Prospective study of the mental ill-health of adults with intellectual disabilities: outcomes and predictive determinants

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ABSTRACT

Background: The prevalence of mental ill-health and problem behaviour within the intellectually disabled population is reported to range from 30 to 50%. However, the longer term outcomes of mental ill-health and problem behaviour, such as persistence, new onset, remission and resilience, are unknown. Accordingly, the factors predictive of such outcomes are also unknown.

Aims: To determine the long term outcomes of mental ill-health and problem behaviour, and the factors predictive of and associated with such outcomes, over a 10 year time-period in a cohort of adults with mild to profound intellectual disabilities.

Method: A population-based cohort of adults with intellectual disabilities (n=100) was investigated at three time points over a 10 year period. Data were collected using a range of measures. Descriptive statistics were derived and regression analyses performed to determine factors predictive of outcomes.

Results: The rate of psychopathology was found to have increased in the cohort over the 10 year period. Factors predictive of this increase were experiencing an angry interaction and trusting to share a secret with only one person, or anyone. The majority of the cohort experienced episodic mental ill-health, with relapse being predicted by being female and experiencing life events. New onset of mental ill-health was predicted by experiencing life events, and resilience was predicted by not experiencing life events and having urinary continence. Problem behaviours were persistent in 50%, with 50% remitting. New onset of problem behaviours was predicted by not experiencing life events, and resilience was predicted by having mild intellectual disabilities, not experiencing an angry interaction and having more than one close friend. Small but significant negative correlations were found between psychopathology and participation in social, leisure, and peer activities. Findings should be interpreted with caution due to the small sample size.

Conclusions: The present study is the only existing longitudinal investigation following an adult cohort with mild to profound intellectual disabilities, at several time points over a 10 year period. Therefore, future research is needed to confirm findings. Given the increase in psychopathology, more effective monitoring, treatment and intervention is needed.

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AUTHOR'S DECLARATION

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

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LIST OF ABBREVIATIONS

ABC	Aberrant Behaviour Checklist
ADAMS	Anxiety, Depression and Mood Scale
ADD	Assessment of Dual Diagnosis
ADHD	Attention Deficit Hyperactivity Disorder
AFS	The Architectural Features Scale
AGG	Aggressive Problem Behaviour
AM	Amanda Muir (research student)
ASD	Autistic Spectrum Disorder
BDS2	Behaviour Disturbance Scale 2
BILD	British Institute of Learning Disabilities
BLESID-SR	Bangor Life Events Schedule for Intellectual Disabilities: Self-report
BSI	Brief Symptom Inventory
CBC	Challenging Behaviour Checklist
CI	Confidence Interval
DAS	Disability Assessment Schedule
DASH-II	Diagnostic Assessment for the Severely Handicapped – Second Edition
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
GCPLA	Guernsey Community Participation and Leisure Assessment
GHMI	The Group Home Management Interview
HARC	Hester Adrian Research Centre
HoNOS	Health of the Nation Outcome Scale

HPA	Hypothalamic-pituitary-adrenal
ICD-9	International Classification of Diseases, 9th edition
ICD-10	International Classification of Diseases, 10th edition
ICD-10-DCR	International Classification of Diseases, 10th edition, Diagnostic Criteria for Research
ICD-11	International Classification of Diseases, 11th edition
ICI	Index of Community Involvement
ID	Intellectual Disabilities
IDR	Intellectual Disability Register
IMSR	Interview Measure of Social Relationships
IPDL	Index of Participation in Daily Living
IQ	Intelligence Quotient
LASS	Leisure activity skills scales
LEC	Life Experiences Checklist
LES	Life Experiences Survey
M	Mean
Mdn	Median
MHIS	Mental Health Information System
MIH	Mental Ill-Health
MMAS	Manifest Abnormalities Scale of the Clinical Interview Schedule
MOAS	Modified Overt Aggression Scale
n	Number
NHS	National Health Service
NOK	Next of Kin
OCD	Obsessive Compulsive Disorder
PAS-ADD	The Psychiatric Assessment Schedule for use with Adults with Developmental Disabilities
PB	Problem Behaviour

PCLT	Primary Care Liaison Team
PDD	Pervasive Developmental Disorder
PPS-LD	Present Psychiatric State – Learning Disabilities
PRQ-85	Personal Resource Questionnaire
QOLQ	Quality Of Life Questionnaire
ROC	Receiver Operating Characteristic
RSSQ	Residential Services Setting Questionnaire
SAC	Professor Sally-Ann Cooper
SCAN	Schedules for Clinical Assessment in Neuropsychiatry
SD	Standard Deviation
SE	Standard Error
SIB	Self-Injurious Behaviour
SIB-R	Scales of Independent Behaviour – Revised
SNM	Social Network Map
T1	Time 1
T2	Time 2
T3	Time 3
VABS	Vineland Adaptive Behaviour Scale
WHO	World Health Organisation

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CHAPTER 1: INTRODUCTION

1.1 Defining intellectual disability

In their most recent version of the International Classification of Diseases, 10th Edition (ICD-10), the World Health Organization (WHO) use the term 'Mental Retardation' to define "*a condition of arrested or incomplete development of the mind, which is especially characterized by skills manifested during the development period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities*" (World Health Organization 1992). This term is equivalent to the term 'ID' as subsequently used in this thesis. The ICD-10 states that all available information should be used when assessing intellectual level, including clinical findings, performance on psychometric tests and adaptive behaviour (respective of cultural backgrounds). It notes that due to the impact of associated mental or physical disorders, a global (and not a specific) assessment of ability should be used when assigning diagnostic category. The ICD-10 defines the following diagnostic categories, indicated by intelligence quotient (IQ):

- **Mild mental retardation -** indicated by an IQ range of 50 to 69
- **Moderate mental retardation** - indicated by an IQ range of 35 to 49
- **Severe mental retardation** - indicated by an IQ range of 20 to 34
- **Profound mental retardation** - indicated by an IQ range of <20
- **Other mental retardation** –"used only when assessment of the degree of intellectual retardation by means of the usual procedures is rendered particularly difficult or impossible by associated sensory or physical impairments, as in blind, deaf-mute, and severely behaviourally disturbed or physically disabled people"
- **Unspecified mental retardation** –"there is evidence of mental retardation, but insufficient information is available to assign the patient to one of the above categories".

According to the ICD-10, the above ranges should be identified through the use of standardized IQ tests; however, the ranges are given as a guide and should not be applied rigidly (due to issues with cross-cultural validity). For this purpose, the ICD-10 states that "*Within most European and North American cultures, the Vineland Social Maturity Scale is recommended for use, if it is judged to be appropriate. Modified versions or equivalent scales should be developed for use in other cultures*". The terms "retardation" and "retarded" which are used in the ICD-10, are under consideration for change to the term "Intellectual Developmental Disorders" in the International Classification of Diseases, 11th Edition (ICD-11) (World Health Organization 2013a), due to be published by the WHO in 2015. The WHO currently uses the term 'intellectual disability' in their publications and fact sheets.

1.2 The prevalence of intellectual disability

An estimated overall general prevalence of ID is reported to be approximately 1%, with prevalence of severe ID estimated to be approximately 6 per 1000 people (American Psychiatric Association 2013). Similarly, the WHO reported an estimated prevalence of 1-3%, noting rates to be higher in developing countries due to an increased incidence of causal factors such as injuries, anoxia and early childhood brain infections (World Health Organization 2001).

It is clear that determining the prevalence of ID is extremely complicated and rates are greatly affected by factors such as: definition of ID, population type, country of origin, age-group, diagnostic criteria, study design and sampling strategy.

1.3 Mental ill-health and problem behaviour in adults with intellectual disability

1.3.1 Defining mental ill-health

The ICD-11 defines mental disorder as "A clinically recognisable set of symptoms or behaviours associated in most cases with distress and with interference with personal functions" (World Health Organization 2011).

Applying the concept of mental ill-health to the ID population is extremely challenging, particularly since impairments in behaviour and functioning are characteristic components of ID. At present, there is no definition of mental ill-health which has been developed specifically for use in the ID population.

1.3.2 Defining problem behaviour

The term problem behaviour, which for the purpose of this thesis will be used as synonymous with the term "challenging behaviour", has been used to describe a broad range of behaviours in people with ID which include "*aggression, destructiveness, self-injury, stereotyped mannerisms and a range of other behaviours, which may be either harmful to the individual (e.g. eating inedible objects), challenging for carers and care staff (e.g. non-compliance, persistent screaming, disturbed sleep patterns, overactivity) and/or objectionable to members of the public (e.g. regurgitation of food, the smearing of faeces over the body)"*(Emerson and Einfeld 2011). There is currently no universal definition of challenging behaviour (Allen 2008), however, a commonly cited definition was proposed by Emerson (1995) as:

- "*culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities*"

The Royal College of Psychiatrists (2007) sought to build on this definition with their modified version which describes behaviour as:

- "*challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion*"

The Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD) which was developed in 2001 (Royal College of Psychiatrists), also provide specific guidance on the classification of problem behaviour. For a problem behaviour diagnosis to be given, there are four requisite criteria:

1. the problem behaviour "is of significant frequency, severity or chronicity as to require clinical assessment and special interventions/support"
2. the problem behaviour "must not be a direct consequence of other psychiatric disorders, drugs or physical disorders"
3. there must be either a "significant negative impact on the person's quality of life or quality of life of others" or a "significant risk to the health and/or safety to the person and/or others"
4. the problem behaviour "is present across a range of personal and social situations"

1.4 Methodological issues with determining prevalence rates of mental ill-health and problem behaviour

Prevalence studies of mental ill-health and problem behaviour in the ID population have produced different findings. As with studies measuring the prevalence of ID, these inconsistencies are largely the result of methodological differences. The primary issues are the method of case ascertainment; the age and representativeness of the sample; the definitions of ID, mental ill-health and problem behaviour; and the type of diagnostic criteria used – all of which can result in different, and sometimes contradictory prevalence rates (Smiley 2005).

Smiley (2005) pointed out that some methods of case ascertainment, such as using case registers or specialist services for people with ID, are good at identifying people with moderate to profound ID, but tend to under-represent those with mild ID. Often, people with mild ID are not known to services, unless they have additional problems, such as mental ill-health. This means that not only do such case ascertainment methods under-represent people with mild ID, they also risk identifying those who tend to be unrepresentative of the wider population, and can thus bias the sample.

Definitions of ID vary between studies, with some being more inclusive than others. As a result, different definitions can lead to vastly different sample sizes. For example, some studies use only IQ test scores to define ID, whereas others also include a measure of adaptive behaviour. Therefore, participants meeting the inclusion criteria for one study researching a particular group (e.g. people with mild ID), might not meet the inclusion criteria for another study, researching the same group of people.

The manner in which mental ill-health is defined and reported can also vary greatly between studies. Some report prevalence rates of specific psychiatric disorders (e.g. depression or anxiety), whereas others report overall rates of psychopathology. Of the studies that report psychiatric disorders, some exclude specific disorders from their overall prevalence rate (e.g. personality disorder, autism or problem behaviour) (Smiley 2005). This can contribute to differences in prevalence rates and make comparison of findings problematic.

Similar issues exist with definitions of problem behaviour. Studies do not always explicitly state how they have defined problem behaviour. Even terms such as 'self-injurious behaviour' can include behaviours which have little in common. For example, Schroeder (1978) defined self-injurious behaviour as "serious", if it occurred at least once daily and resulted in bleeding, bruising, broken bones or other tissue damage. Taylor (2011) on the other hand, rated severity of self-injurious behaviour through calculating the number of topographies, multiplied by the frequency of self-injury. Other studies, although reporting overall rates of problem behaviour, measure very different

subcategories. For example, Reid et al (1978) measured "distractibility" and "hostile irritability" whereas Totsika (2008) measured "physical attacks" and "socially unacceptable behaviour". Such complexities can lead to differences in prevalence rates of both the same types of problem behaviour, and overall rates. Thus, comparisons between studies are complicated, and not always feasible.

1.5 Prevalence rates of mental ill-health and problem behaviour

1.5.1 Studies investigating the prevalence of mental ill-health and/or specific types of psychiatric disorders

Prior to reviewing the literature on longitudinal studies of mental ill-health, it is important first to consider what knowledge exists from the literature on prevalence studies.

Studies were included in this section if they met the following criteria:

Inclusion criteria

1. Adults with intellectual disability
2. Studies investigating the prevalence of mental ill-health and/or specific types of psychiatric disorders
3. Population-based samples
4. Studies published in the past 15 years

Exclusion criteria

1. Childhood studies
2. Studies investigating specific disorders of intellectual disability
3. Treatment and/or intervention studies or trials

Literature published in the past 15 years was deemed as providing the most representative account of current living arrangements of adults with ID – and thus most comparable to

this work – hence the reason for this criteria. Studies investigating the prevalence of mental ill-health and/or specific psychiatric disorders are summarised in table 1.5.1.

The research suggests that prevalence rates of mental ill-health in the adult ID population range between 30 and 50%. However, this range is not an accurate indication of mental ill-health per se, given that the majority of studies also included rates of problem behaviour in their findings. Furthermore, variation in these rates has been shown to arise from methodological differences, particularly the use of different diagnostic criteria. It would appear that Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) and ICD-10 criteria are unable to accommodate the pathoplastic effects of ID on psychopathology. Similar rates of depression were reported by Cooper et al (2007c) and Hassiotis et al (2008), at 4.6% and 4.1%, respectively. However, rates of other specific disorders are incomparable, given that none are reported in the same manner across the different studies. There are no other adult cohort studies which meet the inclusion criteria.

Table 1.5.1 Studies investigating the prevalence of mental ill-health and or/specific psychiatric disorders

Authors	n	Population characteristics	Diagnostic criteria	Prevalence rate	Definition and disorders included/excluded from prevalence rate
Cooper & Bailey (2001)	207	Learning disabilities register Adults aged ≥ 20 (n=73 aged 20-65; n=143 aged >65) Mild-profound ID	International Classification of Diseases, 10th edition, Diagnostic Criteria for Research (ICD-10-DCR)	49.2%	Includes problem behaviour
Deb et al (2001a)	90	Social services case registers Adults aged 16-64 Mild-moderate ID	ICD-10	14.4%	Excludes problem behaviour, autism, attention deficit hyperactivity disorder (ADHD), dementia, personality disorder, and alcohol abuse
Cooper et al (2007a)	1023	Population-based sample from multiple sources Adults aged ≥ 16 Mild-profound ID	Clinical diagnoses DC-LD ICD-10-DCR DSM-IV-TR (text revision)	28.3% 22.4% 16.5% 15.6%	Mental ill-health of any type excluding problem behaviour and specific phobias

Cooper et al (2007c)	1023	Population-based sample from multiple sources Adults aged ≥ 16 Mild-profound ID	Clinical diagnoses DC-LD ICD-10-DCR DSM-IV-TR	4.6% 3.8% 3.0% 2.1%	Depression currently in episode (includes both unipolar and bipolar depression)
Cooper et al (2007d)	1023	Population-based sample from multiple sources Adults aged ≥ 16 Mild-profound ID	Clinical diagnoses DC-LD ICD-10-DCR DSM-IV-TR	2.9% 3.2% 2.3% 3.0%	All psychotic disorders in episode
Bailey (2007)	121	Active case finding from multiple sources Adults aged ≥ 20 Moderate-profound	Clinical diagnoses DC-LD ICD-10-DCR DSM-IV	61.2% 57.0% 24.8% 13.2%	Includes problem behaviour
Hassiotis et al (2008)	1040	Second British National Survey of Psychiatric Morbidity Adults aged 16-74 Borderline ID	Schedules for Clinical Assessment in Neuropsychiatry (SCAN)	20.3% 37.4% 4.1% 2.8% 1.9%	Any type of neurotic disorder Any personality disorder Depressive episode Any phobia Agoraphobia

Morgan et al (2008)	13, 295	Intellectual Disability Register (IDR) and Mental Health Information System (MHIS) Adults aged 23-52 Borderline-profound ID	International Classification of Diseases, 9th edition (ICD-9)	31.7%	Overall psychiatric illness Includes schizophrenia, bipolar disorder, unipolar depression, non-organic psychosis and problem behaviour
Reid et al (2011)	1023	Population-based sample from multiple sources Adults aged ≥ 16 Mild-profound ID	Clinical diagnoses DC-LD ICD-10-DCR DSM-IV-TR	3.8% 3.2% 2.8% 2.4%	Any anxiety disorder in episode except Obsessive Compulsive Disorder (OCD) and specific phobias

1.5.2 Studies investigating the prevalence of problem behaviour and/or specific types of problem behaviour

Prior to reviewing the literature on longitudinal studies of problem behaviours, it is important first to consider what knowledge exists from the literature on prevalence studies.

Studies were included in this section if they met the following criteria:

Inclusion criteria

1. Adults with intellectual disability
2. Studies investigating the prevalence of overall problem behaviour and/or specific types of problem behaviour
3. Studies published in the past 15 years

Exclusion criteria

1. Childhood studies
2. Studies investigating specific disorders of intellectual disability
3. Treatment and/or intervention studies or trials

Consistent with section 1.5.1, publications from the past 15 years were chosen as providing the most representative account of the current living arrangements of adults with ID. Studies investigating the prevalence of problem behaviour and/or specific types of problem behaviour are summarised in table 1.5.2. Several of the studies investigating prevalence of mental ill-health also reported rates for problem behaviour. Cooper & Bailey (2001) reported a rate of 15.09%, Cooper et al (2007a) reported a rate of 22.5%, and Bailey (2007) reported a rate of 33.9% (all according to clinical diagnosis). However both Cooper et al (2007a) and Deb et al (2001a) published further papers investigating problem behaviour within the same cohorts.

As can be seen, studies investigating the prevalence of problem behaviour vary widely. One study of particularly good methodology had to be excluded from this review because it did not distinguish between adult and child rates (Kiernan, Reeves, Hatton, Alborz, Emerson, Mason, Swarbrick, & Mason 1997). The included studies report prevalence rates of problem behaviour ranging from 15% (Cooper & Bailey 2001) to 60.4% (Deb et al 2001b). These inconsistencies are the result of differences in methodologies, such as the definition of problem behaviour, type of problem behaviour, population studied, sampling strategy and instruments used.

Table 1.5.2 Studies investigating the prevalence of problem behaviour and/or specific types of problem behaviour

Authors	n	Population characteristics	Instrument/ Assessment	Prevalence rate	Definition and disorders included/excluded from prevalence rate
Cooper & Bailey (2001)	207	Learning disabilities register Adults aged ≥ 20 (n=73 aged 20-64; n=143 aged ≥65) Mild-profound ID	Psychiatric assessment according to ICD-10-DCR	15.09%	All types of problem behaviour
Deb et al (2001b)	101	Social services case registers Adults aged 16-64 Mild-severe ID	Face-to-face assessment with participant and carer using the Disability Assessment Schedule (DAS)	60.4% 23.8% 22.8% 23.8%	Any problem behaviour Severe problem behaviour Physical aggression Self-injurious behaviour
Joyce et al (2001)	448	ID services within 3 boroughs Adults aged > 19 ID level unspecified	The Challenging Behaviour Checklist (CBC)	52% 49% 37%	Shouting/swearing Hitting Self-injurious behaviour
Crocker et al (2006)	3165	3 ID services in Québec Adults aged ≥ 18 Mild-profound	The (Modified Overt Aggression Scale) MOAS completed by informant	51.8% (53.9%) 37.6% 24% 24.4% 24.4%	Overall rate of aggression (including sexual aggression) Verbal aggression Property aggression Physical aggression Self aggression

Tyrer et al (2006)	3065	Learning disabilities register Adults aged ≥ 19 Mild-profound ID (including unknown level of ID)	Face-to-face assessment with participant and carer using the DAS	14% 3% 2% 9%	Overall rate of physical aggression Severe & frequent physical aggression Less severe & frequent physical aggression Severe & less frequent physical aggression
Bailey (2007)	121	Active case finding from multiple sources Adults aged ≥ 20 Moderate-profound	Psychiatric assessment clinical diagnosis using DAS DC-LD	33.9% 27.1%	All types of problem behaviour
Lowe et al (2007)	705	ID services within 7 unitary authority areas Adults aged ≥ 16 ID level unspecified	Individual schedule and DAS completed with informant	58% 51% 35% 29% 64%	Overall prevalence of problem behaviour Of those with problem behaviour: Aggressive behaviour Self-injurious behaviour Destructive behaviour Other difficult/disruptive behaviour
Cooper et al (2007a)	1023	Population-based sample from multiple sources Adults aged ≥ 16 Mild-profound ID	Face-to-face clinical assessment Purpose designed measure meeting DC-LD criteria	22.5% 18.7%	Overall prevalence of problem behaviour

Jones et al (2008)	1023	Population-based sample from multiple sources Adults aged ≥ 16 Mild-profound ID	Purpose designed measure meeting DC-LD criteria	22.5% 7.53% 6.26% 3.03% 4.89%	Any problem behaviour Verbal aggression Physical aggression Destructive behaviour Self-injurious behaviour
Cooper et al (2009a)	1023	Population-based sample from multiple sources Adults aged ≥ 16 Mild-profound ID	Face-to-face clinical assessment Using a purpose designed measure meeting DC-LD criteria	9.8% 6.3% 7.5% 3.03%	Overall aggressive problem behaviour Physical aggression Verbal aggression Destructiveness

1.6 Long term outcomes of mental ill-health and problem behaviours in adults with intellectual disabilities: review of persistence and change

This section is focussed specifically on the literature relevant to adults with ID. 'Outcome' is used to describe the trajectory of mental ill-health and problem behaviour over time. It is imperative that the trajectory of mental ill-health and problem behaviour is understood, and having reviewed the literature, this is the key aim of this thesis. Now that the background and contextual literature has been presented in this thesis, data on outcomes is now considered in depth. A better understanding of these would enable services to plan for the long-term care of individuals, through considering the necessary support and its associated costs. Understanding the trajectory over time would also benefit research investigating risk factors associated with mental ill-health and problem behaviour outcomes, thus facilitating the development of more effective treatment and interventions.

1.6.1 Method

Electronic searches

A search was conducted of Ovid MEDLINE, Ovid EMBASE, PsychINFO, CINAHL and the Cochrane Library for articles published in English between January 1975 and March 2013. Where indicated, terms were searched for as MeSH headings, and otherwise as keywords in the title and abstract search fields.

In the first search, terms for mental ill-health were combined with terms for problem behaviour. In the second search, terms for mental ill-health/problem behaviour were combined with terms for intellectual disability (ID). In the final search, terms for mental ill-health/problem behaviour and ID were combined with terms for study type. MeSH search terms were tailored to each database searched. Therefore, the search terms differ between databases. For example, the Ovid Medline database MeSH term 'Mental Health' includes subheadings such as 'psychosis' and 'schizophrenia' but not 'obsessive compulsive disorder'. Therefore, 'obsessive compulsive disorder' was entered as a

separate search term. The following search terms were used for searching the Ovid Medline database. Further details of these and the search terms used for the other databases are described in Appendix A.

Search terms for mental ill-health were: ‘Mental Health [MeSH]’ or ‘Obsessive-Compulsive Disorder [MeSH]’ or ‘mental disorders’ or ‘mental* ill*’ or ‘mental ill-health’ or ‘psychopathology’ or ‘psychiatric illness’.

Search terms for problem behaviour were: ‘Self-Injurious Behavior [MeSH]’, or ‘Pica [MeSH]’, or ‘challeng* behavio?r*’, or ‘problem behavio?r*’, or ‘maladaptive behavio?r*’.

Search terms for ID were: ‘Intellectual Disability [MeSH]’, or ‘Mentally Disabled Persons [MeSH]’, or ‘intellec* disab*’ or ‘learning disab*’ or ‘mental* retard*’ or ‘learning impair*’ or ‘mental* handicap*’.

Search terms for study type were: ‘Retrospective Studies [MeSH]’, or ‘Epidemiologic Studies [MeSH]’ or ‘Cohort Studies [MeSH]’ or ‘Longitudinal Studies [MeSH]’ or ‘prospective’ or ‘cohort’ or ‘longitudinal’ or ‘epidemiolog*’ or ‘follow*up’ or ‘retrospective’ or ‘incidence’ or ‘prevalence’.

1.6.1.2 Searching other resources

The following journals were hand searched for articles published between January 2002 and March 2013: Journal of Intellectual Disability Research; Journal of Applied Research in Intellectual Disabilities; Research in Developmental Disabilities; American Journal on Intellectual and Developmental Disabilities; Journal of Intellectual and Developmental Disability and Journal of Mental Health Research in Intellectual Disabilities.

Additionally, the reference lists of relevant articles and books were scrutinised.

