present?	**Criteria A**	**Criteria B**	**Criteria C**	**Criteria D**
Verbally aggressive behaviour	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Physically aggressive behaviour	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Destructiveness to property	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Self-injurious behaviour	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Sexually inappropriate behaviour	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Oppositional behaviour	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Excessively demanding behaviour	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Wandering behaviour	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Faecal smearing	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Pica	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**
Other & specify..……. ……	**[ ]**	**[ ]**	**[ ]**	**[ ]**	**[ ]**

Record frequency and severity of problem behaviour/s.

……
……
……
……

project number [ ] [ ] [ ][ ]

Research Clinic - ADHD CHECKLIST

Name:……

d.o.b:……. Date:…….

Exclude manic episode/dementia/delirium/ hyperthyroidism/drugs as cause of hyperactivity **Only rate items 1,2,3,4 or 5 if they are to an extent that is not accounted for by severity of learning disabilities**		Has not happened in past 12 months	Has been present for most of the time in the past 12 months
1	Has very poor attention and concentration – fails to sustain attention in tasks or play activities		
2	Is easily distracted		
3	Activities tend to be very flitting and fleeting		
4	Is unable to concentrate on a given task for any length of time – will often interrupt tasks		
5	Often acts impulsively with undue care to the consequences for themselves or other people		
6	Often interrupts or intrudes on others		
7	Talks excessively or is generally very noisy		
8	Is very impatient – has difficulty taking waiting in line or awaiting turn		
8	Is very restless, can't keep still - will squirm or fidget, especially when seated		
9	Often runs about – has boundless energy, is always on the go		
10	Reports feeling restless all the time		

Are the symptoms pervasive across a wide range of settings?
Yes [ ] No [ ] Unknown [ ]

Do the symptoms cause clinically significant distress or impairment in social or occupational functioning?
Yes [ ] No [ ] Unknown [ ]

How long have the symptoms been present (in years)? …….. Unknown [ ]

Have the symptoms been present since before 7 years of age?
Yes [ ] No [ ] Unknown [ ]

Project Number [ ] [ ] [ ] [ ]

Research Clinic - PERVASIVE DEVELOPMENTAL DISORDER CHECKLIST

Name:…….

d.o.b.:…….. **date:…….**

		Has not happened in past 12 months	Has been present for most of the time in the past 12 months
1	Rarely uses eye-to-eye gaze, smiling or facial expression when interacting with others		
2	Rarely greets others spontaneously		
3	Rarely looks for or offers comfort or affection at times of distress		
4	Lacks feeling for others or shows abnormal response to other's emotions		
5	Does not share objects or food with others		
6	Does not share enjoyment or interests with others		
7	Does not respond in an appropriate way in social emotional situations		
8	Compared to peers the person has difficulty in developing friendships and social relationships		
9	Person has no verbal communication skills		
10	Delay in or total lack of, the development of spoken language(not accompanied by an attempt to compensate through alternative modes of communication such a gesture or mime)		
11	Repeats the same phrase, word or sound over and over, out of context)		
12	Has difficulty reciprocating in a conversation with others (according to verbal ability		
13	Misuse of subject pronouns e.g. uses 'you', 'he' or 'she', when 'I' is meant		
14	Has attachments to unusual objects		
15	Has hobbies or interests that seem odd to others (abnormal in content or focus, or intensity and circumscribed nature)		
16	Has preoccupation with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration they generate) e.g. touches, smells or tastes objects inappropriately or with an unusual intensity		
17	Repetitive behaviour such as hand or finger flapping or twisting, body rocking or spinning		
18	Has routines or rituals performed in a particular sequence		
19	Becomes distressed over changes in routine or surroundings		
20	Lack of spontaneous make believe or social imitative play appropriate to developmental level		

Have the above features been present since before 3 years of age? Yes [ ] No [ ] Unknown [ ]

Appendix IV - Case note review tool

Mental Ill Health in Learning Disabilities **Case number[ ] [ ] [ ] [ ]**
Form 7 – Case note review Completed by ……..