1.6.1.3 Inclusion and exclusion criteria

Inclusion criteria

1. Adults with intellectual disability

2. Studies investigating mental ill-health, or specific types of mental ill-health or problem behaviours

3. Longitudinal or follow-up studies including those of contemporaneously collected case note data

4. Studies where change or persistence in rates of mental ill-health and /or problem behaviour, and/or their predictors are reported

5. Residents in any type of accommodation or setting, provided enough information and participant characteristics are reported to allow replication and interpretation of the study

Exclusion criteria

1. Studies where total follow-up is less than six months after baseline data collection

2. Childhood studies

3. Studies specifically investigating the effects of deinstitutionalization

4. Studies where n=<15 participants

5. Studies investigating specific disorders of intellectual disability

6. Cross-sectional studies

7. Treatment and/or intervention studies or trials

8. Studies including results which are reported more comprehensively in another paper

1.6.1.4 Selection of studies

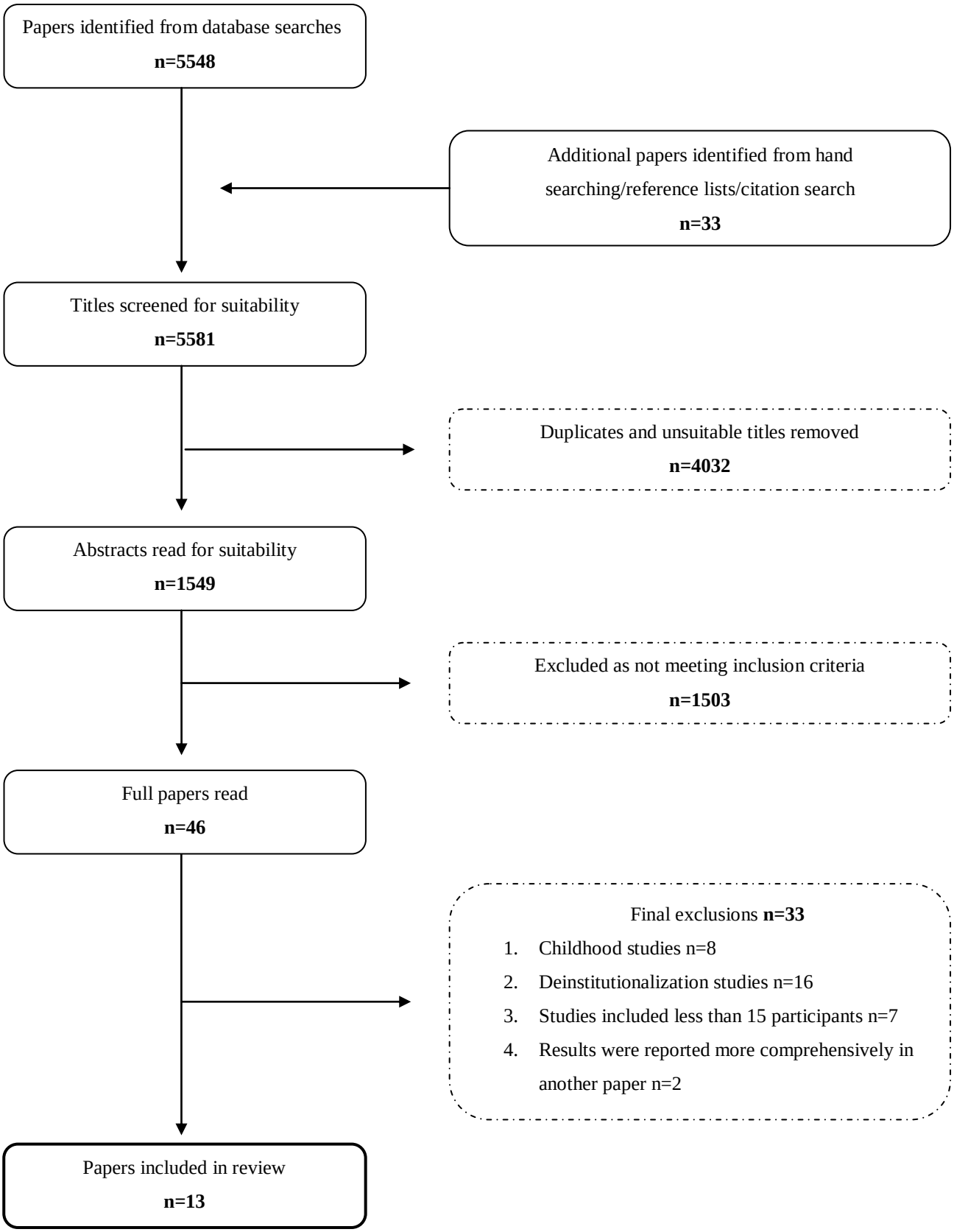
A search was performed using the above strategy and criteria. In order to ensure the search strategy was replicable, a second researcher applied the inclusion and exclusion criteria to a random selection of 150 of the 1549 papers that had their abstract read for suitability. Results were compared to ensure agreement.

This search procedure resulted in the inclusion of 13 papers in the review. See figure 1.6 for a summary. The 13 papers describe 6 longitudinal cohorts which have been grouped into the following categories:

a) studies investigating mental ill-health outcomes in adults

b) studies investigating problem behaviour outcomes in adults

Figure 1.6 Summary of search strategy



1.6.2 Studies investigating longitudinal outcomes of mental ill-health in adults with ID

Four longitudinal studies which investigated the long term outcomes of mental ill-health in adults with ID were identified (see table 1.6.2). These 4 studies also investigated the long term outcomes of problem behaviour.

The first cohort investigated psychopathology in a sample of 100 long-stay hospital residents in a study spanning 26 years (Reid, Ballinger, & Heather 1978; Reid and Ballinger 1995; Thompson and Reid 2002). The sample consisted of adults aged 17-71 years, with severe and profound ID. At baseline (1975), each participant was assessed in 3 ways: nurse ratings of abnormal behaviours; examination of clinical case notes regarding such abnormal behaviours; and clinical interview with a psychiatrist using the modified Manifest Abnormalities Scale of the Clinical Interview Schedule (MMAS). Psychiatric disorder, which was defined as: *"abnormalities of emotions, behaviour, relationship or thinking which are inconsistent with the patients intellectual level and of sufficient duration or severity to cause persistent suffering and handicap to the person and/or distress or disturbance to those in daily contact with him"*, was rated on a 5-point severity scale. Ratings of 0- indicated no psychiatric disorder; 1- indicated '*personality quirks or behavioural eccentricities not amounting to overt psychiatric disorder'*; 2- indicated mild, 3- moderate and 4- severe, degrees of psychiatric disorder. Of the original 100 residents, 67 were assessed again during 1992-1993. At this time, 40 remained hospital residents and 27 had been relocated to the community. The final follow-up took place in 2001 with the remaining 53 residents, of which 42 had been resettled into the community. Between 1975 and 1992 the authors reported psychiatric disorder to remain significantly persistence, with 34 vs. 35 residents receiving ratings of 2 to 4. However, over the 26 years, the authors reported a decrease in severity of psychopathology. They found that the number of residents receiving more severe ratings of 3 or 4 were significantly less in 2001 than in 1975 (3 vs. 5, and 2 vs. 8, respectively). Correspondingly, the number of residents receiving a less severe rating of 1 was significantly higher in 2001 than in 1975 (26 vs. 16). However, the authors did not compare the same individuals across the 3 time points: the

outcomes were reported at the group level, and not the individual level. The findings then, reflect changes in the population, but do not provide an accurate trajectory of mental ill-health within individuals over time. It is not clear therefore, how many individuals experienced persistent illness and how many experienced remission. Furthermore, follow-up assessments were made 16-18, and 26 years after baseline. Therefore any episodes of relapse and remission which could have occurred between these time points would be unknown. With regards to comparison with other studies, the MMAS has been superseded with more modern diagnostic criteria, making this difficult. Also, any comparisons which could be made would be applicable only for those with severe and profound ID.

The second cohort conducted a 2-year follow-up investigation of a sample of hospital and community residents, attending adult training centres (Leudar, Fraser, & Jeeves 1984). The sample consisted of 160 adults with mild to severe ID, aged 16-45. The primary aim of the study was to investigate problem behaviour (see section 1.6.3); however the assessment tool which was used also measured some symptoms of mental ill-health. During the baseline investigations, each subject had a Behaviour Disturbance Scale 2 (BDS2) completed for them by a nurse or other person who knew them well. This process was repeated 20-24 months later, with the 118 remaining participants. These participants did not differ from the original sample in terms of age or gender, but the proportion of participants residing in hospitals was smaller. The BDS2 consists of 51 items, which are loaded onto 6 factors: aggressive conduct; mood disturbance; communicativeness; antisocial conduct; idiosyncratic mannerism and self-injury. The mood disturbance factor consists of items indicative of emotional problems, for example, 'is socially withdrawn' and 'threatened or attempted suicide'. The remaining factors consist of items indicative of problem behaviours. Each item is rated on a 5-point frequency scale: never; rarely; occasionally; frequently and very frequently. Mood disturbance was found to increase slightly for those with initial low scores, and decreased considerably for those with initial high scores. Although this finding suggests that outcomes are not persistent, it is difficult to interpret given that in the context of the BDS2, mood disturbance is a subscale derived from 4 items. As such, it cannot easily be compared with other psychiatric disorders or symptoms. Also, the authors do not state whether the change in scores led to a subsequent

change in mental ill-health status. Furthermore, they stated that regression to the mean may have affected the results.

Using their original population-based cohort of adults living in the Greater Glasgow and Clyde area, Cooper et al (2007a) investigated the 2-year incidence and remission of mental ill-health. All adults who participated in the baseline study were invited to take part in the time 2 investigations, carried out during 2004-2006. Of the original 1023 adults who participated at baseline, 651 participated in the follow-up, giving a retention rate of 70%. A comparison of participants, with those whom consent was not gained, showed no difference in terms of age, gender, level of ID, type of accommodation/support and mental ill-health status at time 1. The same measurements taken at time 1 were repeated at time 2: the Psychiatric Assessment Schedule for use with Adults with Developmental Disabilities (PAS-ADD) Checklist was used to screen for psychopathology and any participants regarded as 'possibly, probably or definitely' having mental ill-health were referred for face-to-face psychiatric assessment. In their follow-up investigation, the authors found the 2-year incidence of mental ill-health (excluding problem behaviour) to be 12.6% for clinical, 11.8% for DC-LD, 8.4% for ICD-10-DCR and 6.8% for DSM-IV-TR diagnostic criteria (Smiley, Cooper, Finlayson, Jackson, Allan, Mantry, McGrother, McConnachie, & Morrison 2007). The majority of incident mental ill-health (excluding problem behaviour) was affective disorder, which was found at a rate of 8.3% for clinical, 7.7% for DC-LD, 5.1% for ICD-10-DCR and 3.5% for DSM-IV-TR diagnostic criteria. Anxiety, organic and psychotic disorders were found to be the most common disorders thereafter, according to both clinical and DC-LD criteria. The prevalence rate of mental ill-health (excluding problem behaviour) reported at time 1 (28.3%) was higher than the incidence rate at time 2 (12.6%), suggesting that the majority of mental ill-health was the result of enduring, rather than incident illness.

In 2007, the authors (Cooper et al 2007d) investigated 2-year incidence of psychosis and reported a rate of 1.4% (i.e. 9 new episodes) according to clinical diagnosis. Of those in episode at time 1, 14.3% were in full remission at time 2, suggesting that the majority experienced persistent illness over this time. The prevalence of psychosis was found to be

higher than incidence (4.0% vs. 1.4%), suggesting that for the majority of people experiencing psychosis, it was persistent over the 2-year period. Two-year incidence of mental ill-health (excluding problem behaviour) in adults with profound ID was found to be 7.6% for clinical, 6.9% for DC-LD, 6.1% for ICD-10-DCR and 6.3% for DSM-IV-TR diagnostic criteria (Cooper, Smiley, Finlayson, Jackson, Allan, Williamson, Mantry, & Morrison 2007b). As with all levels of ID combined, the majority of incident illness (excluding problem behaviour) was explained by affective disorder, which was found at a rate of 6.1% for clinical and 5.3% for DC-LD diagnostic criteria. The prevalence of mental ill-health (excluding problem behaviour) in adults with profound ID was found to be higher than incidence (30.4% vs. 7.6%), suggesting that the majority of mental ill-health was persistent over the 2-year period. These studies benefit from their comprehensive case-ascertainment procedures and large sample size resulting from high cohort retention. However, given that the purpose of the time 2 follow-up study was to investigate incidence of mental ill-health, the authors did not report remission rates of those with mental ill-health at time 1.

The fourth longitudinal study investigated psychopathology in 74 adults residing in a developmental centre (Horovitz, Matson, Sipes, Shoemaker, Belva, & Bamburg 2011). The sample consisted of adults with severe and profound ID, aged an average of 53.96 years. Interviews were conducted by a health care specialist with direct care staff, using the Diagnostic Assessment for the Severely Handicapped – Second Edition (DASH-II). Staff members were asked about the frequency, severity and duration of behaviours occurring in the past 2 weeks. Frequency of behaviour was rated as: 0= behaviour has not been observed, 1= frequency of 1-10 times, or 2= occurred more than 10 times. This procedure was repeated quarterly over a 12-month period for each participant. The authors reported no significant differences on total DASH-II scores, across the 4 time points. No differences were found for any of the subscales across the 4 time points either, with the exception of the pervasive developmental disorder (PDD)/autism subscale, which revealed a significant difference between time 1 and time 3. However, no difference was found for the PDD/autism subscale between time 1 and time 4. The authors concluded that although symptoms on this subscale fluctuated over the assessment period, they remained relatively

stable after 1 year. This is an unusual finding, given that, although change can occur, the manifestation of autism is generally persistent over time (World Health Organization 2013a). The use of quarterly assessments is a major strength of this study; however, it is limited by its small sample size and lack of clarification regarding mental ill-health status at baseline. That is, although the authors report persistence, it is not clear how many people were persistently ill and how many remained healthy (i.e. persistently scored 0 at each investigation). Also, the period of 12-months is a relatively short time, and does not give an indication of longer-term outcomes of mental ill-health.

It is difficult to make any solid conclusions from these studies. The Reid et al (Reid et al 1978; Reid & Ballinger 1995; Thompson & Reid 2002) study does not compare the same individuals over time, and the duration between assessments is too long to assume persistence. The study by Leuder et al (1984) presented outcomes of a subscale and so cannot be compared with other findings reporting outcomes of overall rates of mental ill-health or specific psychiatric disorders. The Horovitz et al (2011) study suggests that psychopathology is persistent, but only over a short time period within a small sample. Furthermore, it is not clear how many people were ill and how many were healthy at baseline. The Cooper et al (Cooper et al 2007a; Cooper et al 2007b; Cooper et al 2007d; Smiley et al 2007) study provides the most robust evidence to date and suggests that for the majority of participants, mental ill-health is persistent over time. However, remission rates between time 1 and time 2 were only reported for those with psychosis, and not overall rates of mental ill-health (excluding problem behaviour).

Table.1.6.2 Studies investigating longitudinal outcomes of mental ill-health in adults with ID

Authors	n	Population characteristics	Baseline & follow-up	Instrument/Assessment	Findings
Reid et al (1978) Reid & Ballinger (1995) Thompson & Reid (2002)	100 67 53	Hospital residents Aged 17-71 Severe-profound ID	Baseline 1975 Follow-up 1992-1993 16-18 years 2001 26 years	Psychiatric assessment using the MMAS	Comparing ratings of psychiatric disorder between 1975 with 1992, 11 vs. 18= 0, 22 vs. 14= 1, 17 vs. 20= 2, 8 vs. 12= 3 and 9 vs. 3= 4 Comparing ratings of psychiatric disorder between 1975 with 2001, 8 vs. 7= 0, 16 vs. 26= 1, 16 vs. 15= 2, 5 vs. 3= 3 and 8 vs. 2= 4 Fewer participants were rated 3 and 4 in 2001 compared to 1975, and more were rated 1 Psychiatrist ratings of "lability of mood", "depressed" and "slow" increased between 1975/76 and 2001
Leudar et al (1984)	160	Hospital residents and adults living in the community and attending adult training centres, in Scotland Age 16-45 Mild-severe ID	Follow-up 20-24 months N=118	BDS2 completed by a nurse or instructor	Mood disturbance increased slightly for those with initial low scores, and decreased considerably for those with initial high scores

Cooper et al (2007a) Smiley et al (2007)	1023 651	Population-based sample of all adults with ID living in the Greater Glasgow & Clyde area Age ≥ 16 Mild-profound ID	Baseline 2002-2004 Follow-up 2004-2006 2 years	Initial face-to-face assessment using the PAS-ADD Checklist and C21st Health Check Psychiatric assessment including use of the Present Psychiatric State – Learning Disabilities (PPS-LD)	Point prevalence of mental ill-health of any type (excluding problem behaviour was 28.3% according to clinical criteria Rate of 2-year incidence was 12.6%
Cooper et al (2007d)	As above	As above	As above	As above	Point prevalence of psychotic disorder was 4.4% according to clinical criteria, of which 14.3% were in remission at time 2 and 85.7% remained ill 2-year incidence was 1.4%
Cooper et al (2007b)	184 131	As above Profound ID	As above	As above	Point prevalence of mental ill-health (excluding problem behaviour) was 30.4% according to clinical criteria. 2-year incidence was 7.6%
Horovitz et al (2011)	74	Residents of a developmental centre in Louisiana Age M=53.96 Severe-profound ID	Baseline Follow-up Quarterly for 1 year	DASH-II completed by direct care staff	No significant differences were found on any of the mental health subscales between time 1 and time 4. Significant differences were found only on the PDD/Autism subscale, between time 1 and time 3, but not between time 1 and time 4

1.6.3 Studies investigating longitudinal outcomes of problem behaviour in adults with ID

Eight longitudinal studies were identified which investigated the long term outcomes of problem behaviour in adults with ID (see table 1.6.3).

As well as mental ill-health, Reid et al (Reid et al 1978; Reid & Ballinger 1995; Thompson & Reid 2002) also investigated self-injurious behaviour and pica over the 26-year period. Both self-injurious behaviour and pica were items included in the MMAS. As with all other items, they were rated on a 5-point severity scale. The authors reported no significant difference between the number of people displaying either behaviour between baseline and follow-up. However, given that they did not report whether the same individuals were compared over time, no conclusions can be drawn. These findings are limited by the same issues highlighted in the previous section i.e. duration between investigations, and use of the MMAS. Similarly, the DASH-II used by Horovitz et al (2011) also included a subscale on self-injurious behaviour. The authors reported no significant difference for symptoms of self-injurious behaviour across the 4 time points. This finding has the same strengths and limitations as previously discussed: short time period between assessments; short time period of study overall; small sample size; and lack of clarification regarding baseline status of self-injurious behaviour.

As previously stated, the main aim of the Leuder et al (1984) study was to investigate problem behaviour outcomes using the BDS2. The authors found that each problem behaviour disturbance on the BDS2 remained relatively stable over the 2-year period. However, they reported different trajectories for the different factors. For example, scores of aggression remained stable for those initially having aggression, but increased for those initially without aggression. Individuals with initial high scores of antisocial conduct, idiosyncratic mannerisms and self-injury showed decreases at follow-up. Those that did not initially show these characteristics at baseline had not acquired them at follow-up. Although the study benefits from its sample size and short duration between baseline and follow-up, it has several limitations. Firstly, the frequency rating scale used for the BDS2 is ambiguous and results could vary depending on informant interpretation of “rarely”,

"occasionally" and "frequently". Secondly, the scale does not measure severity of behaviours, and includes items such as "idiosyncratic mannerisms", making the findings incomparable with studies which use DC-LD criteria. Thirdly, the authors suggested that ceiling effects, floor effects, and regression to the mean may have affected the results, thus they should be interpreted with caution. Furthermore, the results cannot be generalised to those with profound ID.

Incidence of problem behaviour was also investigated in the Glasgow Cohort (Smiley et al 2007). Using the same methods previously described, the authors reported 2-year incidence of problem behaviour to be 4.6% and 3.5%, according to clinical and DC-LD criteria, respectively. Use of ICD-10-DCR and DSM-IV-TR criteria did not identify any problem behaviours. The authors also investigated 2-year incidence rates of aggressive problem behaviour (Cooper et al 2009a) and self-injurious behaviour (Cooper, Smiley, Allan, Jackson, Finlayson, Mantry, & Morrison 2009b). Aggressive problem behaviour was defined as meeting DC-LD criteria for: physically aggressive behaviour and/or destructive behaviour and/or verbally aggressive behaviour. At time 1, 100 participants met these criteria, resulting in a point prevalence of 9.8%. At time 2, 12 participants (from a total of 651) met these criteria, resulting in a 2-year incidence of 1.8%. Of the 100 participants who met criteria for aggressive problem behaviour at time 1, 65 participated in the time 2 investigation. Of these, 27.7% were in remission. Given that prevalence of aggressive problem behaviour was higher than incidence, and remission rates were low, we can infer that the majority of participants with aggressive problem behaviour experienced persistent illness over the 2-year period. At time 1, 50 participants met DC-LD criteria for self-injurious behaviour, resulting in a point prevalence of 4.9%. At time 2, 4 participants (from a total of 651) met the criteria, resulting in a 2-year incidence of 0.6%. Of the 50 participants who met criteria for self-injurious behaviour at time 1, 34 participated in the time 2 investigation. Of these, 38.2% were in remission. As with aggressive problem behaviour, the prevalence of self-injurious behaviour was higher than the incidence, and remission rates were relatively low, suggesting that the majority of participants with self-injurious behaviour experienced persistent illness over the 2-year period.

Problem behaviour in young adults with ID was investigated in an epidemiological study, undertaken in 7 Health Districts and corresponding local authorities in North West England

(Kiernan and Alborz 1996). At baseline, the authors attempted to recruit young adults with ID, who were recognised in residential and day service settings as displaying problem behaviour. From this population, adults residing at home were selected for further investigation. In 1998, the parents of these adults, aged 19-26 years (level of ID unspecified) were invited to participate in the study. Of the 91 parents approached, 56 agreed to participate and completed a semi-structured interview. This interview was developed and administered again in 1993 with the remaining 44 parents who agreed to participate. The interview collected information on the frequency of the following problem behaviours: physical injury; destructive behaviour; self-injurious behaviour; problems with supervision and night disturbances. Overall, problem behaviour was found to be stable across the 5 year time period, with 59% of the sample showing the same levels at both time points. The most persistent type of problem behaviour was night disturbance (96%), followed by physical injury (83%), self-injurious behaviour (75%), problems with supervision (73%) and destructive behaviour (70%). Over the 5 years, problem behaviour improved for 29% of the sample and worsened for 12%. Although the findings indicate a high level of persistence for problem behaviour over time, there are several limitations which must be considered. Primarily, the sample is clearly not representative of the wider population of adults with ID, given that only those adults who resided at home and were recognised by services as displaying problem behaviour were invited to participate. Furthermore, level of ID was not specified, and the sample size is small. The study benefits from its comparison of the same individuals over time, however; the authors did not report the use of any diagnostic criteria and the presence of problem behaviours were based on parental judgements. Furthermore, the psychometric properties of the measure used are unknown. Thus, comparisons cannot be made with other findings and it is unknown whether the behaviours reported would meet criteria for clinical significance.

In the final longitudinal study identified, problem behaviours were investigated in adults living in small villas on a long-term residential facility (Totsika, Toogood, Hastings, & Lewis 2008). The sample consisted of 58 adults aged 23-83 years, and the majority had severe ID (n=46). The Individual Schedule of the Challenging Behaviour Survey was completed by staff members in 1992, and again 11 years later in 2003. Behaviour was dichotomised as serious/controlled and no/lesser problems. Stereotypy was dichotomised as daily or less frequent. In 1992, 38 people were rated as displaying serious/controlled

challenging behaviour, of these 30 (79%) still presented with serious/controlled problem behaviour in 2003. A similarly high persistence rate of 60% was found for individuals displaying no/lesser problem behaviour in 1992 and 2003. The most persistent behaviours were serious/controlled physical attacks (70%), daily stereotypy (65%) and serious/controlled 'other' disruptive behaviour (58%). As with the previous study, this study benefits from its comparison of the same individuals over time, however; it is also limited by its reliance on informant ratings, in this case to decide whether or not behaviours are serious. This study is also limited by the time duration between baseline and follow-up – given that 11 years passed between these investigations it is impossible for persistence of problem behaviour to be concluded.

Analogous to the longitudinal studies investigating mental ill-health, it is difficult to make any solid conclusions. The study by Reid et al (Reid et al 1978; Reid & Ballinger 1995; Thompson & Reid 2002) reports persistence of self-injurious behaviour and pica over the 26 years. However, given that the same individuals were not compared and only one investigation was performed between baseline and 26 year follow-up, these findings cannot be viewed as conclusive. Horovitz et al (2011) found the self-injurious behaviour subscale to remain stable, but the investigation was conducted over a relatively short time period with a small sample. With the exception of the Glasgow cohort, the remaining studies (Leudar et al 1984; Kiernan & Alborz 1996; Totsika et al 2008) all relied on informant ratings and the samples were not representative of the wider population of adults with ID. Only one of these studies measured severity of problem behaviour, but this was based on informant ratings and therefore dependent on individual perceptions of 'serious' (Totsika et al 2008). Again, the Cooper et al (Cooper et al 2007a; Smiley et al 2007; Cooper et al 2009a; Cooper et al 2009b) study provides the most robust evidence. For both aggressive problem behaviour and self-injurious behaviour, prevalence rates were lower than incidence rates, and remission rates were low, suggesting that the majority of adults experienced persistent problem behaviour over the 2-year period. However, the longer term outcomes are unknown. Although two studies conducted follow-up assessments after 10 years, the findings are not conclusive, given the lack of intermediate investigations between baseline and final follow-up.

With regards to longitudinal studies investigating both mental ill-health and problem behaviour, there are not enough high-quality studies to come to definitive conclusion in relation to long term outcomes in adults with ID. One particularly high quality longitudinal study investigating persistence and change of problem behaviour (Kiernan et al 1997) had to be excluded from the review because it did not distinguish between adult and child outcomes. The key methodological limitations of the included studies are: heterogeneity of samples and assessment measures; low frequency of, and long duration between follow-up investigations; reporting outcomes at the group level; lack of clarity regarding baseline status and whether significant change in score, severity or frequency, causes change in outcome. Hence, it remains unknown what the long term outcomes of mental ill-health and problem behaviour are for this population. Clarification of this could result in considerable implications for policies and practices regarding service organization and delivery, and guide key emphases for development and testing of interventions.

Table 1.6.3 Studies investigating longitudinal outcomes of problem behaviour in adults with ID

Authors	n	Population characteristics	Baseline & Follow-up	Instrument/Assessment	Findings
Reid et al (1978) Reid & Ballinger (1995) Thompson & Reid (2002)	100 67 53	Hospital residents Aged 17-71 Severe-profound ID	Baseline 1975 Follow-up 1981-1992 16-18 years 2001 26 years	Psychiatric assessment using the MMAS	No significant difference was found between the number of people displaying self-injurious behaviour between baseline and 26-year follow-up (5.7% vs. 11.3%) No significant difference was found between the number of people displaying pica between baseline and 26-year follow-up (5.7% vs. 11.3%)
Leudar et al (1984)	160 118	Hospital residents and adults living in the community and attending adult training centres, in Scotland Age 16-45 Mild-severe ID	Follow-up 20-24 months	BDS2 completed by a nurse or instructor	Each disturbance was relatively stable over 2 years Scores of aggression remained stable for those initially having aggression, but increased for those initially without aggression Those with initial high scores of antisocial conduct, idiosyncratic mannerisms and self-injury showed decreases at follow-up, and those that did not initially show these characteristics at baseline had not acquired them at follow-up
Kiernan & Alborz (1996)	56 44	Young adults residing in parental home within 7 Health Districts and corresponding authorities in North West England Age 19-26	Baseline 1988 Follow-up 1993 5 years	Semi-structured interview completed by parents	Overall problem behaviour was found to be stable across the 5 year period with 59% showing the same level at both time points, Problem behaviour was persistent in 96% for night disturbance, 83% for physical injury, 75% for SIB, 73% for problems with supervision and 70% for destructive behaviour Problem behaviour improved for 29% and worsened for 12%.

		Level of ID unspecified			
Cooper et al (2007a) Smiley et al (2007)	1023 651	Population-based sample of all adults with ID living in the Greater Glasgow & Clyde area Age ≥ 16 Mild-profound ID	Baseline 2002-2004 Follow-up 2004-2006	Face-to-face clinical assessment and use purpose designed measure meeting DC-LD criteria	Point prevalence of problem behaviour at time 1 was 22.5% according to clinical criteria Rate of 2-year incidence for problem behaviour was 4.6%
Cooper et al (2009a)	100 65	As above	As above	As above	Point prevalence of aggressive behaviour at time 1 was 9.8% (n=100) of which 27.75% were in remission at time 2 Rate of 2-year incidence was 1.8%
Cooper et al (2009b)	50 34	As above	As above	As above	Point prevalence of self-injurious behaviour at time 1 was 4.9% (n=80) of which 38.2% were in remission at time 2 2-year incidence rate was 0.6%
Totsika et al (2008)	58	Residents of group living arrangements (small villas) on a long-term residential facility Aged 23-83 Borderline ID: n=2 Moderate ID: n=9 Severe ID: n=46	Baseline 1992 Follow-up 2003	Individual Schedule of the Challenging Behaviours Survey completed by informants	In 1992, 38 people were rated as displaying serious/controlled challenging behaviour, of these 30 (79%) still presented with serious/controlled challenging behaviour in 2003 Persistence was 70% for physical attacks, 65% for stereotypy, 58% for 'other' destructive behaviour, 47% for self-injury and 11% for destructive behaviour

Horovitz et al (2011)	74	Residents of a developmental centre in Louisiana Age M=53.96 Severe-profound ID	Baseline Follow-up Quarterly for 1 year	DASH-II completed by informants	No significant differences were found between time 1 and time 4 on the self-injurious behaviour subscale

1.7 Factors associated with mental ill-health and problem behaviour

Factors found to be associated with or predictive of mental ill-health and problem behaviour are summarised in tables 1.7.1-1.7.4 below. In keeping with the language of epidemiology, the term 'predictors' is used when reporting longitudinal, prospective findings and the term 'associated' is used when reporting cross section relationships. The majority of studies which investigated prevalence rates and longitudinal outcomes (sections 1.5 and 1.6) also investigated associated and predictive factors (those that did not were Cooper & Bailey (2001), Joyce et al (2001), Hassiotis et al (2008), Morgan (2008) and Horovitz (2011). Other studies which have not investigated prevalence or longitudinal outcomes have investigated factors associated with and predictive of mental ill-health and problem behaviour. These are also discussed below.

1.7.1 Studies reporting factors associated with mental ill-health

Although several studies have investigated factors associated with mental ill-health, most have resulted in contradictory findings. For example, some have found increasing age to be associated with increasing psychiatric disorder (Deb et al 2001a), others have found the opposite effect (Thompson & Reid 2002), and yet others have found no such association (Bailey 2007; Cooper et al 2007a). Similarly, several studies have found no association between gender and mental ill-health (Deb et al 2001a; Thompson & Reid 2002; Bailey 2007), whereas others have found an association between female gender and prevalence of overall mental ill-health (Cooper et al 2007a), as well as depression (Cooper, Smiley, Morrison, Williamson, & Allan 2007c). Numerous studies have investigated the relationship between life events and mental ill-health, the majority of which have reported significant associations (Cooper et al 2007a; Cooper et al 2007c; Reid et al 2011).

One such study investigated this relationship in 1155 adults living in community and residential services, within a county in England (Hastings, Hatton, Taylor, & Maddison 2004). The sample consisted of adults aged ≥17 years, with unspecified levels of ID. Informants were interviewed using the PAS-ADD Checklist to screen for psychopathology

and measure life events experienced in the past 12 months. Both psychopathology and life events were dichotomised i.e. disorder present or absent, and experience of one or more life events vs. none. The authors found that the odds of affective disorder were significantly increased in those who had experienced one or more life events in the past 12 months. This relationship was not found for organic and psychotic disorder.

In a much smaller study, a positive association was found between exposure to life events and psychological problems (Hulbert-Williams, Hastings, Crowe, & Pemberton 2008). The sample consisted of 38 adults, recruited from social services and voluntary organisations providing support for people with ID across 4 counties in North Wales. The participants were aged 18-59 years and their level of ID was unknown; however the authors deemed them eligible because they received supported living or day services from ID services. Interviews were conducted with participants using the Brief Symptom Inventory (BSI) and the Bangor Life Events Schedule for Intellectual Disabilities: Self-Report (BLESID-SR). The BSI is a 53-item self-report measure of psychopathology, which was designed for use in the general population. The authors reduced the number of items to 29 and used different cut-off scores to those suggested for the general population. Life events were measured using the BLESID-SR, which unlike previous measures, asks participants to rate whether reported life events occurred 'once or more than once' and whether they were 'bad, good, or in the middle'. Three types of total score were thus derived: total unique life events score, negative life events score and a weighted life events score (in which repeated events contributed twice as much to the total). Significant positive associations were found between each scoring method and each psychopathology sub-scale of depression, anxiety, hostility and anger. However, the results must be viewed with caution given the small sample size and use of a measure designed for the general population.

Other researchers have investigated the relationship between depression, problem behaviour and life events in adults with ID (Esbensen and Benson 2006). The 104 adults in the sample were aged 21-79, and the majority had mild and moderate ID, 51% and 26%, respectively. Only 8% had severe ID, 9% borderline and level of ID was unknown for the remaining 6%. It is not clear how the participants were recruited, but the majority (94%) were living in the community with support. Informants completed a range of measures

including: the Anxiety, Depression and Mood Scale (ADAMS), the Assessment of Dual Diagnosis (ADD), the Aberrant Behaviour Checklist (ABC), the Problem Behaviour Scale on the Scales of Independent Behaviour – Revised (SIB-R), and the Life Experiences Survey (LES). The ADAMS is a 28-item informant-report measure which screens for symptoms of affective disorder. The ADD screens for a range of psychopathology, but only the depression subscale was used in this study. Both the ABC and the SIB-R measure the severity of a range of problem behaviours. The LES was modified for use in this population, consisting of 45-items measuring life events occurring in the past 4 months. Each life event identified as occurring in the past 4 months is rated as having either a positive, negative or no impact on the individual's life, at the time it occurred. The authors found that depressive symptoms were associated with frequency counts of life events, and life events perceived as being negative. Depressive symptoms were also correlated with (but not predicted by) life changes.

Several studies have also found associations between past medical history and mental ill-health (Cooper et al 2007a; Cooper et al 2007c; Cooper et al 2007d; Reid et al 2011). Associations with health and disabilities are unclear as studies have investigated different factors and different outcomes, making comparisons problematic.

Table 1.7.1 Studies reporting factors associated with mental ill-health

Associated Factors	Study	Findings
Personal Factors:-		
Age	Deb et al (2001a)	Increasing age significantly associated with rate of psychiatric illness.
	Thompson et al (2002)	Significantly higher ratings of psychiatric disorder for those aged ≤59 years compared with those aged ≥60 years
	Bailey (2007)	No association between chronological age and psychiatric disorder, but a significant association between developmental age and psychiatric disorder; which was lower in people with psychiatric disorder in episode, and higher in people with neurotic disorder in episode.
	Cooper et al (2007a)	No association between age and mental ill-health.
Gender	Leudar et al (1984)	Female hospital residents showed a significantly higher increase in mood disturbance than male hospital residents
	Deb et al (2001a)	No association between gender and mental ill-health
	Thompson et al (2002)	No association between gender and mental ill-health
	Bailey (2007)	No association between gender and mental ill-health.

	Cooper et al (2007a)	Female gender independently associated with mental ill-health of any type (excluding autistic spectrum disorders and specific phobia).
	Cooper et al (2007c)	Female gender independently associated with depression
	Cooper et al (2007d)	No association between gender and psychosis
Level of ID	Thompson et al (2002)	No association between level of ID and mental ill-health
	Cooper et al (2007a)	Severe and profound ID was independently associated with mental ill-health (excluding autistic spectrum disorders and specific phobia).
Lifestyle and support:-		
Accommodation and support	Thompson et al (2002)	Significantly higher ratings of psychiatric disorder for those living in hospital compared with those living in the community
	Cooper et al (2007a)	Living with paid carer support was independently associated with mental ill-health (excluding autistic spectrum disorders and specific phobia).
Day activities	Reid et al (2011)	Having no day time occupation was independently associated with anxiety disorder.

Past experiences:-		
Life events	Hastings et al (2004)	Exposure to one or more life events in the past 12 months significantly increased the odds of affective disorder. No relationship was found between exposure to one or more life events in the past 12 months and organic or psychotic disorder.
	Esbensen and Benson (2006)	Frequency counts of life events and all life events perceived as negative were associated with depressive symptoms.
	Bailey et al (2007)	No association between life events and psychiatric disorder.
	Hulbert-Williams et al (2008)	Total unique life events score, negative life events score and weighted life events score were all positively associated with each psychopathology sub-scale of depression and anxiety.
	Cooper et al (2007a)	Experiencing a higher number of life events in the preceding 12-months was independently associated with mental ill-health (excluding autistic spectrum disorders and specific phobia).
	Cooper et al (2007c)	Experiencing a life event in the preceding 12-months was associated with depression
	Cooper et al (2007d)	No association between life events and psychosis.
	Reid et al (2011)	Experiencing a life event in the preceding 12-months was independently associated with anxiety disorder.

Medical history	Cooper et al (2007a)	Experiencing a higher number of consultations with a general practitioner or family physician in the preceding 12-months was independently associated with mental ill-health (excluding autistic spectrum disorders and specific phobia).
	Cooper et al (2007c)	Experiencing a higher number of consultations with a general practitioner in the preceding 12-months was associated with depression
	Cooper et al (2007d)	Being an ex-long-stay hospital resident was independently associated with psychosis.
	Reid et al (2011)	Not being an ex-long-stay hospital resident was independently associated with anxiety disorder.
Health and disabilities:-		
	Moss et al (2000)	Compared to those without problem behaviour, overall psychiatric disorder was over twice as high, hypomania 3 times higher and depression 4 times higher in those with problem behaviour.
	Deb et al (2001a)	Physical disability was associated with rate of psychiatric disorder
	Bailey (2007)	No association between epilepsy and psychiatric 'caseness'. Higher Health of the Nation Outcome Scale (HoNOS) scores were associated with 'psychiatric cases' in episode.
	Cooper et al (2007a)	Having urinary incontinence, not having severe physical disability, not having immobility and being a smoker was independently associated with mental ill-health (excluding autistic spectrum disorders and specific phobia).

	Cooper et al (2007c)	Not having a hearing impairment and being a smoker was associated with depression
	Cooper et al (2007d)	Visual impairment, being a smoker and not having epilepsy were independently associated with psychosis.

1.7.2 Studies reporting factors predicting mental ill-health

Only 2 studies have been found to investigate factors predictive of mental ill-health, both of which investigated mental ill-health within different populations of the same cohort (i.e. adults with all levels of ID, and adults with profound ID). Thus it is very difficult to make definitive conclusions. The studies suggest that the following factors are predictive of incident mental ill-health: moderate rather than mild ID, living in congregate care or with paid carer support, experience of life events in the past year, experience of abuse, neglect or other exploitation in adulthood, having a psychiatric history, having urinary incontinence and impaired mobility (Smiley et al 2007; Cooper et al 2009a).

Table 1.7.2 Studies reporting factors predicting mental ill-health

Predictive Factors	**Study**	**Findings**
Personal Factors:-		
Age	Smiley et al (2009)	Age was not found to be predictive of 2-year incidence of mental ill-health (excluding problem behaviour, dementia and delirium).
Level of ID	Smiley et al (2007)	Moderate, rather than mild ID found to be predictive of 2-year incidence of mental ill-health (excluding problem behaviour, dementia and delirium).
Lifestyle and support:-		
Accommodation and support	Smiley et al (2007)	Living in congregate care with paid carer support or independent of care was predictive of incidence of mental ill-health (excluding problem behaviour, dementia and delirium).
	Cooper et al (2007b)	Living in congregate care was predictive of incidence of mental ill-health (excluding problem behaviour, dementia and delirium) in adults with profound ID.

Past experiences:-		
Life events	Cooper et al (2007b)	Experiencing life events in the past year was predictive of incidence of mental ill-health (excluding problem behaviour, dementia and delirium) in adults with profound ID.
Other adversity or abuse	Smiley et al (2007)	The experience of abuse, neglect or exploitation during adult life was predictive of incidence of mental ill-health (excluding problem behaviour, dementia and delirium).
Medical history	Smiley et al (2007)	Having a past psychiatric history was predictive of incidence of mental ill-health (excluding problem behaviour, dementia and delirium).
Health and disabilities:-		
	Smiley et al (2007)	Urinary incontinence and not having impaired mobility were predictive of incidence of mental ill-health (excluding problem behaviour, dementia and delirium).

1.7.3 Studies reporting factors associated with problem behaviour

Compared with mental ill-health, a much larger number of studies have investigated factors associated with problem behaviour. However, findings are still contradictory. For example, although the majority of studies reported an association between problem behaviour and younger age (Tyrer et al 2006; Lowe et al 2007; Totsika et al 2008), some reported an association with older age (Kiernan & Alborz 1996; Holden and Gitlesen 2003), whereas others reported no such association (Bailey 2007; Cooper et al 2007a). Similarly contradictory findings have been made for associations between gender and problem behaviour. However, the majority of studies have found an association between more severe levels of ID and problem behaviour (Moss et al 2000; Deb et al 2001b; Holden & Gitlesen 2003; Tyrer et al 2006; Lowe et al 2007; Jones et al 2008; Cooper et al 2009a; Cooper et al 2009b). One such study investigated a sample of 320 individuals with administratively defined ID, with and without problem behaviour (Moss et al 2000). The sample consisted of adults aged ≥18 years, with unspecified levels of ID. The PAS-ADD Checklist was used to screen for psychopathology and the Individual Schedule was used to rate: 'aggression', 'destruction of property', 'self-injury', and 'other unacceptable behaviour'. Increasing severity of problem behaviour was significantly associated with increasing number of psychiatric symptoms. Overall prevalence of psychiatric disorder was found to be over twice as high in those with 'more demanding' problem behaviour, compared to those without problem behaviour; depression was 4 times higher, and hypomania was 3 times higher. Of those with problem behaviour, 4 symptoms were found to be significantly more prevalent in those with self-injury than those without: 'odd gestures or mannerisms', 'phobic anxiety', 'jumpy' and 'avoidance/withdrawal'. Two of these symptoms are indicative of anxiety. However, the group displaying self-injury contained more individuals with profound ID and the authors noted that it is unclear whether this association with anxiety was due to presence of self-injury, or level of ID.

Although many studies have investigated the relationship between problem behaviour and health and disabilities, the findings are unclear given both the different types of problem behaviour and the health and disabilities investigated. Some suggest poor mobility is associated with problem behaviour (Kiernan & Alborz 1996), but others do not (Holden & Gitlesen 2003; Totsika et al 2008; Jones et al 2008).

Table 1.7.3 Studies reporting factors associated with problem behaviour

Associated Factors	**Study**	**Findings**
Personal Factors:-		
Age	Kiernan et al (1996)	Increasing age associated with occurrence of destructive behaviour
	Tyrer et al (2006)	Younger age associated with physical aggression.
	Bailey (2007)	No association between chronological age or developmental age and behaviour disorder.
	Lowe et al (2007)	Younger age was associated with destructiveness
	Cooper et al (2007a)	No association between age and problem behaviour
	Totsika et al (2008)	Younger age associated with persistent physical attacks
Gender	Deb et al (2001b)	No association between gender and overall problem behaviour. Female gender associated with severe behaviour disorder and self-injurious behaviour, but not physical aggression.
	Crocker et al (2006)	No difference between males and females for verbal and physical aggression scales Males scored significantly higher on the property aggression and sexual aggression scales than females

		Females scored significantly higher on the self-aggression scales than males
	Tyrer et al (2006)	Male gender associated with physical aggression.
	Bailey (2007)	No association between gender and problem behaviour.
	Jones et al (2008)	Female gender independently associated with problem behaviour
	Totsika et al (2008)	No significant difference between those with and without persistent problem behaviour in terms of gender
	Cooper et al (2009a)	Female gender independently associated with aggressive problem behaviour
	Cooper et al (2009b)	No association between gender and self-injurious behaviour
Level of ID	Moss et al (2000)	Severe ID associated with self-injurious behaviour.
	Deb et al (2001b)	Severe ID associated with severe behavioural disorders and self-injurious behaviour. No association between level of ID and less severe problem behaviour or physical aggression.
	Tyrer et al (2006)	Physical aggression more common in those with more severe ID.
	Lowe et al (2007)	Lower ability was associated with self-injurious behaviour.
	Jones et al (2008)	Lower ability level was associated with the prevalence of problem behaviour.

	Totsika et al (2008)	No significant difference between those with and without persistent problem behaviour in terms of level of ID
	Cooper et al (2009a)	Lower ability level independently associated with incidence of aggressive problem behaviour.
	Cooper et al (2009b)	Lower ability level independently associated with incidence of self-injurious behaviour.
Lifestyle and support:-		
Accommodation and support	Deb et al (2001b)	Living in congregate care was associated with behavioural disorders
	Tyrer et al (2006)	Compared with living independently, physical aggression was almost 5 times more likely in residents of National Health Service (NHS) accommodation and almost 3 times more likely in those living in residential care.
	Jones et al (2008)	Living in congregate care or with paid carer support rather than with a family carer was independently associated with prevalence of problem behaviour.
	Totsika et al (2008)	No significant difference between those with and without persistent problem behaviour in terms of length of stay in residential facility
	Cooper et al (2009b)	Not living with a family carer was independently associated with incidence of self-injurious behaviour.
	Cooper et al (2009a)	Not living with a family carer was independently associated with incidence of aggressive problem behaviour.

Day activities	Deb et al (2001b)	Severe behavioural disorders were found to be significantly more common in those who had current day activities. This association was not found for those with less severe behavioural disorders, physical aggression or self-injurious behaviour.
Past experiences:-		
Life events	Esbensen and Benson (2006)	Frequency counts of life events and all life events perceived as negative were associated with problem behaviour.
	Hulbert-Williams et al (2008)	Total unique life events score, negative life events score and weighted life events score were all positively associated with each psychopathology sub-scale of hostility and anger.
Health and disabilities:-		
	Kiernan et al (1996)	Poor mobility associated with occurrence of problem behaviour, having several problem behaviours, occurrence of physical attacks and self-injurious behaviour.
	Deb et al (2001b)	Epilepsy was significantly associated with having severe behavioural disorder. Those taking psychotropic medication were more likely to have severe behavioural disorders, physical aggression and self-injurious behaviour.
	Bailey (2007)	Higher HoNOS scores were associated with problem behaviour.

	Jones et al (2008)	Urinary incontinence, visual impairment, attention deficit hyperactivity disorder and not having severe physical disabilities were associated with prevalence of problem behaviour.
	Totsika et al (2008)	Fewer mobility problems associated with persistent physical attacks, self-injurious behaviour, 'other' disruptive problem behaviour and overall problem behaviour. No significant difference between those with and without persistent problem behaviour in terms of epilepsy, vision, hearing impairment, psychiatric disorder or communication skills.
	Cooper et al (2009a)	Urinary incontinence and attention deficit hyperactivity disorder were independently associated with incidence of aggressive problem behaviour.
	Cooper et al (2009b)	Visual impairment and attention deficit hyperactivity disorder was independently associated with incidence of self-injurious behaviour.

1.7.4 Studies reporting factors predicting problem behaviour

Only 1 study has been found to investigate factors predictive of problem behaviour. Thus it is not possible to make definitive conclusions. The study suggests that lower level of ID, not living with a family carer, experiencing life events and experiencing parental divorce in childhood are predictive of incident problem behaviour (Smiley et al 2007). No relationship was found between incident problem behaviour and age.

The findings above suggest that more research is required to investigate the factors associated with and predictive of mental ill-health and problem behaviour. Specifically, research investigating associated factors is needed in order to elucidate some of the contradictory findings, and research investigating predictive factors is needed to address the paucity of current findings. Comparison of the existing literature is problematic given the different types of mental ill-health and problem behaviour investigated. This is further complicated when studies investigate different variables which have been measured and categorised using different methods. Future research is needed to address this issue and provide clarification. This is important so that 'at risk' individuals can be identified at an early stage.

Table 1.7.4 Studies reporting factors predicting problem behaviour

Predictive Factors	**Study**	**Findings**
Personal Factors:-		
Age	Smiley et al (2007)	No relationship between age and 2-year incidence of problem behaviour.
Level of ID	Smiley et al (2007)	Lower ability level found to be predictive of incidence of problem behaviour.
Lifestyle and support:-		
Accommodation and support	Smiley et al (2007)	Not living with a family carer was related to incident episodes of problem behaviour.
Past experiences:-		
Life events	Smiley et al (2007)	A higher number of life events in the preceding 12-months were related to incident episodes of problem behaviour.
Other adversity or abuse	Smiley et al (2007)	Experience of parental divorce in their childhood was predictive of incident problem behaviour.

1.7.5 Determining causality of predictive factors

Given the paucity of research investigating factors predictive of mental ill-health and problem behaviour outcomes, future research must attempt to determine whether predictive factors are indeed causally related to the outcome of interest. However, determining causality is a complicated process. Howick, Glasziou and Aronson (2009) suggest the use of three categories, to aid establishing causal relationships. The three categories are:

1. **Direct evidence** 'from studies (randomized or non-randomized) that a probabilistic association between intervention and outcome is causal and not spurious'
2. **Mechanistic evidence** 'for the alleged causal process that connects the intervention and the outcome'
3. **Parallel evidence** 'that supports the causal hypothesis suggested in a study, with related studies that have similar results'

Evidence which is 'direct' shows an effect which is not attributable to plausible confounding factors; is preceded by the cause, within an appropriate time interval; and may have a dose-response relationship. Evidence which is 'mechanistic' provides a plausible explanation of the link between cause and effect; or is coherent with existing knowledge. Finally evidence which is 'parallel' has been replicated in other studies; or has been shown in similar studies.

1.8 Resilience to mental ill-health and problem behaviour

In a recent literature review, the term resilience was understood to be "*positive adaptation, or the ability to maintain or regain mental health, despite experiencing adversity*" (Herrman; Stewart; Diaz-Granados; Berger; Jackson & Yuen, 2011). The authors concluded this to be an important construct, and one which "*mental health professionals should collaborate with policy-makers* to bolster, through *developing policies and interventions*". Despite its clear importance, none of the literature reviewed in sections 1.6 and 1.7 investigated resilience: i.e. it was not explored in any of the longitudinal studies investigating mental ill-health and problem behaviour outcomes, nor any of the studies investigating factors associated with or predictive of mental ill-health and problem behaviour outcomes. Clearly, there is a dearth of literature investigating resilience in the adult ID population. Consequently, findings from the general population will be examined, in order to inform the work of this PhD.