Forename……..
Surname……D
ate of birth……Sex……..
Case note number……..
Psychiatrist/Psychologist……....

Today's date= [ ] [ ] / [ ] [ ] / [ ] [ ]
Date of health check= [ ] [ ] / [ ] [ ] / [ ] [ ]
Date of MIHLD interview= [ ] [ ] / [ ] [ ] / [ ] [ ]

1. Has the aetiology of persons LD been newly identified since the health check? [ ]
no=1, yes=2, unknown=3

2. Aetiology of LD = [ ]

Unknown=1, Down's=2, TS=3, complications of pregnancy=4, birth injury=5, meningitis/encephalitis=6, Fragile X=7, Head injury=8, Brain tumour=9, Hydrocephalus=10, Microcephaly=11, PKU=12, Prader Willi=13, Smith Magenis=14, Congenital Rubella=15, Rett=16, unclear if ever assessed=88, other=17 & specify……

3. Level of LD (clinicians opinion) = [ ]
mild=1, moderate=2, severe=3, profound=4, unknown=8, no LD=9
Vineland [ ] date=……result=……..
IQ test [ ] date=……result=……

4. Reason for referral/case note review= A. [ ] B. [ ] C. [ ]
Positive score on PAS-ADD checklist=1, Positive score on PDD (and not previously assessed)=2, Diagnostic Clarification required= 3, Positive score on retrospective PAS-ADD=4, Known problem behaviour has become worse=5, Onset of new problem behaviour/change in behaviour=6, Missed referral at health check=7, Already open to psychiatry/psychology=8, Other reason=9 & specify ……

5. Type of referral= [ ]
(already open to psychiatry/psychology=0, routine=1, soon=2, urgent=3, unknown=4,)

6. Current contact with psychiatric services= [ ]
No=1, Yes=2
Name of consultant……

7. Previous contact with psychiatric services= [ ]
No=1, Yes=2
date of last contact =[ ] [ ] / [ ] [ ] / [ ] [ ]
months between last contact and MIHLD = [ ]
reason for discharge = [ ]
treatment complete=1, DNA=2, lost to follow up=3, moved=4, unknown=5, other=6 & specify…….. ……

8. appt. date pre-MIHLD = [ ] [ ] / [ ] [ ] / [ ] [ ] weeks [ ]
appt. date post- MIHLD = [ ] [ ] / [ ] [ ] / [ ] [ ] weeks [ ]
Seen by= [ ] [ ]
Consultant psychiatrist=1, SPR=2, Staff grade=3, SHO=4, unknown=8, other=9 & specify……

Case number[ ] [ ] [ ] [ ]

9. Medication at time of MIHLD =

……
……
……
……
……

hypnotic= [ ] [ ] (benzodiazepine=1,zolpidem/zopiclone=2, antihistamine=3)
anxiolytic= [ ] [ ] [ ] (benzodiazepine=1, beta blocker=2, antidepressant=3,)
antidepressant=[ ] [ ] [ ] (tricyclic & related=1, MAOI =2, SSRI=3, Others=4)
mood stabiliser=[ ] [ ] [ ] (lithium=1, carbamazepine=2, valproate=3)
oral antipsychotic=[ ] [ ] [ ] (typical=1, atypical=2, clozapine=3)
depot antipsychotic=[ ] (depixol=1, haldol=2, fluphenazine=3, clopixol=4 other=5)
anticholinergic=[ ] (any anticholinergic=1)
stimulant= [ ] (methylphenidate=1, dexamphetamine=2, other=3)

Total number of different psychotropic drugs (excluding anticholinergics)= [ ]

Chlorpromazine equivalent for antipsychotics= [ ]mg/day

On antipsychotics but CPZ equivalent not available=NA
Number of anticonvulsant drugs = [ ]