Hermann et al (2011) suggest that resilience comes from a range of sources, including personal, biological, and environmental-systemic factors. Personal factors include, for example, intellectual functioning, emotional regulation, social attachment and positive self-concepts. Research investigating biological factors has reported that harsh early environments can affect the development of the brain, causing changes which further impact biological processes, affecting vulnerability to psychopathology (Curtis & Nelson, 2003; Cicchetti & Curtis, 2006). On a macro-environmental level, Herman et al (2011) suggest that constructs such as social support are correlated with resilience. Similarly, they suggest that in maltreated children, secure attachments with non-abusive parents and good parenting skills are associated with better psychological wellbeing and fewer behavioural problems. Other research has reported similar findings. For example, a study investigating early life stress found that 26 patients with major depressive disorder reported greater exposure to inter-parental violence than a group of age and gender matched healthy controls (Seok; Lee; Kim; Lee; Kang; Ham; Yang & Chae, 2012). Seok et al (2012) also reported that with regards to resilience, self-confidence and self-control were significantly associated with depressive symptom score.

It is apparent then that in the general population, any investigation of resilience must consider a range of factors. As such it is likely that a range of factors will play an important role in the ability to maintain health in the ID population; however, whether these factors will be similar remains unknown. It is therefore necessary to determine what these factors are, so that, once validated by future research, interventions can be targeted at maintaining mental health in the ID population.

1.9 Social factors associated with mental ill-health: preliminary indications

Few studies have directly investigated the associations between social components (such as support, inclusion and exclusion) with mental ill-health. However, some studies have measured both social components and mental health, allowing preliminary indications to be made. For example, in their prevalence study, Hassiotis et al (2008) compared social relationships between adults with borderline ID and adults without ID. They found that those with borderline ID were more likely to have no close friends or fewer close friends, and were less likely to live as part of a couple. Although those with ID had both poorer mental health and social relationships, the authors did not directly compare these measures to determine whether a significant association exists.

In a more recent study, a comparison was made between adults with ID living in a rural area on the West Coast of Scotland (n=39) with adults with ID living in an urban area (n=633) (Nicholson 2012). A range of factors were compared, including social exclusion and mental health. No significant differences were found between the two groups in terms of age, gender, level of ID, ethnicity, mental ill-health or a range of common comorbidities. However, the rural sample was significantly more likely to have regular daytime opportunities – including employment and attendance at resource centres – relative to the urban sample. The rural sample was also more likely to have been on holiday, but less likely to regularly use community facilities. The author also investigated social support and the quality of social relationships. They found that both groups had a similar number of contacts with people across different situations, but suggested that relationships may have been closer for the urban sample. For example, the rural sample were less likely to have one or more best friends, tell secrets to anybody, and have meals with family or friends on a regular basis. However, they were more likely to stay away overnight with friends or relatives, or to have friends or relatives stay overnight at their own home. Given that differences were found between the two groups for social factors but not mental ill-health, it may be that such factors have little impact or are not connected reliably with mental health. However, because the relationship between social factors and mental ill-health were not directly investigated, conclusions cannot be made. Also,

although differences were found in the type of activities the two groups participated in, it is not known whether there were any differences between other factors which may be more relevant to wellbeing. For example, autonomy over which activities to participate in and with whom to participate, as well as whether such interactions were positive or negative.

Miller and Chan (2008) investigated the role of life skills and higher-order predictors of life satisfaction in a sample of 56 adults with ID. Participants, aged an average of 43.3 years, were recruited from two community support agencies. Level of ID was unknown, however all participants were in paid employment and the authors stated that they could be described as having a 'relatively high level of adaptive functioning'. Interviews were conducted with the participants using 3 self-report questionnaires to measure life satisfaction. These included the Quality of Life Questionnaire (QOLQ), the Personal Resource Questionnaire (PRQ-85) and the Leisure Activity Skills Scale (LASS). The life skills they investigated included 'interpersonal, instrumental and leisure', and the higher-order predictors included 'social-support, self-determination, and productivity'. Using hierarchical regression analysis they found that higher levels of social support predicted higher levels of life satisfaction. However, given the cross-sectional nature of the study causality of the relationship cannot be determined. Nevertheless, the findings provide evidence of a relationship between social support and life satisfaction.

Other research has provided evidence of a relationship between satisfaction and mental ill-health: the authors investigated factors associated with 'expressed satisfaction' in a community sample of 96 adults with ID (Gregory, Robertson, Kessissoglou, Emerson, & Hatton 2001). The participants were residents of village communities (n=45) and residents of community-based residential supports (n=51), aged an average of 41.9 years with unspecified level of ID. Interviews were conducted with the participants using a range of measures including: the Residential Services Setting Questionnaire (RSSQ), The Architectural Features Scale (AFS), The Group Home Management Interview (GHMI), The Index of Community Involvement (ICI), the Social Network Map (SNM), The Choice scale, The Risks Scale and the PAS-ADD Checklist. From these, seven domains of satisfaction were investigated: home; daytime activities; social and recreational activities; support from services; friendships and relationships; choice; and risks. For the 'friendships and relationships' domain the authors investigated activities undertaken with friends, and

the frequency of contact with friends and family. They found a positive association between the number of days and hours per week which participants had regular access to structured day-activities, and expressed satisfaction of their accommodation, day activities, and friendships and relationships. They also found that individuals who had more people with ID in their social networks, and a greater proportion of people with ID in their social networks, showed an association with increased satisfaction with friendships and relationships. Mental health was associated with satisfaction with friendships and relationships. Specifically, a direct association was found between fewer mental health problems and increased satisfaction. Given that Miller and Chan (2008) found social support to predict satisfaction, and Gregory et al (2001) found satisfaction and mental health to be related, it seems reasonable to investigate whether a relationship also exists between social support and mental health.

Other research has provided more direct indications of a relationship between social components and mental ill-health. In their study on life events and psychological problems in those with ID, Hulbert-Williams et al (2011) investigated the impact of social support. The authors used the SNM to determine whether social support had a moderating effect on the relationship between life events and mental ill-health. They found no evidence to support this theory. However, they suggested 2 possible reasons for this result: 1) unlike the general population, social support may not moderate the relationship between life events and psychological problems in adults with ID, or 2) the SNM may not have the sensitivity necessary to measure the aspects of social support which are important to people with ID. The authors stated that there is a need for further investigation in this area.

Similarly, Emerson and Hatton (2007) found no relationship between social components and self-rated health. They recruited 1273 adults with mild and moderate ID from an existing survey investigating learning difficulties in England. The majority of participants were aged 16-54 years (89%) and lived in private households (75%). Face-to-face interviews were conducted with participants either alone (56%) or in the presence of another individual (such as a paid carer, advocate, family member, friend or partner). Health was measured by asking participants whether they would rate their health as ‘very good, fairly good, or not good’ in the last year. Five indicators were used to collect data on social participation and networks (instrument unspecified). For example, the first indicator

measured whether or not individuals had participated in 9 different community-based activities in the previous month. The findings revealed no significant association between health status and social participation or networks. However, being interviewed alone was found to be independently associated with poor health status. The authors suggest that this may be a reflection of third party influence on responding, or the influence of some other unmeasured variable relating to third party presence and self-related health. They do not speculate whether it may also be a reflection of social support. This research suggests that there is no relationship between health and social components; however given that a self-report measure of general health was used, and not an assessment of mental health, conclusions cannot be made.

Conversely, other research has reported an association between social support and mental ill-health. The authors analysed data from an existing survey of 3392 young adults aged 15-29 years (Honey, Emerson, & Llewellyn 2011). Of these, 475 were self-reported to have a physical-, sensory- or intellectual- disability. It is not clear what proportion of the sample had ID, and the level of severity was not specified. Mental health was measured in the survey using the Mental Health Scale of the SF-36 which measures symptoms of depression, anxiety and positive mental health. It consists of 5 questions which ask participants to indicate how they have felt in the past 4-weeks, based on a 6-point scale from 'all of the time' to 'none of the time'. Social support was measured using 10 statements, which participants were asked to indicate the extent of their agreement based on a 7-point scale (from 'strongly agree' to 'strongly disagree'). For both those with and without disabilities, lower social support was found to be associated with poorer mental health. This effect was found to be stronger for people with disabilities compared to people without disabilities, thus providing evidence for a relationship between social support and mental ill-health. However, given that this finding refers to a combination of people with physical, sensory and intellectual disabilities, it is not possible to make any definitive inferences regarding the ID population per se.

None of these studies directly measured whether a relationship exists between mental ill-health (using psychiatric assessment) and social components, in a sample of adults with ID. Therefore it is not known whether such a relationship exists. However, the findings from each of these studies, once considered together, are suggestive and indicate that further

research is warranted. In the general population, various social components have been identified as risk and protective factors against mental ill-health. For example, 'peer rejection', and 'isolation and alienation' have been identified as risk factors, whereas 'social support and community networks' and 'positive interpersonal interactions' have been identified as protective factors for mental health problems (World Health Organization 2013b). It is possible that such constructs could have a similar role in the ID population, but further research is needed to determine this.

1.10 Summary of literature and rationale for current study

It is now widely agreed that people with ID can and do experience the same mental health problems as the general population, but at higher rates and manifesting through different patterning (e.g. problem behaviour). However, accurate estimates of mental ill-health in this population remain unclear. Prevalence rates have varied greatly between studies, and this is due to methodological issues such as; method of case ascertainment, representativeness of samples, use/type of diagnostic criteria and definitions of ID, mental ill-health and problem behaviour (Smiley 2005). Considering the range of published studies, the prevalence of mental ill-health and problem behaviour in adults with ID is reported to be between 30 and 50%.

There is limited research on the incidence and remission rates of mental ill-health in the adult ID population. Some research has reported incidence rates to be much lower than prevalence rates (Smiley et al 2007), suggesting that the majority of mental ill-health is made up of persistent illness. However, it remains unknown whether mental ill-health is indeed persistent in adults with ID over time. Few studies have conducted longitudinal investigations into the long term outcomes of mental ill-health and problem behaviour, and those that have are restricted by methodological limitations. Such limitations include those observed in prevalence studies; however, longitudinal studies are further complicated by additional design issues. For example: the frequency of, and duration between follow-up investigations; whether outcomes are reported at a group or individual level; and the manner in which outcomes are defined. Only 2 studies have carried out investigations spanning over a 10-year period in adults with ID (Reid et al 1978; Reid & Ballinger 1995; Thompson & Reid 2002; Totsika et al 2008). Neither of these studies conducted

intermediate follow-up investigations within the 10-year period and they do not report trajectories of mental ill-health. Thus there have been no longitudinal studies of adults with ID over a 10-year period, including intermediate investigations. Therefore, it has not been possible to determine whether adults with ID experience persistent mental ill-health, or episodes of relapse and remission over time.

Although several studies have investigated the factors associated with mental ill-health and problem behaviour, few have investigated predictive factors. Most of the factors investigated have resulted in contradictory findings, suggesting that more research is needed. No research has directly investigated associations between mental health and social components, such as support, inclusion and exclusion.

In a Cochrane review of behavioural and cognitive behavioural interventions for aggressive behaviour in adults with ID, the authors (Hassiotis and Hall 2008) reported the maximum follow-up assessment period to be 4 months post intervention. They concluded that further intervention studies are needed which would continue over a longer time frame, and consider other factors such as quality of life and cost effectiveness. Such findings will undoubtedly be of great importance to policies and good clinical practice accordingly. A logical first step is to identify the natural history of the trajectory of mental ill-health and problem behaviour in adults with ID over time. It is imperative to understand this trajectory in order to: allow services to plan for the long term support needs of individuals; identify the risk factors associated with mental ill-health, in order to facilitate research of new interventions; and to thus help policies implement efficacious changes which are proven to improve mental health in the ID population. Crucially, such knowledge will enable people with ID, together with their family and/or carers to plan for their future.

CHAPTER 2: AIMS AND HYPOTHESES

2.1 Aims

2.1.1 Primary aim

- To determine the trajectory of mental ill-health and problem behaviour over a 10-year time-period, in a cohort of adults with mild to profound ID.

2.1.2 Secondary aims

- To determine the factors predictive of mental ill-health and problem behaviour outcomes over a 10-year time-period, in adults with mild to profound ID.

- To investigate the relationship between lifestyles, social support, and mental ill-health, in adults with mild to profound ID.

2.2 Research questions

The primary outcome is the trajectories of mental ill-health as measured by the PAS-ADD Checklist and Problem Behaviour Checklist

1. What is the distribution of mental ill-health and problem behaviour in adults with ID, at 3 time points over a 10-year period?

2. Does mental ill-health persist or remit over a 10-year time-period, in adults with ID?

3. Does problem behaviour persist or remit over a 10-year time-period, in adults with ID?

4. To what extent do total PAS-ADD Checklist scores change, at 3 time points over a 10-year period?

The secondary questions are investigations of the longitudinal predictive determinants, and cross-sectional associated factors with mental ill-health

5. What factors predict deterioration in mental health, in terms of an increase in total PAS-ADD Checklist scores over time?

6. What factors predict mental ill-health outcomes, such as relapse, onset and resilience, over a 10-year time-period?

7. What factors predict problem behaviour outcomes, such as relapse, onset and resilience, over a 10-year time-period?

8. Is there a relationship between total PAS-ADD Checklist scores and lifestyle factors, at the time 3 investigation?

9. Is there a relationship between total PAS-ADD Checklist scores and social support, at the time 3 investigation?

2.3 Hypotheses

Hypotheses related to the descriptive primary outcome are:

1. There will be a similar distribution of mental ill-health and problem behaviour at 3 time points over a 10-year period.

2. Mental ill-health will be persistent over the 9-10 year time-period, for the majority of adults who were identified as having mental ill-health at baseline.

3. Problem behaviour will be persistent over the 9-10 year time-period, for the majority of adults who were identified as having problem behaviour at baseline.

4. Psychopathology will remain relatively stable over the 10-year time-period, in terms of total PAS-ADD Checklist scores.

Testable hypotheses related to the secondary research questions are:

5. Deterioration of mental health, in terms of increase in total PAS-ADD Checklist scores will be predicted by a range of factors, such as level of ID, gender, living arrangement, experience of life events and presence of urinary incontinence.

6. Mental ill-health outcomes will be predicted by a range of factors, such as level of ID, gender, living arrangement, experience of life events and presence of urinary incontinence.

7. Problem behaviour outcomes will be predicted by a range of factors, such as level of ID, gender, living arrangement, experience of life events and presence of urinary incontinence.

8. Severity of psychopathology, in terms of higher total PAS-ADD Checklist scores, will be associated with less frequent participation in social activities with peers.

9. Severity of psychopathology, in terms of higher total PAS-ADD Checklist scores, will be associated with lower levels of perceived social support.

CHAPTER 3: METHOD

3.1 Study design

During 2002-2004 (T1), a large scale population-based cohort was established to investigate mental ill-health in adults with ID, living in the Greater Glasgow & Clyde area of Scotland (Cooper et al 2007a). During 2004-2006 (T2) a follow-up was conducted to investigate incidence rates of mental ill-health (Smiley et al 2007).

This thesis presents a time 3 (T3) follow-up study, conducted during 2011-2012, investigating the longer term outcomes of mental ill-health and problem behaviour, as well as the risk factors associated with such outcomes. During the T1 investigations, all participants underwent detailed assessments conducted by one of six nurses specialising in ID, and trained in the use of the assessment measures. The assessments included a review of primary health-care case notes and face-to-face interviews with each participant and their paid or family carer. The team used the Vineland Scale, C21st Health Check, past IQ test scores and primary care records in order to ascertain level of ID, consistent with ICD-10-DCR criteria. In order to rule out any physiological causes of psychiatric symptoms, a phlebotomy protocol was devised. The PAS-ADD Checklist and Problem Behaviour Checklist were used to screen for psychopathology, and participants were identified as 'possibly, probably or definitely' having mental ill-health. In order to improve sensitivity from that previously reported, the authors used a lower cut-off threshold of any two symptoms (excluding specific phobias), or any one high-risk item. High risk items were defined as suicidal attempts or thoughts, persecutory behaviour, and hallucinations or delusions. Any participants meeting these criteria were referred to the project psychiatrists and underwent full face-to-face psychiatric assessment. Psychiatric assessment included completion of the PPS-LD: a semi-structured psychopathology scale allowing classifications to be made according to clinical, DC-LD, ICD-10-DCR and DSM-IV-TR criteria. All psychiatric assessments were then case conference by the project psychiatrists to agree diagnoses. This process, including use of the same assessments, was repeated during the T2 follow-up investigations. Some additional assessments were also completed. At the T3 follow-up, the research student Amanda Muir (AM) repeated the same psychopathology, problem behaviour, demographics, life experiences and social networks

assessments. Several new measures of lifestyle and social support were also administered (see section 3.6.14).

3.1.1 Power and sample size

The power of a significance test is the measure of "*how likely that test is to produce a statistically significant result for a population difference of any given magnitude*". In other words "*it indicates the ability to detect a true difference of clinical importance*" (Altman, 1980).

However, a power calculation was not performed for two reasons: firstly, the sample size was already defined by the size of the existing cohort (i.e. only those who participated in the baseline and T2 investigations could be invited to take part at T3); and secondly, there is no current literature which investigates the long term outcomes of mental ill-health and problem behaviour in the adult ID population, over a 10 year period, with intermediate follow-up investigations, hence assumptions to inform a power calculation would not be evidence based.

It was possible to potentially increase the T3 sample size by attempting to also recruit individuals who participated in the study at T1, but not at T2. However, this option was rejected due to 2 reasons. Firstly, the primary aim of the study was to investigate the trajectory of mental ill-health and problem behaviour at several time points over a 10-year period. The review of longitudinal studies investigating mental ill-health and problem behaviour found that only 2 studies had followed-up cohorts over a 10-year period. The major limitation of these studies was their lack of intermediate investigations: it was not possible to make definitive conclusions about whether psychopathology followed a persistent or relapsing-remitting course by conducting only 2 investigations which were 10 years apart. Thus, it was not desirable to choose a study method which would result in this same limitation. Secondly, my PhD studies allowed only 1 year for tracing, recruiting and interviewing participants; all of which was carried out solely by me. It would not have been possible to interview more than about 100 participants in the time available. This resulted in several potential participants not being traced. This is the major limitation of the

study. This time constraint also made it impossible to recruit individuals who had participated at T1 only.

It is not possible to perform an a priori power calculation given the lack of current literature which would be required to inform such a calculation. However, a post-hoc power calculation will be performed.

3.2 Ethical approval

Ethical approval was granted by the 'Scotland A Research Ethics Committee', and site approval by the sponsor, NHS Greater Glasgow and Clyde (Appendix A).

3.3 Cohort identification

During 2002-2004, all adults with ID aged 16 or older, living in the Greater Glasgow Health Board area were identified through multiple services. These included: the Health Board; the Scottish Executive Information and Statistics Department; social work services for people with ID; primary healthcare services; local specialist health services for people with ID and local authority funding arrangements for people receiving any paid support. In addition, all general practitioners in Greater Glasgow identified adults with ID registered with them. This led to an initial over-identification of potential participants, generally those who had low intellectual functioning and other needs, but did not meet ICD-10 criteria for ID. Such individuals were subsequently excluded. A total of 1548 adults were identified as meeting inclusion criteria and were invited to participate in a prevalence study (the baseline investigation at T1). Of these, 1202 completed baseline assessments; however, 179 were living outside of the defined geographical area for the prevalence study and so were not included. During 2002-2004, the 1023 adults who had been included in the prevalence study, along with the 179 who had not, were all invited to participate in an incidence study (the T2 investigation). Consent was received and assessments completed for 651 adults (giving a cohort retention rate of 70% after excluding deaths). In the T3 study, all 651 participants who had agreed to be re-contacted in the future were sent an invitation to participate to their last known address.

3.4 Consent

Consent to participate in the T3 follow-up was taken by the research student. The research student, trained in assessing capacity to consent, used developmentally appropriate explanations and gestures, in order to assess capacity to consent. Consent was sought from each participant who had the capacity to decide whether or not to consent. Where participants did not have capacity to consent for themselves, consent was sought from their next of kin or welfare guardian, in accordance with the Adults with Incapacity (Scotland) Act. Potential participants who did not have capacity to consent, or a next of kin or welfare guardian with capacity to consent on their behalf, were not included in the study. All participants and either their carer, or next of kin or welfare guardians were provided with an information sheet about the study. Participant information sheets were made in an easy read format in large font.

3.5 The T3 follow-up interview

The details of all adults who participated in the T2 investigations were held on a database, which was updated annually by the primary care liaison team (PCLT). The most recently updated version of this database was used to identify any participants who had died since T2, and the last known address of the remaining participants. An attempt was made to trace participants who no longer lived at the last known address. All participants were sent a written invitation and DVD (featuring the research student AM and a person with ID), which provided some information about the T3 follow-up. Invitations included a response sheet which participants were asked to return, indicating whether or not they were interested in finding out more about the study. Participants who responded as being interested in the study, and those who did not respond at all, were contacted via telephone to find out if they would like more information about the study. Those who responded indicating that they were not interested in the study were not contacted again. Arrangements were made to meet participants who had received information about the study and had indicated that they were interested in participating. Consent was taken from the participant where appropriate, and the interview was carried out by the research student. Where consent could not be given by the participant, their next of kin or welfare guardian was contacted and consent sought. Arrangements were subsequently made to

interview the participant. Where next of kin or welfare guardians could not be contacted or declined to consent, participants were excluded from the study. For each interview, the research student requested the presence of a paid or family carer who knew the participant well, and with whom the participant was comfortable to discuss private issues. Each interview lasted between 1 to 4 hours and was usually completed in one visit, although on some occasions several visits were made at the request of the participant and/or their carer. All interviews were face-to-face, although on occasion it was necessary to make telephone calls afterwards to gather additional information after discussion of findings on each participant with the supervisor.

3.6 Assessments used in the present study

Data from all of the following instruments were used in the present study; however, not all of the following instruments were completed at T3. The time points at which each instrument was completed are detailed in table 3.6.14 (page 110).

3.6.1 The Modified PAS-ADD Checklist

The PAS-ADD Checklist is a questionnaire which was developed to screen for mental ill-health in adults with ID. It was primarily designed to be used by non-professionals such as family members, or paid carers who have known the individual for a minimum of 6 months. A modified version of the PAS-ADD Checklist was used to screen all participants for mental ill-health. The PAS-ADD Checklist consists of two sections: the first which measures life events, and the second which measures psychiatric symptoms. The life events section lists 20 events, for example: the death of a parent or family member; a change in day centre/day opportunities; bullying or harassment. Respondents are asked to identify which, if any, the individual has experienced in the past 12 months. They are also asked to identify any other life events experienced by the individual, which have not been covered by the 20 items on the list. There is a final option for the respondent to indicate that the individual has not experienced any life events in the past 12-months. The psychiatric symptom section in the original PAS-ADD Checklist consists of 29 items. For example, "*irritable or bad tempered*" or "*startled by sudden sounds or movements*". For each item, respondents are asked to choose one of four possible responses most appropriate

for the individual. The four possible responses indicate that the symptom has: 1) not happened in the past 4 weeks, 2) happened in the 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. Each response receives a different score (from 0-2) depending on which item it refers to. These scores may be grouped into 3 categories of disorders: affective/neurotic, organic and psychotic. Each disorder has a proposed threshold score (affective/neurotic= 6, organic= 5 and psychotic= 2). A participant is indicated to have a potential disorder if they exceed the threshold for that disorder.

The psychometric properties of the PAS-ADD Checklist have been found to be acceptable by both its authors (Moss et al 1998; Simpson 1998) and independent researchers (Sturmey, Newton, Cowley, Bouras, & Holt 2005), who reported its subscales to have high internal consistency, with Cronbach's Alphas ranging from 0.5-0.9. Moss et al (1998) stated that as the primary purpose of the PAS-ADD Checklist is to identify 'at-risk individuals', the most important measure of inter-rater reliability is the agreement between raters on scores which exceed the thresholds. They found that 79% of decisions were in agreement and considered this to be reasonably acceptable. The PAS-ADD Checklist has also been found to have satisfactory validity, with Moss et al (1998) reporting detection rate to increase with severity of disorder. Sturmey et al (2005) also reported good validity, finding the affective/neurotic scale to correctly identify people with depressive disorder, and similarly the psychotic scale to identify those with schizophrenia spectrum disorder. They also reported the PAS-ADD Checklist to have sensitivity of 66%, specificity of 70% and concluded it to be 'the best psychometric measure available'. As part of the development of the PAS-ADD Checklist, Simpson (1998) performed analyses using receiver operating characteristic (ROC) curves to identify the optimum method for completing and scoring the PAS-ADD Checklist. The four scoring methods analysed were 'Likert scoring', 'any positive', 'midpoint' and 'HARC'. 'Likert scoring' comprised the summation of scores based on a 0-3 point scale; 'any positive' consisted of recoding all positive scores as 1 before summation; 'midpoint' consisted of scores of 0 or 1 recoded as 0, and scores of 2 or 3 recoded as 1 before summation; 'HARC' consisted of a scoring method devised by Dr Steve Moss of the Hester Adrian Research Centre (HARC). For each of these methods, Simpson investigated: which source of information provided the greatest area under the ROC curve; performance if a second informant only was used;

performance when composite score from main carer and second informant was used; and the effect of excluding people with profound ID. He found little difference between the 4 scoring methods, although use of main carer information always achieved the greatest area under the ROC curve. No effect was found by excluding people with profound ID. Simpson concluded that the best overall performance was achieved through using the main carer only, with the 'any positive' scoring method. Furthermore, he found that the best sensitivity cut off between cases and non-cases was obtained with a score of ≥1 when using this method with DSM-IV and ICD-10 criteria. However, the false positive rate was found to be around 50% until the cut off reached ≥3.

In order to address some of these limitations, 5 modifications were made to the PAS-ADD Checklist in an attempt to improve its overall detection rate.