10. Psychiatric diagnoses at time of health check=

Clinician	DC-LD	DCR	DSM IV

Schizophrenia=1 (complete remission=40), Schizoaffective=2 (complete remission=41), Delusional disorder=3, Other psychotic disorder=4, Depressive disorder=5, Bipolar disorder=6 (not in episode=44), Generalized anxiety disorder=7, Specific phobia =8, agoraphobia= 51, Obsessive-compulsive disorder=9, Panic disorder=10, Personality disorder=11, Dementia=12, Self-injury=13, Substance misuse=14, Eating disorder=15, Problem behaviour=16, Pervasive Developmental Disorder=17, Psychosexual disorder=18, other anxiety disorder=19, PTSD=20, adjustment disorder=21, delirium=22, pica=24, dysthymia=25, cyclothymia=28, ADHD=29, psychogenic polydipsia=30, premenstrual dysphoria=32, manic episode= 33, mixed anxiety and depression=34, organic personality disorder=38, sleep disorder=45, pseudoseizures=46, organic hallucinosis=47, atypical autism= 39, other & specify ……

Appendix IV - Case note review tool

Case number[ ] [ ] [ ] [ ]

11. Psychiatric diagnoses at time of MIHLD=

Clinician	DC-LD	DCR	DSM IV

12. Episodes of mental ill-health occurring within 24m prior to MIHLD but not present at time of MIHLD=

Clinician	DC-LD	DCR	DSM IV

13. Clinical global impression: severity of mental illness at MIHLD= [ ]
Normal, not at all ill=1, borderline ill=2, mildly ill=3, moderately ill=4, markedly ill=5, severely ill=6, among the most extremely ill patients=7, unknown=8

14. **Clinical Global Impression: improvement in mental illness at MIHLD (compared to status at health check) = [ ]**
Very much improved=1, much improved=2, improved=3, no change=4, worse=5, much worse=6, very much worse=7, death=8, unknown=9

If no change or worse, is there a reason for this? e.g. sub-therapeutic dose of medication, lost to follow up, non-compliance by patient or carer, still waiting to have treatment, give details
……
……
……
……

Appendix IV - Case note review tool

Case number [ ] [ ] [ ] [ ]

Details of Episodes of Mental Ill-Health in 24m pre MIHLD
Date of MIHLD interview= [ ] [ ] / [ ] [ ] / [ ] [ ]
Date of Health Check= [ ] [ ] / [ ] [ ] / [ ] [ ]

Episode Number = [ ]
Episode date = from [ ] [ ] / [ ] [ ] / [ ] [ ] to [ ] [ ] / [ ] [ ] / [ ] [ ]

1. Episode diagnosis

Clinician	**Coding**
DC-LD	
DCR	
DSM IV	

2. Assessed by whom? [ ] [ ]
Consultant psychiatrist=1, SPR=2, Staff grade=3, SHO=4, unknown=8, other=9 & specify……..
Was it a UAP assessment? [ ]
No=0 Yes=1
Was the assessment retrospective? [ ]
No=0 Yes=1
Date of assessment [ ] [ ] / [ ] [ ] / [ ] [ ]

3. Medication given for this episode
……..
……..
……..
……..
……....

Case number[ ] [ ] [ ] [ ]

hypnotic= [ ] [ ] (benzodiazepine=1,zolpidem/zopiclone=2, antihistamine=3)
anxiolytic= [ ] [ ] [ ] (benzodiazepine=1, beta blocker=2, antidepressant=3,)
antidepressant=[ ] [ ] [ ] (tricyclic & related=1, MAOI =2, SSRI=3, Others=4)
mood stabiliser=[ ] [ ] [ ] (lithium=1, carbamazepine=2, valproate=3)
oral antipsychotic=[ ] [ ] [ ] (typical=1, atypical=2, clozapine=3)
depot antipsychotic=[ ] (depixol=1, haldol=2, fluphenazine=3, clopixol=4 other=5)
anticholinergic=[ ] (any anticholinergic=1)
stimulant= [ ] (methylphenidate=1, dexamphetamine=2, other=3)

total number of different psychotropic drugs (excluding anticholinergics)= [ ]

Chlorpromazine equivalent for antipsychotics= [ ]mg/day

On antipsychotics but CPZ equivalent not available=NA

Other treatments given for this episode

……
……
……
……
……

4. Number of days in psychiatric hospital for this episode [ ]

5. Number of days in other hospital for this episode [ ]

6. Use of Mental Health Act for this episode

Section 24[ ] Section 25[ ] Section 26 [ ] Section 18[ ]
Guardianship [ ] Other……**[ ]**

7. Identified aetiological factors for this episode

biological……
……
social……
……
psychological……
……
developmental……
……
other……
……

Appendix IV - Case note review tool: symptom checklist

Symptom Checklist – Episode Number [ ] Case number [ ] [ ] [ ] [ ]

	Yes	Due to add	Trait	In previous
Generalised anxiety				
Panic disorder				
Agoraphobia				
Animal phobia				
Social phobia				
Rituals				
Orderly				
Cleanliness				
Thoughts				
Low Mood				
Labile mood				
Irritable				
Withdrawn				
Anhedonia				
Talk loss				
Talk gain				
Tearful				
Self care loss				
Energy loss				
Energy gain				
Cognitive loss				
Name loss				
Place loss				
Understanding				
Expansive				
Memory				
Recognition				
Time loss				
Literary skills loss				
Financial skills loss				
Dysphasia				
Personality				
Personality change				
Sleep problem				
Appetite loss				
Appetite gain				
Weight gain				
Weight loss				
Weight gain				
Diurnal mood variation				
Concentration				
Verbal aggression				
Verbal loss				
Physical aggression				
Physical loss				
Damage to property				
Damage to property				
Damage loss				
Reassurance				
Self-harm				

	Yes	Due to add	Trait	In previous
Somatic				
Increased Libido				
Reduced libido				
Other behaviour change				
Reckless				
Indiscretion				
Guilt				
Morbid				
Esteem				
Hopeless				
Strange experiences				
Paranoid ideas				
New odd ideas				
Talking to self				
TV talking				
Talking about them				
Talking what they do/think				
See things				
Body interfered with				
Telepathy				
Thoughts interfered				
Delusions				
Auditory hallucinations				
Visual hallucinations				
First rank symptoms				
Impossible delusions				
Congruity				
Psychomotor retardation				
Agitation				
Distractible				
Overactive				
Catatonia				
Negative				
Hostile/suspicious				
Motor tics				
Vocal tics				
Pressure of speech				
Flight of ideas				
Excessive laughter				
Mute				
Retardation of thoughts				
Thought disorder				
Depressed Affect				
Manic affect				
Irritable affect				
Euthymic Affect				
Flat affect				
Incongruous affect				
Insight				

Duration of symptoms = ……
Previous episode = ……

Appendix IV - Case note review tool: symptom checklist

Case number [ ] [ ] [ ] [ ]

Anxiety Disorders Symptom Checklist – Episode Number [ ]

	No	Yes
Autonomic Symptoms		
Hyperventilation		
Palpitations		
Dizzy		
Chest pain		
Dry mouth		
Lump in throat		
Sweating		
Flushing		
Trembling/shaking		
Churning stomach		
*Marked startle response		
*Increased restlessness		
*Increased distractibility		
*Increased irritability		
*Initial insomnia		
Incontinent/rush to toilet		
Belief of dying		
Belief of losing control		
Panic Attacks		
Number in 4 week period		
Phobic situation only		
Unpredictable		
Agoraphobia		
Crowds		
Going out		
Public transport		
Shops/town centre		
Checkout		
Theatre seat		
Queues		
Haircut		
Leaving Home		
Escape		
Avoidance		

[ ]

	No	Yes
Social Phobia		
Blushing/shaking		
Fear of vomiting		
Urgency or fear of micturition		
Eating		
Speaking		
Group participation		
Focus of attention		
Embarrassing		
Phobia		
Aware that fear is excessive		
Snakes		
Birds		
Spiders		
Animals		
Thunder		
Heights		
Enclosed spaces		
Blood		
Dentist		
Hospital		
Other		