1. In order to eliminate the subjective decision by carers as to whether a symptom was a problem or not, the response 'has happened in the past 4 weeks but has not been a problem for the person' was removed. The response 'has been a problem for the person in the past 4 weeks' was thus changed to 'has occurred for the person in the past 4 weeks'.

2. Additions (shown in bold font) were made to the wording of 6 items in order to enhance the description of each symptom, thus facilitating their identification:
   - "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 **(socially withdrawn), or reduced speech/communication**"
   - "restless or pacing, unable to sit still; **or increased over-activity**"
   - "**more** irritable or bad tempered **than usual or reduced tolerance**"
   - "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 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**"

3. Six new items were added in order to improve the detection rate of psychosis and mania:
   - "Increased lability of mood; mood rapidly alternating between misery and elation"
   - "Excessive talking, singing or laughing, more so than usual for the person"
   - "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"
   - "Increased interest in sex, or sexual indiscretions which are out of keeping with usual behaviour"
   - "More tearful than usual"
   - "Concern that people or the television are referring to her/him, or giving her/him messages or instructions (when this is not the case)"

4. A glossary of symptom definitions (see Appendix B) was developed by a research psychiatrist (Dr Elita Smiley) which provided instructions for completing the modified PAS-ADD Checklist and detailed descriptions of its 35 items. The glossary provides an explanation of the difference between long-term symptoms which are present due to chronic mental illness and those which are thought to be life-long traits of the individual. It also clarifies the circumstances under which a symptom should be rated as severe.

5. The scoring system was modified so that a total score of ≥2 was used to indicate possible mental ill-health. However, 2 exceptions to this rule were implemented. Firstly, any total score equal to 2, due to positive scoring (of 1 or 2) on question 4 were excluded as meeting criteria for possible mental ill-health. Question 4 indicates phobias, which are of a high frequency and could thus be over-inclusive. Secondly, any of the following 'high risk' items scoring 1 were used to indicate possible mental ill-health:

- "Attempts suicide or talks about suicide"
- "Suspicious, untrusting, behaving as if someone is trying to get at or harm her/him"
- "Strange experiences for which other people see no cause, such as hearing voices or seeing things that other people do not"
- "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"
- "Concern that people or the television are referring to her/him, or giving her/him messages or instructions (when this is not the case)"

In this thesis, comparisons are drawn between PAS-ADD Checklist scores at T1, T2 and T3. This same definition was used at all 3 time points, i.e. total score of ≥2, excluding score on question 4; or 1 high risk item scored positively. Throughout the rest of this thesis, participants reaching this threshold will be referred to as having mental ill-health. At T1, screening using the PAS-ADD Checklist identified 367 participants (35.9% of the cohort) as 'possibly, probably or definitely' having mental ill-health (excluding problem behaviours, autism and specific phobia). After receiving a full psychiatric assessment, 227 (22.2% of the cohort) were diagnosed with a mental illness. Therefore, 61.9% of those who underwent psychiatric assessment as a result of PAS-ADD Checklist screening received a clinical diagnosis of mental ill-health. Given the modifications made to the PAS-ADD Checklist, we cannot assume that its psychometric properties are the same as previously reported. However, the modified version of the PAS-ADD Checklist was used at both previous investigations. This suggests that the modifications made to the PAS-ADD Checklist did not impair its validity or sensitivity, and in fact may have improved its sensitivity.

At T3, the PAS-ADD Checklist was completed by the interviewer in the presence of a paid or family carer. When required, further explanation or examples of the items were provided by the interviewer, in accordance with the Glossary of Symptoms. The interviewer recorded all information reported by the individual and their carer, as well as observations of relevant behaviour. Each case was discussed with a psychiatrist (SAC)

specialised in working with adults with ID to ensure the PAS-ADD Checklist had been scored appropriately. Where the psychiatrist deemed a participant as requiring further psychiatric assessment or treatment, consent was sought from the appropriate person to allow a referral to be made to the participant's general practitioner or psychiatrist.

3.6.2 The Problem Behaviour Checklist

The Problem Behaviour Checklist (Appendix B) is a purpose designed measure, used to diagnose a range of problem behaviours in adults with ID, according to DC-LD criteria. Information is recorded for verbal aggression, physical aggression, destructive behaviour, self-injurious behaviour, sexually inappropriate behaviour, excessively demanding behaviour, oppositional behaviour, pica, faecal smearing, wandering, and 'other' problem behaviour. The checklist determines whether the participant experiences current problem behaviour, has experienced a past episode, or does not experience problem behaviour. For current or past problem behaviour, information is collected regarding the frequency, duration and severity of the behaviour. The checklist then determines: the setting within which the behaviour occurs; whether the person is known to have a physical illness; whether the person is known to have a psychiatric illness; whether the problem behaviour has a negative impact on the person's life; whether the problem behaviour has a negative impact on another person's quality of life; and whether the problem behaviour risks the health and safety of the person or someone else.

In the DC-LD field trials, investigators were asked to provide clinical diagnoses for 709 cases (Cooper et al 2003). Exact agreement between clinical opinion and DC-LD diagnosis was found for 96.3% of the 709 cases. Of the 709 cases, 319 were specific subtypes of problem behaviour. The psychometric properties of the Problem Behaviour Checklist were also investigated in the Cooper et al (2009b) self-injurious behaviour study (based on T1 data). Inter-rater reliability was tested for 30 participants, whose measurements for 7 categories of problem behaviour were blindly repeated with a different rater. This resulted in a comparison of 210 pairs of problem behaviours. Inter-rater reliability was found to be high across these categories, with Cohen's Kappa ranging from 0.79-1.0.

The psychiatrist (SAC) reviewed the information recorded on each Problem Behaviour Checklist and determined whether the information was indicative of a DC-LD problem behaviour. Where necessary, the psychiatrist consulted participant case notes to inform her decision. In accordance with DC-LD criteria, a distinction was made between problem behaviour which resulted from physical illness, mental illness or that which was present in the absence of either physical or mental illness. Consent was sought from the appropriate person to refer any participant deemed as requiring further psychiatric assessment or treatment.

3.6.3 Demographics questionnaire

A demographics questionnaire (Appendix B) was compiled to collect information on a range of personal and health factors; contact with other professionals; and medications. Personal factors included age; type of accommodation/support; and employment/day opportunities. Health factors were coded 'yes' or 'no' and included whether the participant was a smoker; had epilepsy; urinary incontinence; impaired mobility; visual impairment and hearing impairment. Participants were asked about whether they were currently in contact with a range of professionals including a: dietician, speech and language therapist, physiotherapist, occupational therapist, psychologist, psychiatrist, other doctor, community learning disabilities nurse, epilepsy nurse, practice nurse, social worker, care manager, or 'other' professional. Participants were asked for a list of any medications they were currently taking, and the dose and frequency of these was recorded.

3.6.4 The Modified Interview Measure of Social Relationships (IMSR)

The IMSR (Appendix B) was developed to measure the size and density of a person's primary social network, and contacts with acquaintances or others. It also measures satisfaction of interactions and whether relationships are supportive. The authors describe the measure as being concrete and direct, which they suggest make it more appropriate for use with people who are 'mentally ill or poorly educated' than other abstract measures (Brugha, Sturt, MacCarthy, Potter, Wykes, & Bebbington 1987). In its original evaluation, the IMSR was reported to have good inter-rater reliability and high temporal stability, when used in typically developing people with depression. Inter-rater reliability was based

on analysis of 19 audio-taped interviews, and resulted in an overall mean weighted Kappa of 0.85. Stability of measures was based on 2 interviews (4 months apart) with 110 participants. Highly significant Pearson correlation coefficients ranging from 0.5 to 0.8 were found for the variables 'number of relationships' and 'social contacts' in the previous week, suggesting high stability. However, the variables 'adequacy of social interaction' and 'social support' were found to be much less stable over time, although significant positive correlations were found for the most part. In a more recent study with the general population, the IMSR was reported to have excellent internal consistency for the measures of network size and perceived social support (Leskelä, Melartin, Rytsälä, Jylhä, Sokero, Lestelä-Mielonen, & Isometsä 2009). In order to make it applicable for use in the ID population, the IMSR was modified. The modified version determined the number of social contacts made in the past week; the number of positive and negative interactions in the past week; and whether the individual had any close relationships. Participants were asked to think about the past week and report how many people they had been in contact with who: they saw at home; were relatives they did not live with; they worked with; were other friends; were at faith gatherings; were other acquaintances, and who were professionals. For each of these, some examples or prompts were given. For example, for people who they lived with, participants were asked about other tenants, flat-mates, residents, live-in partners, relatives at the same address and support workers. If participants were not in employment they were asked about their usual day opportunity, for example college or day centre. To assess positive and negative interactions, participants were asked to report in the past week the number of people with which they had experienced: some form of angry exchange, confrontation or argument; a minor disagreement or problem, and an enjoyable social interaction. Any description of bullying or harassment was included as an angry exchange. To assess close relationships, individuals were asked whether they had someone they were particularly close to, and how many people they would trust to share a secret with.

3.6.5 The BILD Life Experiences Checklist (LEC)

The LEC was designed specifically for use in adults with ID to measure 'the extent to which they enjoy experiences common to many other members of the population' (Ager 1998). It consists of 50 items divided between 5 broad topics: 'Home', 'Leisure',

'Relationships', 'Freedom' and 'Opportunities'. An example of an item is: 'I stay overnight with friends at least once a year'. Participants are asked to indicate which items apply to themselves. Ager (1997) reported high inter-rater reliability for the LEC, with overall agreement of 0.96. Ager, Myles and Green (2001) also reported validity of the LEC, which they found to be highly correlated with the ICI at pre-move (0.78) and post move (0.72) assessments, of adults resettling into the community. Six items were adapted from the LEC and included in the current study. Four of these asked participants to rate the frequency with which they met friends and family in different situations. They were also asked whether they were on a first name basis with their neighbours, and to rate how often they spoke to them. Finally they were asked whether they spent most of their social and leisure time with other people with ID, other people without ID, or a combination of both.

3.6.6 The Modified Index of Perceived Social Support

The modified Index of Perceived Social Support consists of 7 statements adapted from a social support measure, developed for use in the general population in 1981 (Davidson, Bowden, Tholen, James, & Feller). The original measure, which consisted of 5 statements, was reported to have acceptable internal consistency, with Cronbach's Alpha coefficient of 0.86 for overall social support (Davidson et al 1981). The measure was used in the 1987 Health and Lifestyle Survey (Cox, Blaxter, Buckle, Fenner, Golding, Gore, Huppert, Nickson, Roth, Stark, Wadsworth, & Wichelow) and more recently in 2005 (Brugha, Weich, Singleton, Lewis, Bebbington, Jenkins, & Meltzer), when it had acquired 2 extra statements. It is not clear which author added the extra items, and neither study reported on the psychometric properties of the measure. The 7 statements used in the general population study by Brugha et al (2005) were as follows:

There are people I know – amongst my family or friends –

(1) Who do things to make me happy

(2) Who make me feel loved

(3) Who can be relied on no matter what happens

(4) Who would see that I am taken care of if I needed to be

(5) Who accept me just as I am

(6) Who make me feel an important part of their lives

(7) Who give me support and encouragement

Participants were asked to state whether each statement was 'not true', 'partly true', or 'certainly true' with regards to their family or friends.

In order to make the questions applicable for use in the ID population, the wording of each was changed as follows:

My friends and family

(1) Make me happy

(2) Love me

(3) I can depend on them

(4) Take care of me when I need them

(5) Accept me

(6) I am important to them

(7) Support and encourage me

Participants were asked to state whether they felt each statement was 'never', 'sometimes' or 'always' true. This measure was used at T3 only.

3.6.7 The Index of Community Involvement (ICI)

The ICI (Raynes, Sumpton, & Pettipher 1989a) was designed specifically for use with adults with ID to measure 'the extent of involvement in activities and use of facilities based in the local community' (Raynes 1988). It was originally designed in 1979 for adults residing in institutions in the USA (known as Form I). In 1986 it was modified for use with adults living in a variety of residential facilities in England (known as Form II).

Form II consists of 15 items and can be scored using either group-based ratings or individual-based ratings. The present study used the ICI Form II, scored using individual-based ratings. Each item describes an activity, for example, 'been to a café' or 'been to a hairdresser'. For 14 of the items, individuals are asked to state whether they have participated in each activity in the past month (using a yes or no response). For the last item, participants are asked to rate whether or not they have 'been on holiday in the past 12 months'. An extra item was added to the measure, asking participants whether they had been on 'trips out with family or friends' in the past month. A response of 'yes' is scored as 1 and a response of 'no' is scored as 0, all items are then summed to give a total score. Both versions of the ICI were originally evaluated in a study of 145 people residing in 28 hospital and Local Authority hostels, and 17 Private and Voluntary residential facilities in England. Raynes (1988) reported inter-rater reliability to be high, with agreement ranging from 95-96%. Internal reliability was found to be acceptable, with a Cronbach's Alpha of 0.77. The ICI was also reported to have validity in that it could differentiate between living units accommodating people with ID. The Ager et al (2001) finding of a high correlation between the LEC and the ICI also provides evidence of validity for the ICI. They also reported high inter-rater reliability of 0.98, based on 20 blind coded assessments. This measure was used at T3 only.

3.6.8 The Index of Participation in Domestic Life (IPDL)

The IPDL (Raynes, Sumpton, & Pettipher 1989b) was designed specifically for use with adults with ID to measure 'the extent to which residents are given opportunities to participate in everyday domestic tasks' (Raynes 1988). It was developed in a study including 150 living units in 3 different types of residential facilities for adults with ID in England. The IPDL consists of 13 items, each of which describes a domestic task, for example, 'shopping for food' or 'cleaning own bedroom'. Participants are asked to indicate whether in the past month they have participated in each activity using a 3-point scale: alone, supported, or not at all. All items are then totalled, with higher scores indicating greater opportunity for participation. Raynes (1988) reported inter-rater reliability to be high, with agreement ranging from 95-96%. Internal reliability was found to be acceptable, with a Cronbach's Alpha of 0.90, and the IPDL was reported to have validity due to its ability to differentiate between environments in similar, as well as

differing service delivery systems. In subsequent analysis, Raynes et al (1994) reported high internal reliability with a Cronbach's Alpha coefficient of 0.93. Perry and Felce (2005) found inter-respondent agreements across items to average 77%. This measure was used at T3 only.

3.6.9 The Guernsey Community Participation and Leisure Assessment (GCPLA)

The GCPLA was designed to measure the use of community and leisure facilities by people with ID, through obtaining such individual's perceptions of their own experiences (Baker 2000). However, if an individual does not have sufficient communication skills to complete the checklist themselves, it can be completed by their carer. The GCPLA covers a range of items within 7 categories: services, public transport, indoor leisure, leisure, sport & recreation, social, and facilities/amenities. Participants are asked how often they participate in each activity, using a 5-point rating scale ranging from "never" to "daily". They are then asked to rate the type of support with which they participate in each activity on a 4-point scale. Response options are 'supervised', 'accompanied', 'unaccompanied' or 'with a peer group'. A distinction is made between 'supervised' where the onus of choice lies with the carer, and 'accompanied' where the participant has greater autonomy. Each category is then scored in terms of the range of items a person participates in, how often they do this, and the type of support they do this with. The GCPLA therefore differs from the ICI and IPDL in that it measures: a wider variety and number of activities; the frequency with which individuals take part in the activities; and with whom individuals take part in the activities. Inter-rater reliability was investigated by examining 12 individuals with severe and profound ID. Each individual had a GCPLA completed by both their 'heads of homes' and their key worker. A Spearman rank-order correlation coefficient was calculated for each pair of scores, and the majority were found to be >0.7. However, a lower score of 0.62 was found for the support type 'accompanied'. Test-retest reliability was evaluated by interviewing 9 individuals on 2 occasions, separated by a 2-week interval. Spearman rank-order correlation coefficients were again calculated for each pair and all scores were acceptable, with the exception of the number of 'very frequent activities'. Test-retest reliability was also examined using 12 carers as responders, interviewed on 2 occasions, separated by a 2-week interval. Acceptable levels were found

for all categories (>0.77) with the exception of 'accompanied' which was slightly lower (0.62). Internal reliability was acceptable, with Cronbach's Alpha coefficient of 0.93 for 'frequency of contact' and 0.82 for 'mode of contact'. Content validity was assessed using questionnaires which were completed by clinical psychologists. The questionnaires were designed to evaluate the relevance of each item to its sub-category. The items were on average rated highly, suggesting acceptable content validity. Concurrent validity was investigated through asking staff to complete the GCPLA, the LEC and diaries of community and leisure participation for 11 individuals. The relationship between the GCPLA and both the LEC and diaries was then investigated. Modest correlations were found between the GCPLA and diary records. Significant correlations were found between the GCPLA categories 'leisure, sport and recreation' and 'facilities/amenities' with the LEC categories 'leisure' and 'opportunities', respectively. To further support the evidence of validity, the relationship between the GCPLA was investigated with measures of problem behaviour (using the BPI) and adaptive behaviour (using the ABS Part 1). A significant correlation of 0.33 was found between the GCPLA and the ABS (Part 1) using Pearson's Product moment coefficient. The relationship between the GCPLA and the BPI was non-significant, but as expected showed a negative relationship. This measure was used at T3 only.

3.6.10 Scottish Index of Multiple Deprivation (SIMD)

The SIMD is the Scottish Government's official tool for measuring level of deprivation across each area, or 'datazone', in Scotland. In this context, deprivation is defined as "the range of problems that arise due to lack of resources or opportunities, covering health, safety, education, employment, housing and access to services, as well as financial aspects". All 'datazones' are ranked from the most deprived to the least deprived and categorised into 1 of 5 quintiles. Quintile 1 contains the 20% most deprived datazones and quintile 5 contains the 20% least deprived datazones in Scotland (The Scottish Government 2013b). The SIMD quintiles are assigned according to post code. Deprivation index at T2 was generated retrospectively at T3, according to T2 post codes.

3.6.11 Vineland Adaptive Behaviour Scales (VABS)

The VABS (Sparrow, Balla, & Cicchetti 1984) is a standardized test of adaptive behaviour which is widely used, and is recommended by the WHO as an appropriate tool for assessing level of ID within most European and North American cultures (World Health Organization 1992). The VABS survey form measures adaptive behaviour in 3 domains: communication, socialisation, and daily living skills. Used in a sample of 826 children and adolescents with ID, the VABS was reported to have robust psychometric properties (de Bildt, Kraijer, Sytema, & Minderaa 2005). Internal consistency was high, with Cronbach's Alpha ranging from 0.97 to 0.99 for each of the domains and total scores. Convergent validity was also high, with Pearson's coefficient of 0.93. The authors concluded that their investigation resulted in strong evidence for the applicability of the VABS in the ID population.

3.6.12 C21st Health Check

The C21st Health Check (Glasgow University Affiliated Programme 2001) is a purpose designed tool used to collect a range of information on mental ill-health, problem behaviour, autistic spectrum disorder (ASD), ability level and support needs. It allows possible physical causes of psychiatric presentations to be identified. General physical health is measured and where required, blood tests are also administered. A physical examination is included to assess any problems with vision, hearing and mobility. Vision is assessed in 2 stages; firstly 9 questions are asked to help detect whether there are any possible problems. For example, if a participant is unable to self-report, their carer is asked whether they have noticed the participant screw up their eyes when is bright sunlight. The second stage involves testing visual acuity using images from The Kay Pictures Test at a distance of 33 centimetres, and then 3 metres. Individuals with possible visual impairment are referred to the University Visual Sciences Department for further specialist assessment. Individuals with refractive errors which were appropriately corrected by spectacles were not coded as having a visual impairment. However individuals with refractive errors which were not corrected by spectacles (for example, because the individual would not wear them) were coded as having a visual impairment. Similarly, hearing was also assessed in 2 stages; firstly questions are asked to help detect

whether there are any possible problems. Secondly, hearing is tested using otoscopy and if the tympanic membrane can be visualised, examination is carried out using Warblers at 1/2m at the level of 30db/500Hz, 30db/1000Hz, 30db/2000Hz, and 30db/4000Hz. If the tympanic membrane cannot be visualised because of impacted cerumen, drops are first used to clear it. Individuals with possible hearing impairment are referred for further specialist assessment. Individuals with hearing impairments which were appropriately corrected by hearing aids were not coded as having a hearing impairment. However individuals with hearing impairments which were not corrected by hearing aids (for example, because the individual would not wear them or because they did not fully correct the problem) were coded as having a visual impairment. Mobility is assessed through discussion with the individual and their paid or family carers to determine whether the individual is fully mobile, walks with a stick/s, frame or assistance, requires a wheelchair outside only, requires a wheelchair inside and outside, could weight-bear to transfer only, or could not weigh-bear. For the purpose of analysis, mobility is dichotomised as fully mobile or not.

3.6.13 Past and Personal History Questionnaire

The past and personal history questionnaire (Appendix B) is a purpose designed, semi-structured instrument, used to collect information on past experiences which could be relevant to the mechanisms underpinning mental ill-health and problem behaviour. The questionnaire is completed with a carer or relative and details are collected regarding family background, accommodation and experiences. The family background section collects information regarding how many biological or adoptive siblings the individual has, and the birth order of the individual with respect to these siblings. A range of information is then collected about the individual's parents regarding: whether their mother and father are still alive, and if not, how old the individual was when they died; whether the individual's parents divorced, and if so, how old the individual was when this happened; parental qualifications and age of attainment; the occupation of the head of household in the parental home when the individual was 10 years old, and at the present time. The accommodation section collects information regarding who the individual grew up with between birth and the age of 16 years. It then determines how much time was spent in different accommodations such as: the family home; the home of other relatives or family

friends; residential schools; foster care; children's homes, and hospitals. The experiences section collects information regarding type and length or schooling; any periods of hospitalisation due to illness occurring in childhood; whether the individual was ever taken into social care; experienced financial hardship; and experienced any discrimination, neglect or abuse. It also asks carers whether they are aware of any traumatic or distressing events that the individual experienced during childhood and whether there has been any other event of importance that has not been discussed.

3.6.14 Time points at which assessments used in the present study were conducted

For each of the measures described in section 3.6, the time points at which they were completed are detailed in table 3.6 below. This shows which new instruments have been added at T3.

Table 3.6 Time points at which assessments used in the present study were conducted

Assessment tool	T3	T2	T1
The Modified PAS-ADD Checklist	✓	✓	✓
The Problem Behaviour Checklist	✓	✓	✓
Demographics questionnaire	✓	✓	✓
IMSR	✓	✓	x
LEC	✓	✓	x
The Modified Index of Perceived Social Support	✓	x	x
ICI	✓	x	x
IPDL	✓	x	x
GCPLA	✓	x	x
SIMD	✓	✓	x
VABS	x	✓	✓
C21st Health Check	x	x	✓
Personal history questionnaire	x	✓	x

3.7 Groups of potential risk factors

3.7.1 Groups of potential risk factors derived from assessments used in the present longitudinal study

The assessments used in the present study collected information on a wide range of variables. These are categorised into 5 groups of potential risk factors:

Group 1: Personal Factors

- Age at T1
- Gender
- Level of ID as measured at T1
- Down's syndrome as assessed at T1

Group 2: Lifestyle & support

- Accommodation at T1
- Accommodation at T2
- Deprivation Index at T2
- Smoker at T1
- Smoker at T2

Group 3: Social networks & activities

- Contacts in past week at T2
- Angry interaction in past week at T2
- Minor disagreement in past week at T2
- Enjoyable interaction in past week at T2
- Having a close relationship at T2
- People trusted with a secret at T2
- Meets family/ friends for a meal at T2
- Meets family/ friends at their home or pub at T2
- Has family/friends stay overnight at own home at T2
- Stays overnight at family/friends home at T2
- Most social time spent with at T2

Group 4: Past experiences

- Life events for the year preceding T1
- Life events for the year preceding T2
- Life events for the year preceding T3
- Parental divorce in childhood as measured at T2
- Abuse or adversity in adulthood as measured at T2
- Former long-stay hospital resident as measured at T2

Group 5: Health & disabilities

- Urinary incontinence as assessed at T1
- Impaired mobility as assessed at T1
- Visual impairment as assessed at T1
- Hearing impairment as assessed at T1
- ASD as assessed at T1
- Epilepsy as assessed at T1

3.7.2 Groups of potential risk factors derived from assessments used in the present cross-sectional study

Lifestyle factors

- ICI total score
- IPDL total score
- GCPLA subscales:
  - All categories: total /frequent/supervised/accompanied/solitary/peer activities
  - Services: total /frequent/supervised/accompanied/solitary/peer activities
  - Public transport: total /frequent/supervised/accompanied/solitary/peer activities
  - Indoor leisure: total /frequent/supervised/accompanied/solitary/peer activities
  - Outdoor leisure: total /frequent/supervised/accompanied/solitary/peer activities
  - Social: total /frequent/supervised/accompanied/solitary/peer activities
  - Facilities: total /frequent/supervised/accompanied/solitary/peer activities

- Community: total /frequent/supervised/accompanied/solitary/peer activities
- Total leisure: total /frequent/supervised/accompanied/solitary/peer activities

Social support factors

Modified index of perceived social support total score

3.8 Analyses

3.8.1 Data analysis

All analyses were discussed with a statistician based at the Robertson Centre for Biostatistics to ensure the most appropriate tests were used for the data. All data were analysed using the statistical software package SPSS version 19.

3.8.2 Terms and definitions

The terms and definitions used throughout the results section are defined in table 3.8.

Table 3.8 Terms and definitions

Term	**Definition/Criteria**
A. Mental ill-health	Total modified PAS-ADD Checklist score ≥2 (excluding any total scores =2 where item 4 has received a positive score) or A positive score on any 'high risk' item
Persistent mental ill-health	Criteria A. Has been met at all 3 time points
Relapse of mental ill-health	Criteria A. has been met and T1 and T3 (but not T2)
New onset of mental ill-health	Criteria A. has been met only at T3
Resilience to mental ill-health	Criteria A. Has not been met at any of the 3 time points
B. Problem behaviour	DC-LD criteria for problem behaviour has been met (determined by a psychiatrist specialising in learning disability)
Persistent problem behaviour	Criteria B. Has been met at all 3 time points
Relapse of problem behaviour	Criteria B. has been met and T1 and T3 (but not T2)

New onset of problem behaviour	Criteria B. has been met only at T3
Resilience to problem behaviour	Criteria B. Has not been met at any of the 3 time points
C. Aggressive problem behaviour	DC-LD criteria for aggressive problem behaviour has been met (determined by a psychiatrist specialising in learning disability)
Persistent aggressive problem behaviour	Criteria C. Has been met at all 3 time points
D. Self-injurious behaviour	DC-LD criteria for self-injurious behaviour has been met (determined by a psychiatrist specialising in learning disability)
Persistent self-injurious behaviour	Criteria D. Has been met at all 3 time points

3.8.3 Demographics of the cohort at T3 and potential bias

Demographics of the cohort at T3, in terms of age, gender, level of ID, Down's syndrome, accommodation type, day time activity, smoking status, use of psychotropic medication and use of services, were investigated using descriptive statistics and frequency counts.

Potential bias resulting from differences between T3 participants and non-participants was examined, in terms of age, gender, level of ID, Down's syndrome, accommodation type, deprivation code, mental ill-health status at T2, and problem behaviour status at T2 using Chi squared tests. Differences between participant and non-participant total PAS-ADD Checklist scores at T2 were investigated using Mann-Whitney tests.

3.8.4 Distribution of mental ill-health and problem behaviour at T3: descriptive statistics

The distribution of mental ill-health and problem behaviour at T3 was investigated using frequency counts. Bar charts were then used to display the distribution of total PAS-ADD Checklist scores at T3, and the number of participants meeting criteria for mental ill-health. Frequency counts were also used to determine the number of participants meeting criteria for each type of DC-LD problem behaviour investigated. This information was then used to calculate the number of participants meeting DC-LD criteria for any type of problem behaviour and aggressive problem behaviour. Bar charts were used to display this information.

The distribution of contact with clinical services and use of psychotropic medications in those with mental ill-health and problem behaviour at T3 were investigated using frequency counts.

3.8.5 Distribution of mental ill-health and problem behaviour over the 10 year period: descriptive statistics

In order to address research question 1, frequency counts were used in two ways. Firstly, frequency counts were used to determine the number of people meeting criteria for mental

ill-health at T1. The data of participants who met criteria for mental ill-health at T1 was selected, and frequency counts were used to determine how many of these did and did not meet criteria for mental ill-health at T2. Next, the data of participants who did not meet criteria for mental ill-health at T1 was selected, and frequency counts were used to determine how many of these did and did not meet criteria for mental ill-health at T2. This resulted in 4 possible combinations of T1-T2 mental health status. For each combination, frequency counts were used to determine those who did and did not meet criteria for mental ill-health at T3. This method allowed the number of participants following each of the 8 potential trajectories across the 3 time points to be identified. This information was then displayed visually, showing the individual outcomes of persistence, new onset, relapse and resilience.

Secondly, frequency counts were used to determine the number of participants meeting criteria for mental ill-health at each of the 3 time points. This information was then displayed graphically, showing the distribution of mental ill-health at the group level.

These two processes were repeated for DC-LD problem behaviour of any type, DC-LD aggressive problem behaviour and DC-LD self-injurious behaviour.

In order to address research question 2, persistence rates with 95% confidence intervals were calculated using ratio statistics to compare those who met criteria for persistent mental ill-health (as described above) with the rest of the sample.

In order to address research question 3, persistence rates with 95% confidence intervals were calculated using ratio statistics to compare those who met criteria for persistent DC-LD problem behaviour (as described above) with the rest of the sample. This process was repeated for those meeting criteria for persistent DC-LD aggressive problem behaviour and self-injurious behaviour.

3.8.6 Change in mental ill-health over time

In order to address research question 4, total PAS-ADD Checklist scores at T1 were subtracted from total PAS-ADD Checklist scores at T3, thus showing the change in score

between these time points for each participant. A histogram was used to display the distribution of change, allowing visual analysis to determine normality of the data. A paired-samples t-test was then used to investigate change in total PAS-ADD Checklist scores between T1 and T3. This process was repeated for change in total PAS-ADD Checklist scores between T2 and T3. Box plots were then used to display the distribution of total PAS-ADD Checklist scores across the 3 time points.

In order to determine whether the results of this test were indicative of a true clinical difference, the statistical software 'G*Power 3.1.7' was used to perform a post-hoc power calculation. G*Power requires information to be input regarding the type of test conducted and parameter values from that test. In this case, selections were:'t-test', 'Means: Difference between two dependent measures', and 'Post hoc: Compute achieved power – given α, sample size and effect size'. A power of 0.8 or more provides an 80% chance of detecting an effect if one genuinely exists. Therefore a power of ≥0.8 will be used to signify a clinically relevant finding.

3.8.7 Predicting change in mental ill-health over time

In order to address research question 5, change in total PAS-ADD Checklist scores between T1 and T3 were adjusted so that all change scores were positive, ranging from zero. This was to allow factors predicting increase in score to be investigated. Controlling for total PAS-ADD Checklist scores at T1, univariate analyses of potential risk factors as measured at, or retrospective to T1 (see section 3.7.1), were conducted using one way ANOVAS. The independent variable was the adjusted change score between T1 and T3. A significance level of $p \leq .1$ was deemed acceptable for determining possible risk factors.

At the next stage of analysis, any variables meeting the $p \leq .1$ level of significance were checked for missing data and their cases removed from the analysis. At this stage, the variables 'age at T1' and 'people trusted with a secret' were re-coded so that the referent categories were 'age 36-55' and 'trust 2-5 people with a secret', respectively. These levels were chosen as the referent category because they were the respective mid-points within the variables and univariate analysis indicated them to be the most appropriate comparator. These variables were then entered into a general linear model, with total PAS-ADD

Checklist score at T1 entered as a covariate. A backwards method was used to remove the least significant variable. This process was repeated until all variables in the model were significant, at a level of $p \leq .05$. Standard residuals were then checked for any outliers (those greater than +2.58 or less than -2.58), which were removed from model and the regression was rerun.

Total PAS-ADD Checklist scores at T1 were controlled for in the univariate analysis and entered as a covariate in the regression model because those with higher initial scores cannot increase as much as those with lower initial scores. Therefore failing to control for this difference could result in spurious findings.

This process was repeated for change in total PAS-ADD Checklist score between T2 and T3, controlling for total PAS-ADD Checklist scores at T2 accordingly. Univariate analyses were conducted with potential risk factors as measured at T1 and T2 (see section 3.7.1).

3.8.8 Predicting mental ill-health outcomes over time: relapse, onset and resilience

In order to address research question 6, analyses were conducted for each of the 3 outcomes: relapse of mental ill-health, new onset of mental ill-health and resilience to mental ill-health (for definitions see table 3.8). Each outcome and their corresponding comparator group are defined as follows:

- **relapse of mental ill-health** – those meeting criteria for relapse were compared with those meeting criteria for resilience to mental ill-health.

- **new onset of mental ill-health** – those meeting criteria for new onset were compared with those meeting criteria for resilience to mental ill-health.

- **resilience to mental ill-health** – those meeting criteria for resilience were compared with the remainder of the cohort, who had met criteria for mental ill-health during at least 1 of the 3 time points.

For each of the outcomes described above, the same 2 stage analyses were conducted.

For each outcome at stage 1, univariate analysis of the 5 groups of potential risk factors were carried out using chi-square tests. A significance level of $p \leq .1$ was deemed acceptable for determining possible risk factors. At the second stage of analysis, any variables meeting the $p \leq .1$ level of significance were checked for multi-collinearity. The variables were entered into a logistic regression, and a backwards stepwise method was used to determine which variables independently predicted each outcome. The regressor with the smallest partial correlation was removed at each iteration. Removal criteria were set at a significance level of .05. Standard residuals were then checked for any outliers (those greater than +2.58 or less than -2.58), which were removed from model and the regression was rerun.

Post hoc analyses were performed using chi-square tests to determine whether potential risk factors were associated with mental ill-health at T3

3.8.9 Predicting problem behaviour outcomes over time: onset and resilience

In order to address research question 7, analyses were conducted for each of the 2 outcomes: new onset of problem behaviour and resilience to problem behaviour (for definitions see table 3.8). Each outcome and their corresponding comparator group are defined as follows:

- **new onset of problem behaviour** – those meeting criteria for new onset were compared with those meeting criteria for resilience to problem behaviour.

- **resilience to problem behaviour** – those meeting criteria for resilience were compared with the remainder of the cohort, who had met criteria for problem behaviour during at least 1 of the 3 time points.

For each of the outcomes described above, the same 2 stage analyses were conducted.

For each outcome at stage 1, univariate analysis of the 5 groups of potential risk factors were carried out using chi-square tests. A significance level of $p \leq .1$ was deemed acceptable for determining possible risk factors. At the second stage of analysis, any variables meeting the $p \leq .1$ level of significance were checked for multi-collinearity. The variables were entered into a logistic regression, and a backwards stepwise method was used to determine which variables independently predicted each outcome. The regressor with the smallest partial correlation was removed at each iteration. Removal criteria were set at a significance level of .05. Standard residuals were then checked for any outliers (those greater than +2.58 or less than -2.58), which were removed from model and the regression was rerun.

3.8.10 Associations between mental ill-health and lifestyles

In order to address research question 8, spearman's correlations were used to investigate associations between total PAS-ADD Checklist scores at T3 and: ICI total scores; IPDL total scores; and GCPLA subscales (see section 3.7.2). The GCPLA subscales were defined by combinations of type of activity (services, public transport, indoor leisure, outdoor leisure, social and facilities/amenities), frequency with which activities are participated (regular or frequent) and type of support with which the activity was participated (supervised, supported, solitary or with peers).

3.8.11 Associations between mental ill-health and perceived social support

In order to address research question 9, spearman's correlations were used to investigate associations between total PAS-ADD Checklist scores at T3 and total perceived social support scores.

CHAPTER 4: RESULTS

4.1 The cohort at T3

At T1, the cohort consisted of 1023 adults, of which 651 participated in the T2 follow-up. Of these 651, 97 had died by T3, leaving a potential cohort size of 554. All 554 participants were invited to participate in the research at T3. For 262 of these potential participants, we received no response and were unable to trace them. Of the remaining potential participants, 172 declined to participate and 120 indicated interest in receiving further information regarding participation. Of these 120 people, 5 gave no further response, and next of kin consent was withheld for 14 who did not have capacity to consent for themselves. Consent was received for 101 participants, one of whom was unable to complete the study within the given time limit. Thus 100 participants completed the T3 follow-up, giving a participation rate of 18.0% (100/554). A flow chart displaying the T3 follow-up process is displayed in figure 4.1.

At T3 the cohort comprised 50 males and 50 females, with a mean age of 49.4 years (SD=12.9, range 26.6 -79.7). Level of ID was mild in 39, moderate in 29, severe in 19 and profound in 13. Fifty-five participants received paid-carer support, 33 lived with a family carer and 12 lived in 'other' accommodation. The majority of participants (57) participated in structured day-time activities such as attending day centre (37), college (17) or some form of employment (13). The remaining 43 participated in 'other' unstructured day activities. Twenty-two participants had Down's syndrome. These demographics are displayed in table 4.1.1. The distributions of contact with services at T3 are displayed in table 4.1.2.

Figure 4.1 Flow chart displaying T3 follow-up process

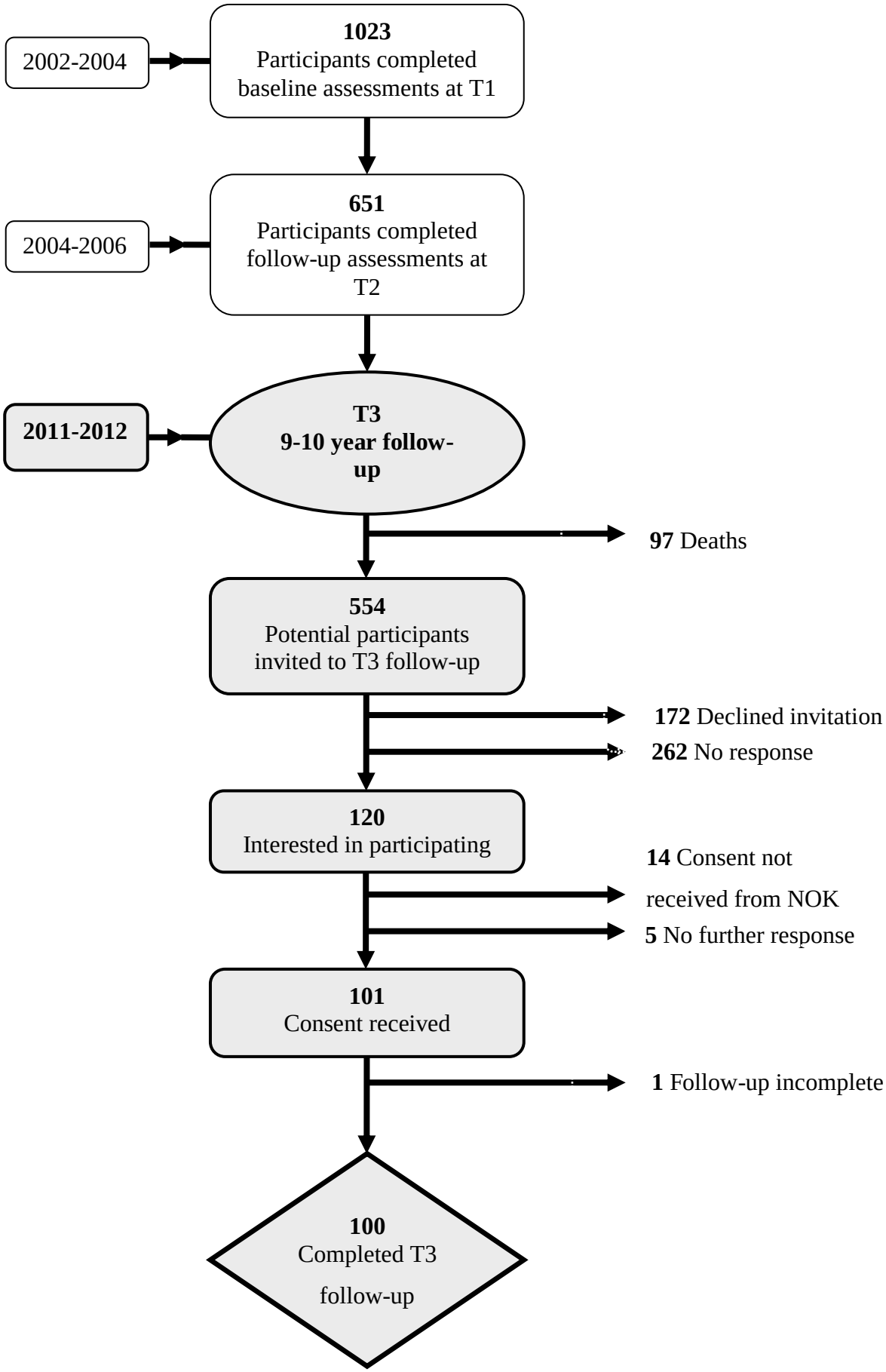


Table 4.1.1 Demographics of the cohort at T3

Demographic	Participants, n = 100 (%)
Age, years	
Mean (SD)	49.4 (12.9)
Range	26.6-79.7
Gender	
Male	50 (50.0)
Female	50 (50.0)
Level of ID	
Mild	39 (39.0)
Moderate	29 (29.0)
Severe	19 (19.0)
Profound	13 (13.0)
Down's syndrome	
Yes	23 (23.0)
No	77 (77.0)
Accommodation type	
Paid carer	55 (55.0)
Family carer	33 (33.0)
Other	12 (12.0)
Day time activity	
Structured activity*	57 (57.0)
Day centre	37 (37.0)
College	17 (17.0)
Employment	13 (13.0)
Unstructured activity	43 (14.0)
Smoker	
Yes	8 (8.0)
No	92 (92.0)

Psychotropic medication	
Yes	54 (54.0)
Antipsychotics	19 (19.0)
Antidepressants	20 (20.0)
Anxiolytics	4 (4.0)
Antiepileptics	38 (38.0)
Cognitive enhancers	2 (2.0)
Lithium	0 (0.0)
No	46 (46.0)

*Some participants engaged in more than one structured daytime activity hence the total attending each activity exceeds the total engaging in structured activity.

Table 4.1.2 Distributions of contact with services at T3

Services/professional	**Number of participants in contact with services**
Psychiatrist	27
Psychologist	6
Occupational therapist	14
Speech and language therapist	11
'Other' doctor	68
Community learning disabilities nurse	32
Epilepsy nurse	9
Practice nurse	56
Social worker	35
Care manager	52
Physiotherapist	14
Dietician	16
Other professional	62

4.2 Representativeness of the cohort at T3

There was no significant difference between T3 participants and non-participants, in terms of the T2 demographics of age; gender; level of ID; Down's syndrome; accommodation type; mental ill-health and problem behaviour (Table 4.2). A significant difference was found for deprivation code, but there was not a gradient across deprivation areas (i.e. the difference was non-linear), suggesting that the finding may be spurious.

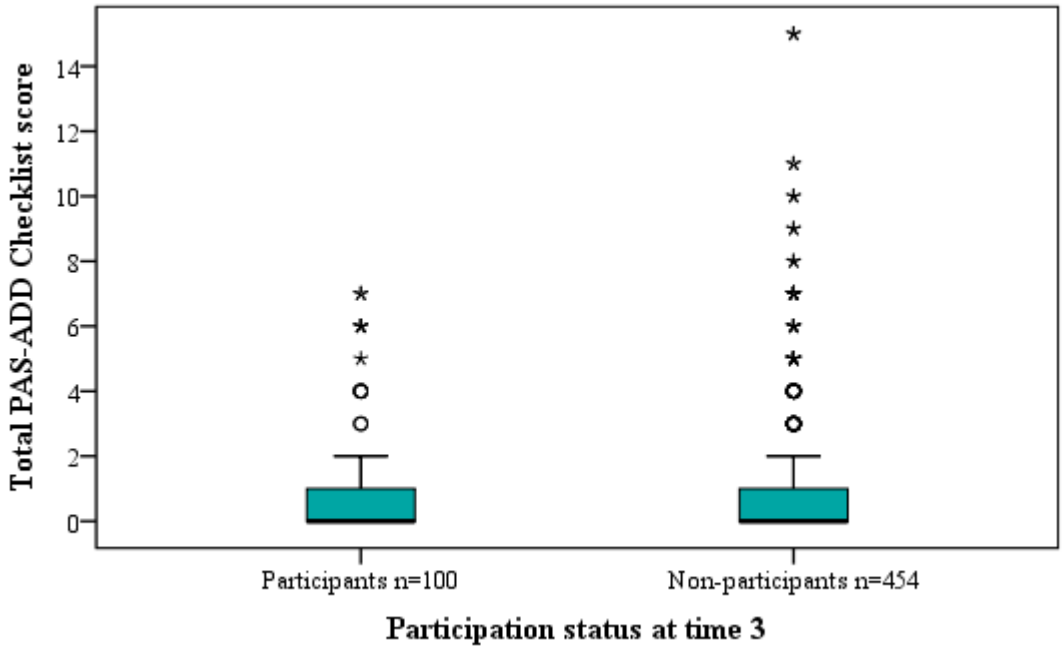
Table 4.2 Comparison of T2 demographics between participants and non-participants at T3

Demographics	Participants n = 100	Non-participants n = 454	x^2 value	*p* value
Age (%)				
18-37	39 (39.0)	135 (29.7)	3.28	.089
38-57	45 (45.0)	233 (51.3)		
58+	16 (16.0)	86 (18.9)		
Gender (%)				
Male	50 (50.0)	250 (55.1)	0.85	.377
Female	50 (50.0)	204 (44.9)		
Level of ID (%)				
Mild	38 (38.0)	168 (37.0)	1.43	.198
Moderate	30 (30.0)	154 (33.9)		
Severe	19 (19.0)	89 (19.6)		
Profound	13 (13.0)	43 (9.5)		
Down's syndrome (%)				
No	77 (77.0)	365 (80.4)	0.59	.492
Yes	23 (23.0)	89 (19.6)		
Accommodation type (%)				
Paid carer	47 (47.0)	200 (44.1)	0.66	.381
Family carer	39 (39.0)	176 (38.8)		
Other	14 (15.2)	78 (17.2)		

Deprivation code (%)				
1	37 (37.0)	185 (40.7)	5.40	.016*
2	32 (32.0)	107 (23.6)		
3	11 (11.0)	68 (15.0)		
4	11 (11.0)	36 (7.9)		
5	9 (9.0)	58 (12.8)		
Mental ill-health at T1 (%)				
No	56 (56.0)	280 (61.7)	1.11	.310
Yes	44 (44.0)	174 (38.3)		
Mental ill-health at T2 (%)				
No	80 (80.0)	356 (78.4)	0.12	.788
Yes	20 (20.0)	98 (21.6)		
Problem behaviour at T1 (%)				
No	86 (86.0)	386 (85.0)	0.06	.877
Yes	14 (14.0)	68 (15.0)		
Problem behaviour at T2 (%)				
No	84 (84.0)	390 (85.9)	0.24	.638
Yes	16 (16.0)	64 (14.1)		

To further ensure our cohort of 100 adults did not significantly differ from the original cohort, we compared the T2 total PAS-ADD Checklist scores of the 100 adults with the remainder of the original cohort (excluding deaths). Figure 4.2 below shows box plots comparing T2 total PAS-ADD Checklist scores, between T3 participants and non-participants. A Mann-Whitney test was performed and found no significant difference in T2 total PAS-ADD Checklist scores, between T3 participants (*Mdn*=.0) and non-participants (*Mdn*=.0), *U*=22490.5, *ns*, *r*= -0.01.

Figure 4.2 T2 Total PAS-ADD Checklist scores for T3 participants and non-participants

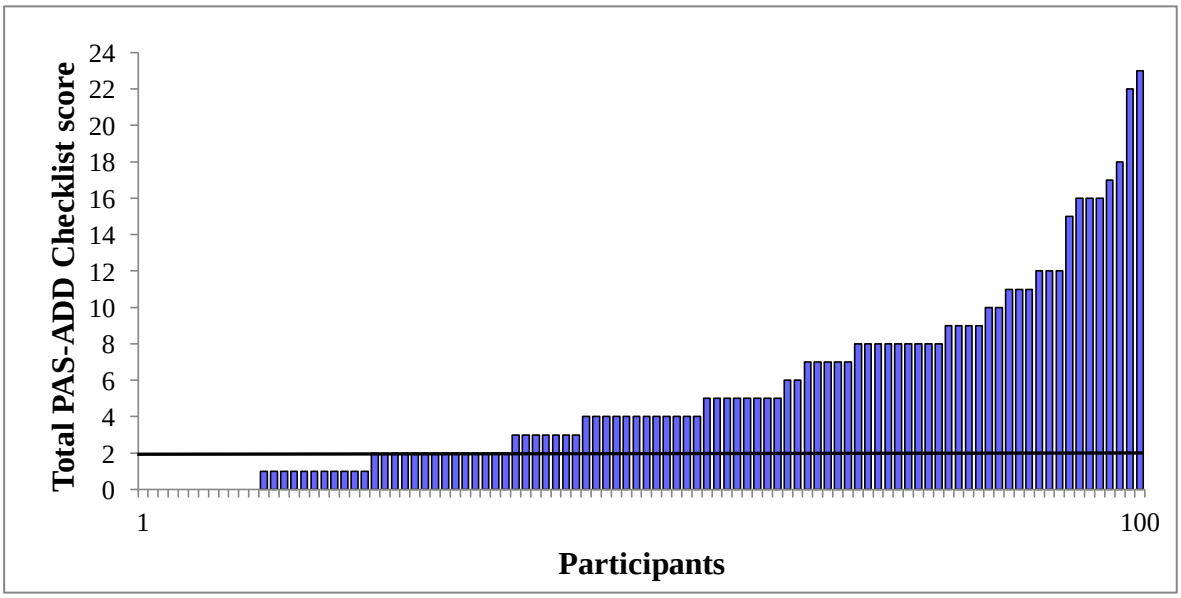


4.3 The distribution of outcomes at T3

4.3.1 The distribution of mental ill-health at T3

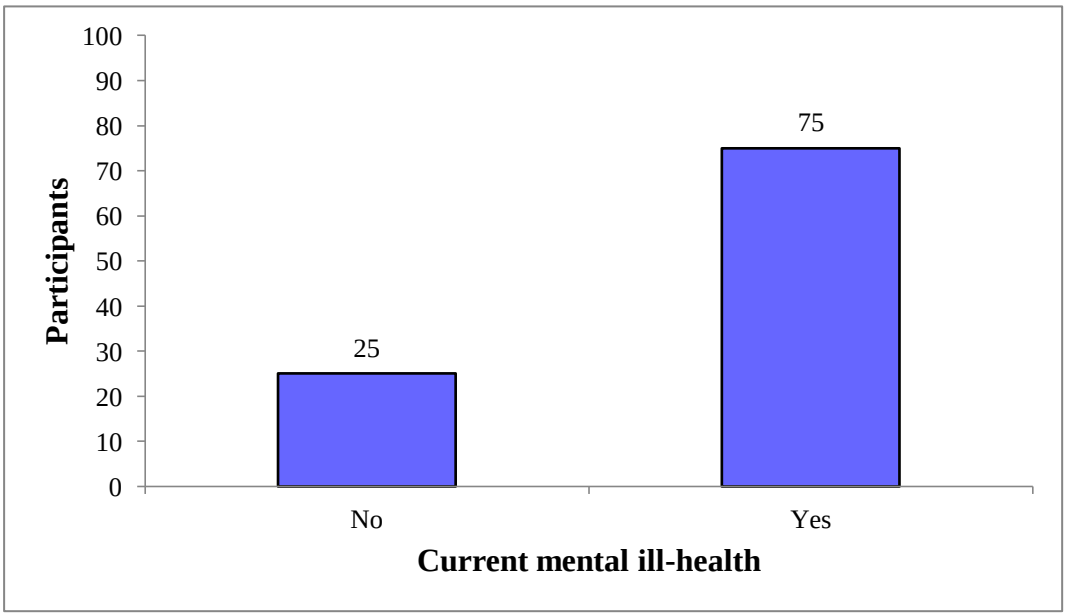
The distribution of total PAS-ADD Checklist scores at T3 is displayed in figure 4.3.1, where each bar represents one participant. Scores ranged from 0 to 23, with a mean of 5.4 (SD=5.02) and a median of 4. Seventy-five participants exceeded the threshold score of 2 (represented by the intersecting horizontal line). Based on the T1 data, it is expected that 62% of these adults would have been found to have a psychiatric diagnosis if they had had a full research psychiatric assessment, i.e. 47 adults. Two adults who had a total PAS-ADD Checklist score equalling 2 were not included in the 75 participants classed as meeting criteria for mental ill-health, because they had a positive score on question 4, the specific phobia item. None of the participants who had a total PAS-ADD Checklist score equalling 1 had a positive score on any of the high risk items. That is, all of the individuals who scored on the high risk items also scored on other items, resulting in a total PAS-ADD Checklist Score greater than 1.

Figure 4.3.1 Total PAS-ADD Checklist scores at T3 follow-up (2011-2012)



This data is displayed categorically in figure 4.3.2, showing that 75 participants met the criteria for having mental ill-health at T3, compared with 23 participants who were found to be healthy at T3.

Figure 4.3.2 Participants meeting criteria for mental ill-health at T3 follow-up (2011-2012)



4.3.2 The distribution of contact with clinical services and use of psychotropic medication in those with mental ill-health at T3

The distributions of contact with clinical services and use of psychotropic medication in those with mental ill-health at T3 are displayed in table 4.3.1. Of the 75 participants meeting criteria for mental ill-health at T3, 34.7% were in contact with clinical services, the majority of which was psychiatric (28.0%). Over half (61.3%) of the participants meeting criteria for mental ill-health at T3 were taking psychotropic medication. The most commonly prescribed medications were antiepileptics (44.0%), prescribed for the management of epilepsy. Almost all however have additional mood stabilising properties, so it is highly relevant in this research to consider how many were taking such medications.

Table 4.3.1 Distribution of contact with clinical services and use of psychotropic medication in those with mental ill-health at T3

Participants meeting criteria for mental ill-health n=75	
Contact with clinical services (%):	
Any	26 (34.7)
Psychiatrist	21 (28.0)
Psychologist	2 (2.7)
Both	3 (4.0)
Psychotropic medication (%):	
Any	46 (61.3)
Any mood stabiliser	35 (46.7)
Antipsychotics	17 (22.7)
Antidepressants	17 (22.7)
Antiepileptics	33 (44.0)
Anxiolytics	3 (4.0)
Lithium	0 (0.0)
Cognitive enhancers	2 (2.7)

4.3.3 The distribution of problem behaviours at T3

The distribution of DC-LD problem behaviour is displayed in figures 4.3.3-4.3.5 below. Figure 4.3.3 shows the total distribution of problem behaviours, with 34 out of the 100 participants meeting DC-LD criteria for problem behaviour (of any type). Of these, 18 participants met DC-LD criteria for aggressive problem behaviour (of any type). Aggressive problem behaviour is defined by meeting DC-LD criteria for one or more of the following behaviours: verbal aggression, physical aggression or destructiveness.

Figure 4.3.3 Presence of DC-LD problem behaviours at T3 follow-up (2011-2012)

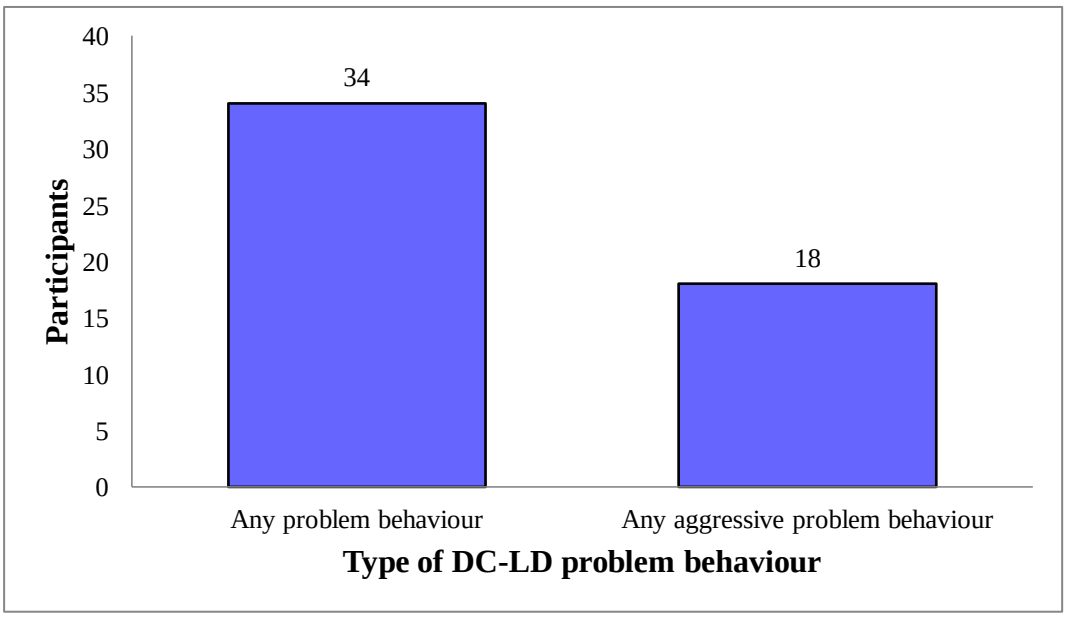
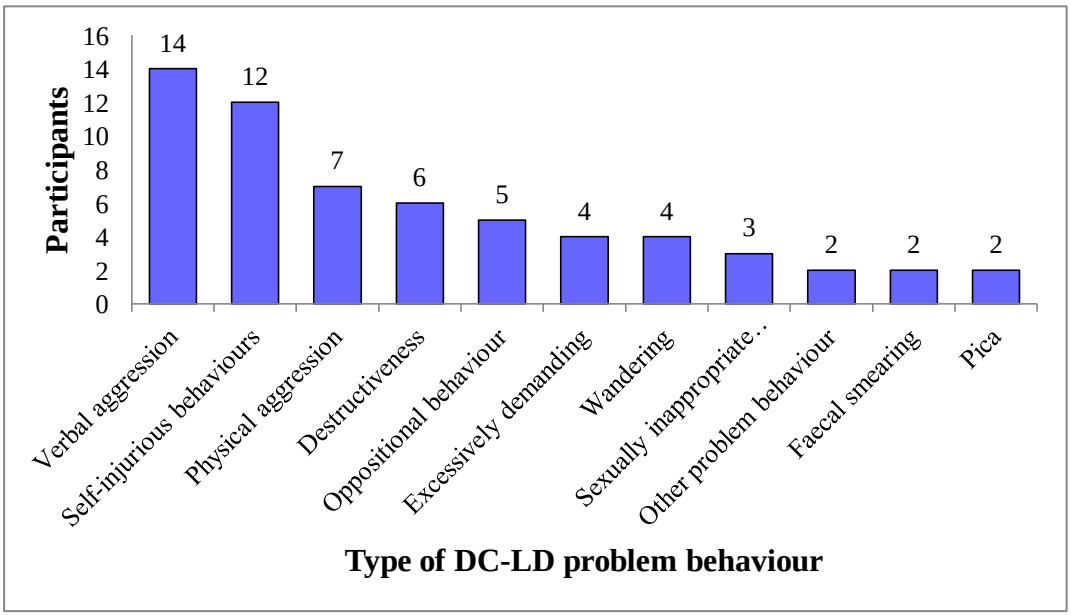


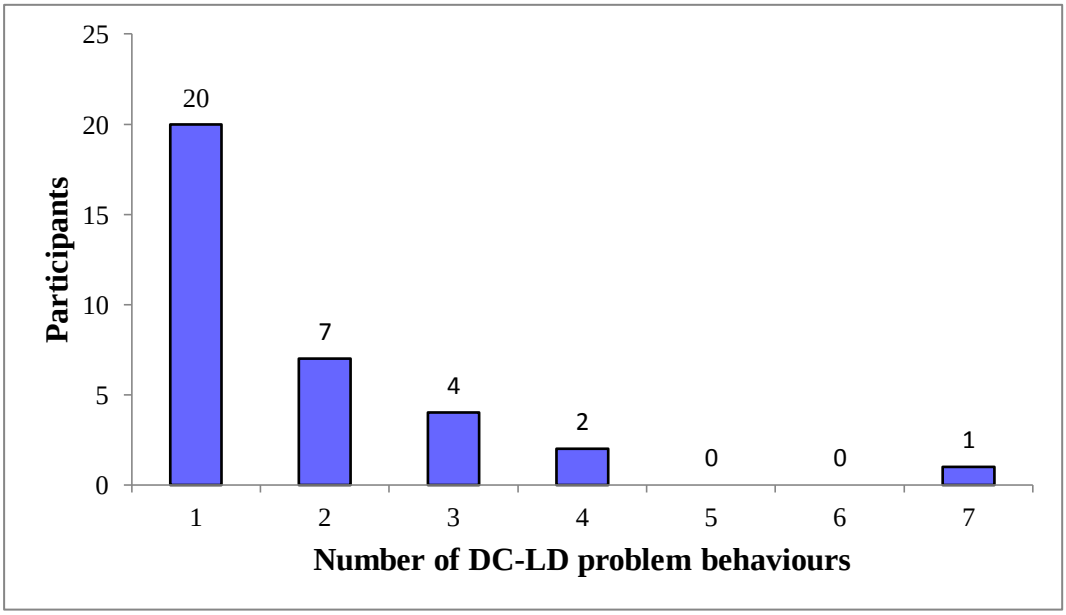
Figure 4.3.4 shows all of the problem behaviours that were screened for, and the number of participants who met DC-LD criteria for these behaviours. The most common problem behaviour was verbal aggression, with 14 participants meeting the criteria; 12 met criteria for self-injurious behaviour; 7 for physical aggression; 6 for destructiveness; 5 for oppositional behaviour; 4 for excessively demanding behaviour; 4 for wandering; 3 for sexually inappropriate behaviour; 2 for 'other' problem behaviour; 2 for faecal smearing and 2 participants met criteria for pica. Therefore, a total of 61 problem behaviours met DC-LD criteria. However, a total of 88 problem behaviours were identified within the sample, 61 of which met DC-LD criteria, 23 which were due to mental illness and 4 which were due to physical illness.

Figure 4.3.4 Presence of DC-LD problem behaviours at T3 follow-up (2011-2012)



Of the 34 participants who met DC-LD criteria for problem behaviour, some met criteria for more than one type of problem behaviour. Figure 4.3.5 shows the number of problem behaviours displayed by each participant. Twenty participants met DC-LD criteria for 1 problem behaviour, seven for 2, four for 3, two for 4, and one met criteria for 7 problem behaviours.

Figure 4.3.5 Total number of DC-LD problem behaviours at T3 follow-up (2011-2012)



4.3.4 The distribution of contact with clinical services and use of psychotropic medication in those with problem behaviour at T3

The distributions of contact with clinical services and use of psychotropic medication in those with problem behaviour at T3 are displayed in table 4.3.2. Of the 34 participants meeting criteria for mental ill-health at T3, 41.2% were in contact with clinical services, the majority of which was psychiatric (35.3%). Over half (67.6%) of the participants meeting criteria for problem behaviour at T3 were taking psychotropic medication. The most commonly prescribed medications were antiepileptics (50.0%), prescribed for the management of epilepsy. Almost all however have additional mood stabilising properties, so it is highly relevant in this research to consider how many were taking such medications.

Table 4.3.2 Distribution of contact with clinical services and use of psychotropic medication in those with problem behaviour at T3

Participants meeting criteria for problem behaviour n=34	
Contact with clinical services (%):	
Any	14 (41.2)
Psychiatrist	12 (35.3)
Psychologist	2 (5.9)
Both	0 (0.0)
Psychotropic medication (%):	
Any	23 (67.6)
Any mood stabiliser	22 (64.7)
Antipsychotics	10 (29.4)
Antidepressants	8 (23.5)
Antiepileptics	17 (50.0)
Anxiolytics	2 (2.9)
Lithium	0 (0.0)
Cognitive enhancers	1 (2.9)

4.4 Longitudinal findings: the trajectory of outcomes over 10 years

4.4.1 Mental ill-health outcomes over 10 years

To answer research question 1, figure 4.4.1 displays the trajectory of mental ill-health for 100 participants at three time points over a 10 year period: at T1, 41 participants met criteria (as defined in this thesis) for mental ill-health, of which 28 were in remission and 13 remained ill at T2. Of these 28, 2 remained in remission at T3, with the other 26 experiencing a relapse of mental-ill health. The 13 participants who were ill at both T1 and T2 all remained ill at T3, indicating mental ill-health to be persistent in the cohort at a rate of 13% (95% CI: 6.3-19.7%) over the 3 time points. Of the 41 participants who met criteria for mental ill-health at T1, 39 also met criteria for mental ill-health at T3. Of the 59 participants who did not have mental ill-health at T1, 53 remained without mental ill-health at T2, and of these 21 were still without mental ill-health at T3. The remaining 32 met criteria for mental ill-health at T3. Of the 59 participants who were without mental ill-health at T1, 6 met criteria for mental ill-health at T2. Of these, 4 still met criteria for mental ill-health at T3, with 2 recovering. Figure 4.4.2 shows the total number of participants who met criteria for mental ill-health compared with those who were healthy, for each of the 3 time points.

Figure 4.4.1 Trajectory of mental ill-health over 10 years

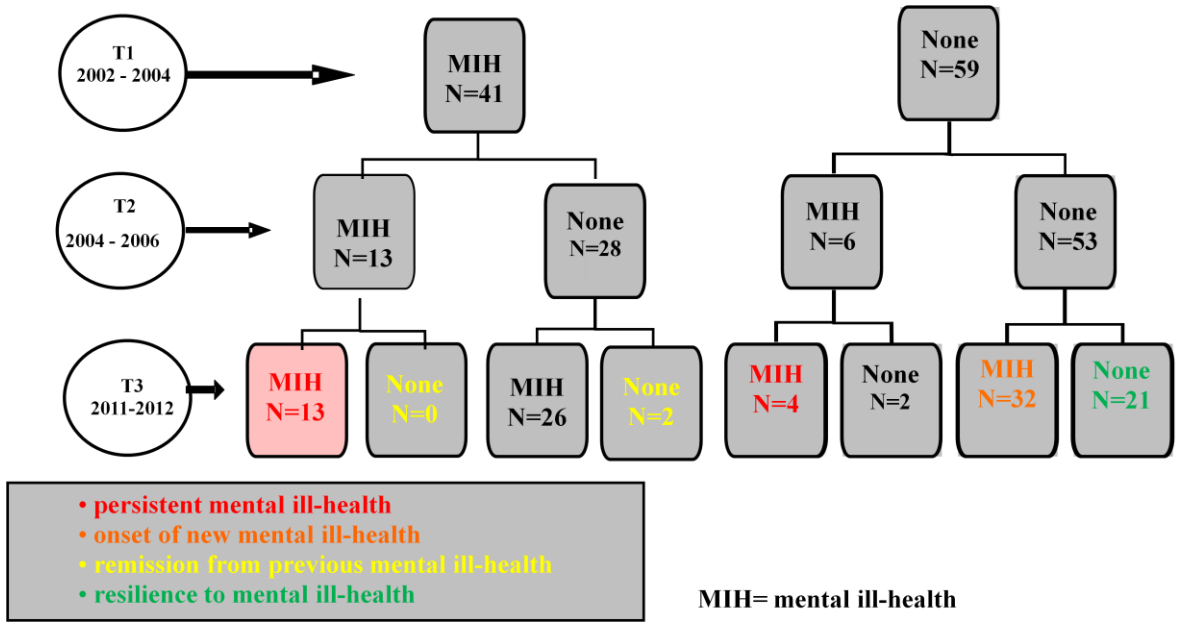
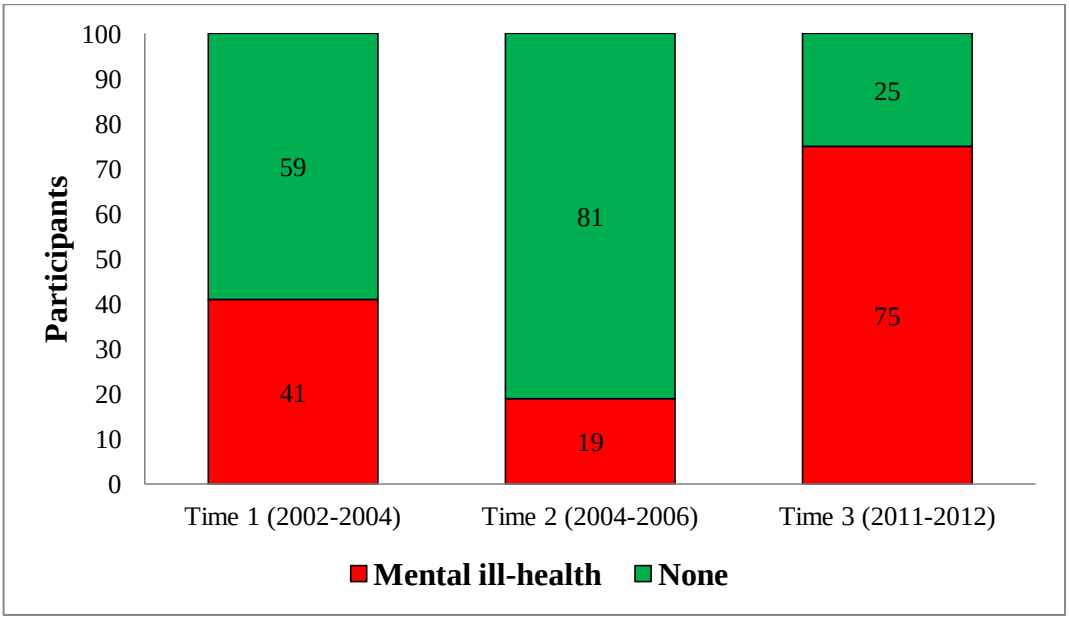


Figure 4.4.2 Mental ill-health at T1, T2 and T3



4.4.2 Problem behaviour outcomes over 10 years

Figure 4.4.3 displays the trajectory of DC-LD problem behaviour (of any type) for the 100 participants at three time points over a 10 year period: at T1, 14 participants had problem behaviour, of which 11 still had problem behaviour at T2. Of the 3 who had recovered at T2, 1 remained without problem behaviour at T3 and 2 were found to have problem behaviour. Of the 11 who had problem behaviour at both T1 and T2, 7 still had problem behaviour at T3, with 4 people recovering. This indicates DC-LD problem behaviours (of any type) to be persistent in the cohort at a rate of 7% (95% CI: 1.9-12.1%) over all 3 time points. Of the 86 participants without problem behaviour at T1, 81 remained without problem behaviour at T2, and of these 61 still had no problem behaviour at T3. The remaining 20 were found to meet DC-LD criteria for problem behaviour at T3. Of the 86 participants without problem behaviour T1, 5 met criteria for problem behaviour at T2. Of these, all 5 still met criteria for problem behaviour at T3. Figure 4.4.4 shows the total number of participants who met DC-LD criteria for problem behaviour compared with those who were healthy, for each of the 3 time points.

Figure 4.4.3 Trajectory of DC-LD problem behaviour (of any type) over 10 years

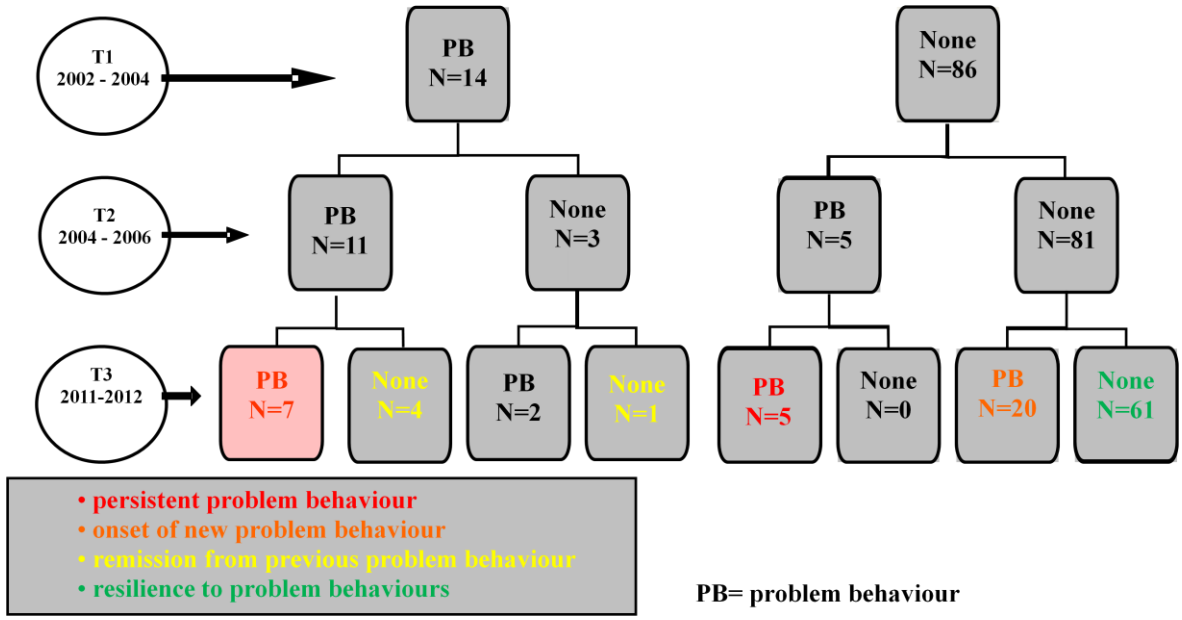


Figure 4.4.4 DC-LD problem behaviour (of any type) at T1, T2 and T3

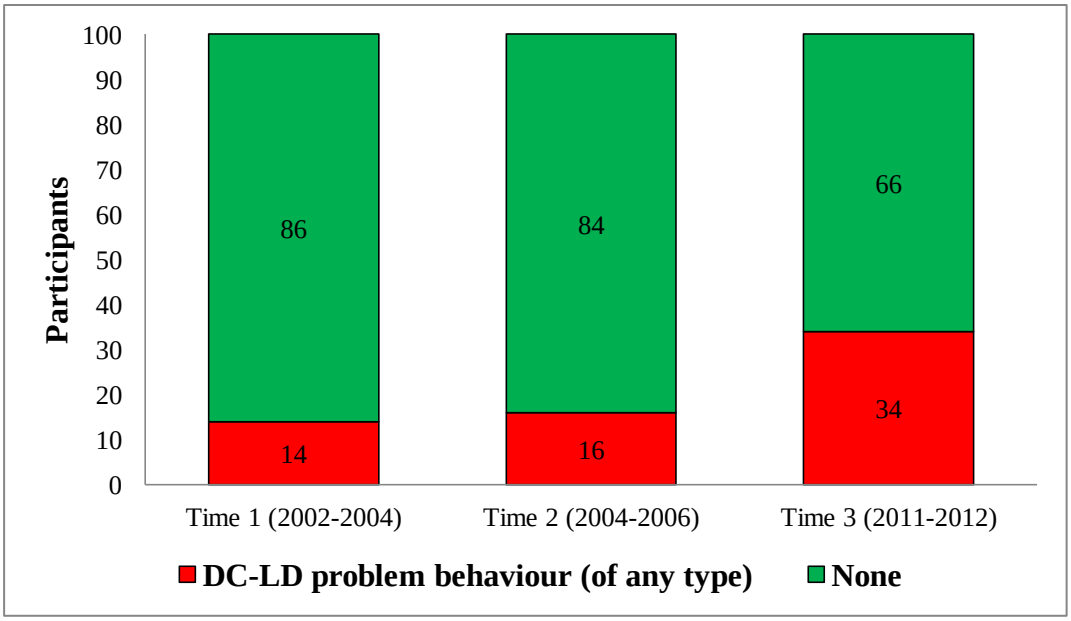


Figure 4.4.5 displays the trajectory of DC-LD aggressive problem behaviours (of any type) for 100 participants at three time points over a 10 year period: at T1, 7 participants had aggressive problem behaviour, of which 5 still had aggressive problem behaviour at T2. Of these, 2 had recovered and 3 still had aggressive problem behaviour at T3. This indicates DC-LD aggressive problem behaviours (of any type) to be persistent in the cohort at a rate of 3% (95% CI: 0.4-6.4%) over the 3 time points. Of the 2 who had recovered at T2, both were still without aggressive problem behaviour at T3. Of the 93 participants that did not have aggressive problem behaviour at T1, 90 remained without aggressive problem behaviour at T2, and of these 77 were still without aggressive problem behaviour at T3. The remaining 13 were found to meet DC-LD criteria for aggressive problem behaviour at T3. Of the 93 participants who did not have aggressive problem behaviour T1, 3 met criteria for aggressive problem behaviour at T2. Of these, 2 still met criteria for aggressive problem behaviour at T3 and 1 did not. Figure 4.4.6 shows the total number of participants who met DC-LD criteria for aggressive problem behaviour compared with those who were healthy, for each of the 3 time points.

Figure 4.4.5 Trajectory of DC-LD aggressive problem behaviour (of any type) over 10 years

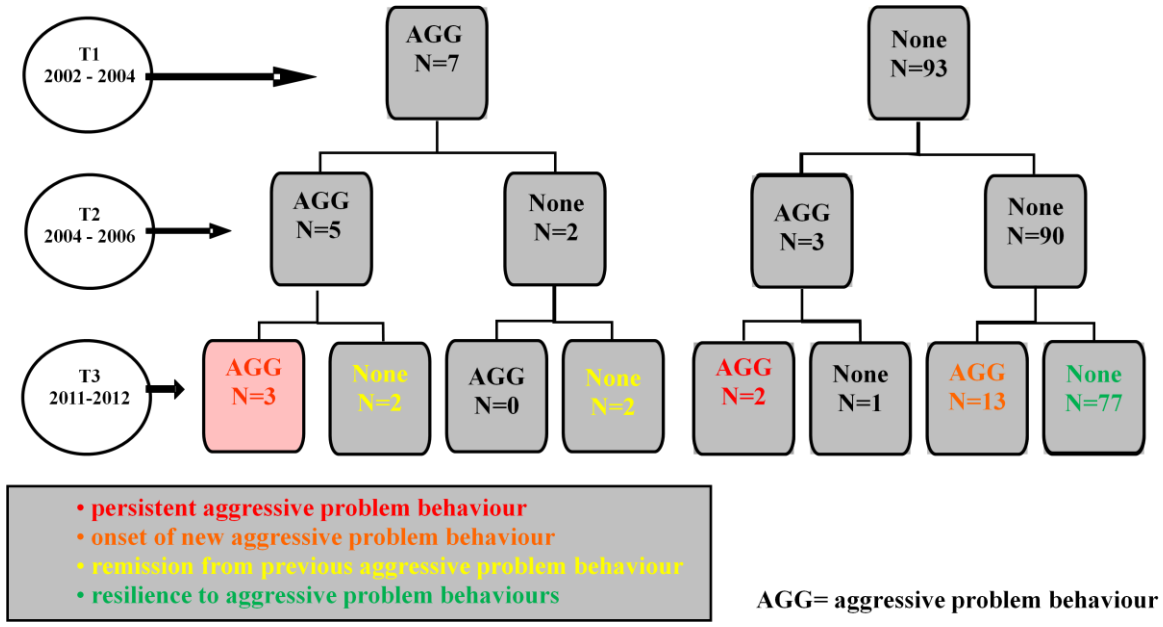


Figure 4.4.6 DC-LD aggressive problem behaviour (of any type) at T1, T2 and T3

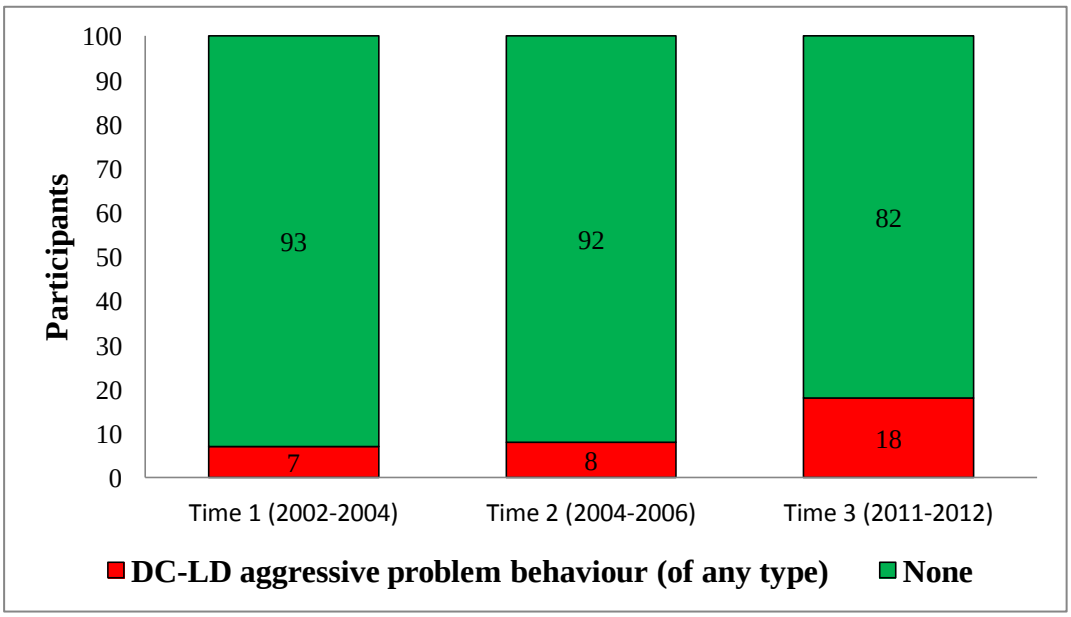


Figure 4.4.7 displays the trajectory of DC-LD self-injurious behaviours for 100 participants at three time points over a 10 year period: at T1, 5 participants had self-injurious behaviour, of which all 5 still had self-injurious behaviour at T2. Of these, only one participant was found not to display self-injurious behaviour, with the other 4 still meeting criteria for self-injurious behaviour at T3. This indicates DC-LD self-injurious behaviour to be persistent in the cohort at a rate of 4% (95% CI: 0.1-7.9%) over the 3 time points. Of the 95 participants that did not display self-injurious behaviour at T1, all 95 remained without self-injurious behaviour at T2. Of these, 87 still did not display self-injurious behaviour at T3. The remaining 8 were found to meet DC-LD criteria for self-injurious behaviour at T3. Figure 4.4.8 shows the total number of participants who met DC-LD criteria for self-injurious behaviour compared with those who were healthy, for each of the 3 time points.

Figure 4.4.7 Trajectory of DC-LD self-injurious behaviour over 10 years

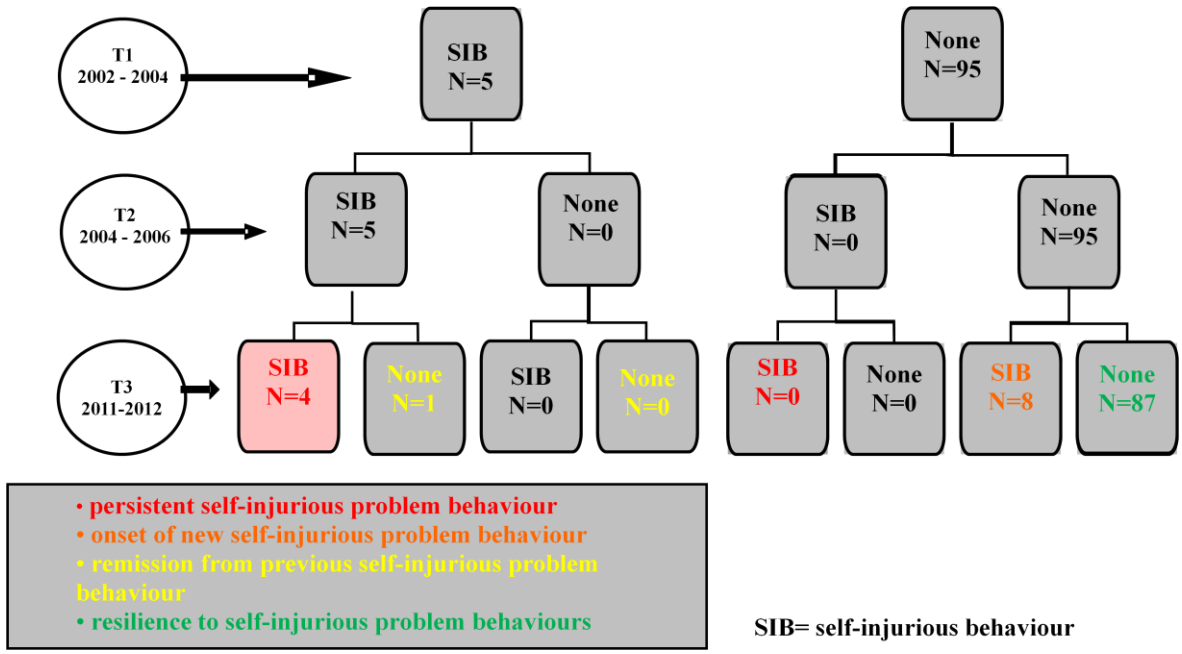
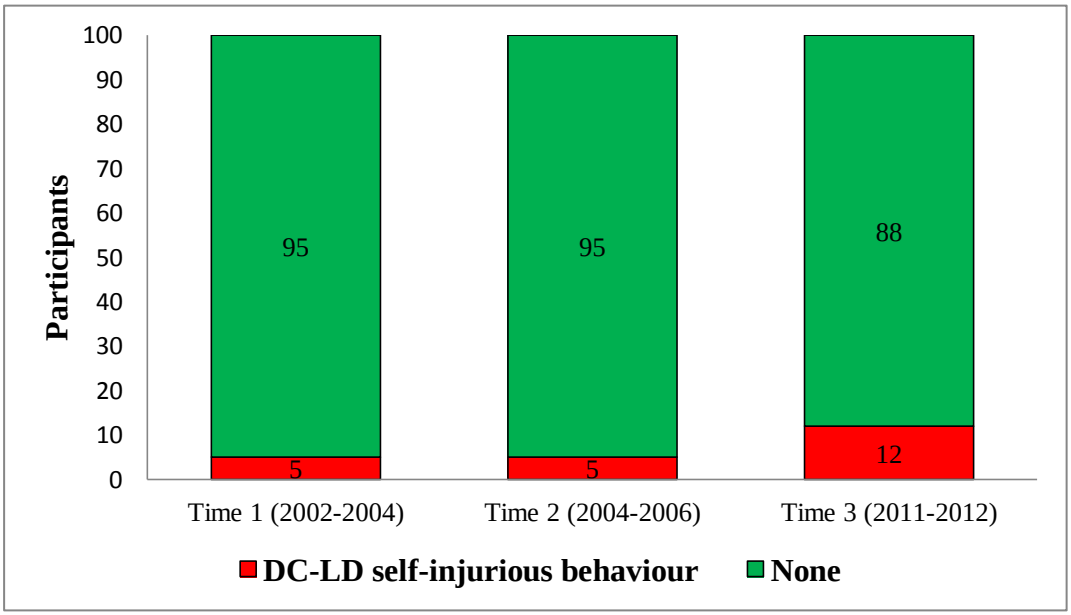


Figure 4.4.8 DC-LD self-injurious behaviour at T1, T2 and T3



4.4.3 Summary of findings regarding trajectories of mental ill-health and problem behaviour over time (research questions 1-3)

Mental ill-health follows a remitting-relapsing course, although it was persistent across the 3 time points for 31.7% of those with mental ill-health at T1. Problem behaviour also follows a remitting-relapsing course, but to a lesser extent, with persistence across the 3 time points found in 50% of those who had problem behaviour at T1.

Hypothesis 1: There will be a similar distribution of mental ill-health and problem behaviour at 3 time points over a 10 year period – **rejected**.

Hypothesis 2: Mental ill-health will be persistent over the 8-10 year time-period, for the majority of adults who were identified as having mental ill-health at baseline – **rejected**.

Hypothesis 3: Problem behaviour will be persistent over the 8-10 year time-period, for the majority of adults who were identified as having problem behaviour at baseline – **rejected**.

4.5 Longitudinal findings: changes in mental ill-health over time

4.5.1 Type of distribution

Change in total PAS-ADD Checklist scores between T1 & T3 and T2 & T3 for each participant were investigated. First, the distributions of these changes were explored using histograms (see figures 4.5.1 & 4.5.2). Visual analysis of the histograms showed the distribution of change scores to be approximately normal. Therefore, parametric tests were used to investigate change in total PAS-ADD Checklist scores between T1 & T3 and T2 & T3.

Figure 4.5.1 Histogram of change in total PAS-ADD Checklist scores between T1 and T3

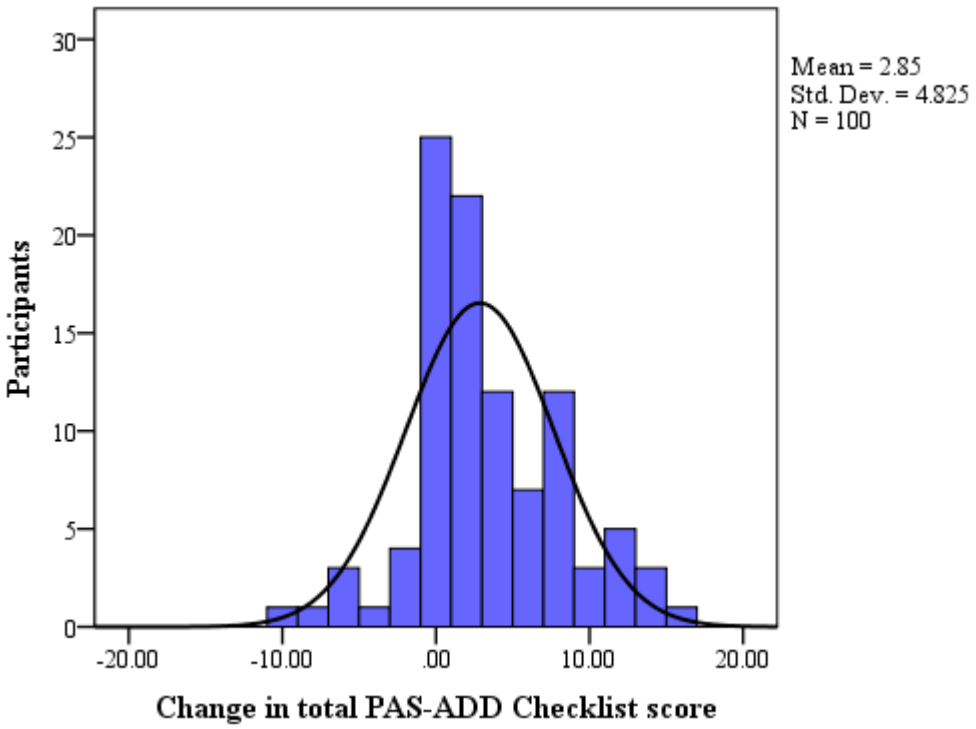
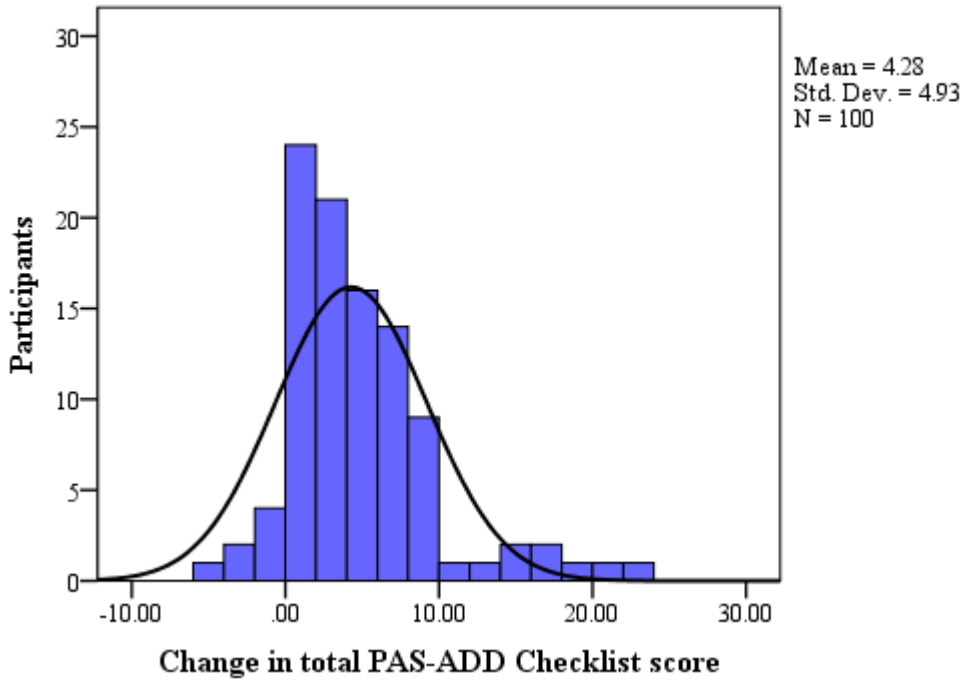


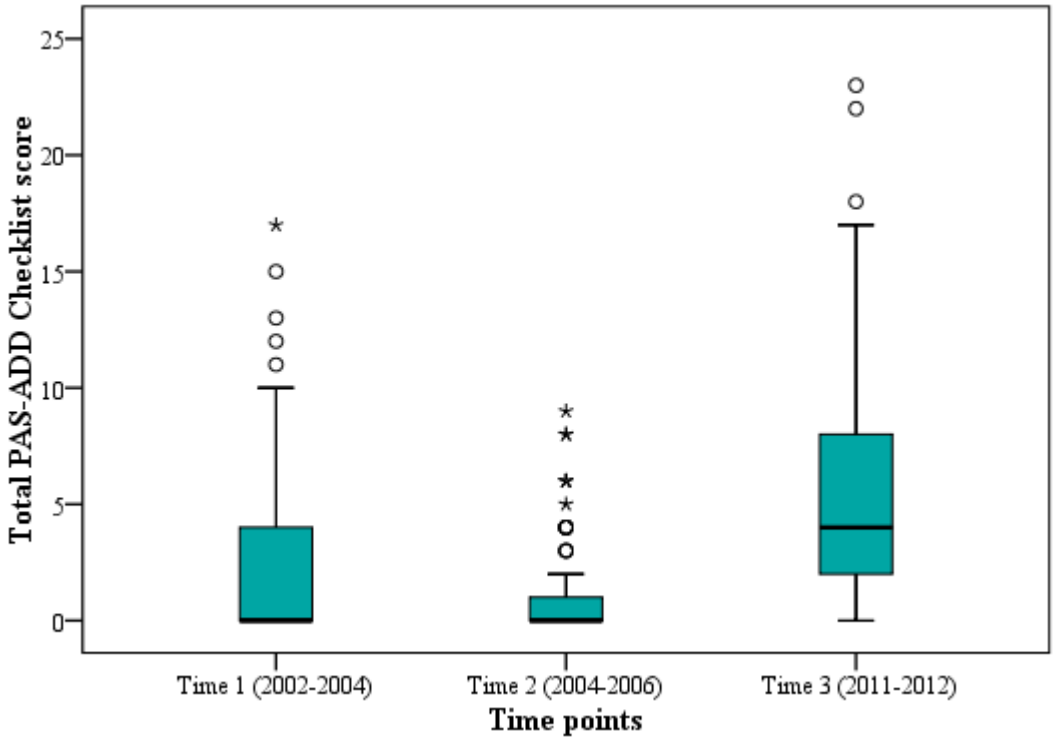
Figure 4.5.2 Histogram of change in total PAS-ADD Checklist scores between T2 and T3



4.5.2 Comparison of total PAS-ADD Checklist scores over time

Total PAS-ADD Checklist scores were found to be significantly higher at T3 (*M*=5.34, *SE*=0.50) than T1 (*M*=2.50, *SE*=0.37, *t*(99)=5.91, *p* <.001, *r*=0.51) and T2 (*M*=1.07, *SE*=01.94, *t*(99)=5.66, *p* <.001, *r*=0.66). Figure 4.5.3 displays the distribution of total PAS-ADD Checklist scores across each of the 3 time points.

Figure 4.5.3 Box plots showing total PAS-ADD Checklist scores at T1, T2 and T3



4.5.3 Post hoc power calculation

For change in total PAS-ADD Checklist score between T1 and T3, the parameters: effect size (0.51), α err prob (.001) and sample size (100) were entered into G*Power, and post hoc power was calculated to be 0.97.

For change in total PAS-ADD Checklist score between T2 and T3, the parameters: effect size (0.66), α err prob (.001) and sample size (100) were entered into G*Power, and post hoc power was calculated to be 0.99.

4.5.4 Summary of findings regarding changes in mental ill-health over time (research question 4)

Total PAS-ADD Checklist scores were significantly higher at T3 than both T1 and T2, indicating severity of mental ill-health increased over time. Post hoc power calculations indicated this to be a true difference of clinical importance.

Hypothesis 4: Psychopathology will remain relatively stable over the 10 year time-period, in terms of total PAS-ADD Checklist scores – **rejected**.

4.6 Longitudinal findings: factors predicting mental ill-health outcomes over time

Throughout the following two sections investigating predictive determinants of mental ill-health and problem behaviour, initial analyses of the individual predictors are presented in the appendices. The subsequent analyses investigating independent predictors are presented in the main text. This is to focus attention on the key findings.

4.6.1 Factors predicting greatest increase in total PAS-ADD Checklist scores between T1 and T3

Change in total PAS-ADD Checklist scores between T1 and T3 ranged from -10 to +16, and the distribution of this data was found to be normal (table 4.5.1) These scores were adjusted to range from 0 to +26 in order to investigate factors associated with greatest increase in scores over time. Factors from the univariate analysis predicting the greatest increase in total PAS-ADD Checklist scores between T1 and T3 (controlling for differences in score at T1) are detailed in Appendix C, tables C1-4. Greatest increase in total PAS-ADD Checklist scores between T1 and T3 was found to be associated with age, with those aged 36-55 (M=14.00, SE=0.67) showing a greater increase in scores compared with those aged 16-35 (M=12.06, SE=0.73), $t(99)=1.95$, $p=.054$, or those aged 56+ (M=11.58, SE=1.09), $t(99)=1.88$, $p=.062$.

As this was the only significant finding, a second stage of analysis was not required. However, this finding is not significant at the level of $p \leq .05$.

4.6.2 Factors predicting greatest increase in total PAS-ADD Checklist scores between T2 and T3

Change in total PAS-ADD Checklist scores between T2 and T3 ranged from -5 to +22, and the distribution of this data was found to be normal (table 4.5.2) These scores were adjusted to range from 0 to +27 in order to investigate factors associated with greatest increase in scores over time. Factors from the univariate analysis predicting the greatest increase in total PAS-ADD Checklist scores between T2 and T3 (controlling for differences in score at T2) are detailed in Appendix C, tables C5-9. Greatest increase in total PAS-ADD Checklist scores between T2 and T3 were found to be predicted by: being aged 36-55 (*M*=10.50, *SE*=0.72) compared with being aged 16-35 (*M*=8.55, *SE*=0.78), *t*(99)=1.84, *p*=.069, or aged 56+ (*M*=7.70, *SE*=1.17), *t*(99)=2.04, *p*=.044; living with a paid carer (*M*=10.47, *SE*=0.71) compared with living with a family carer (*M*=8.13, *SE*=0.76), *t*(99)=2.23, *p*=.028; having an angry interaction in the past week (*M*=12.36, *SE*=1.24) compared with not having an angry interaction (*M*=8.72, *SE*=0.53), *t*(97)=2.71, *p*=.008; having no close relationships (*M*=12.15, *SE*=1.31) compared with having one close relationship (*M*=9.10, *SE*=1.03), *t*(99)=1.82, *p*=.071, or more than 1 close relationship (*M*=8.71, *SE*=0.60), *t*(99)=2.38, *p*=.019; trusting anyone with a secret (*M*=12.20, *SE*=1.49) compared with trusting 2-5 people (*M*=7.98, *SE*=0.69), *t*(97)=2.56, *p*=.012, or >5 people (*M*=8.37, *SE*=1.00), *t*(97)=2.13, *p*=.036; trusting one person with a secret (*M*=11.79, *SE*=1.57) compared with trusting 2-5 people (*M*=7.98, *SE*=0.69), *t*(97)=2.22, *p*=.029; and trusting no one with a secret (*M*=11.79, *SE*=1.43) compared with trusting 2-5 people (*M*=7.98, *SE*=0.69), *t*(97)=2.41, *p*=.018.

At the next stage of analysis, these variables, excluding cases with missing data (n=3) were entered into a general linear model. Total PAS-ADD Checklist score at T2 was also entered as a covariate to control for differences in initial scores. A backwards method was used to remove the least significant variable. This process was repeated until all variables in the model were significant. The standard residuals were checked for outliers (those greater than +2.58 or less than -2.58). Identified outliers (n=3) were removed from the model and the regression was rerun.

Changes in total PAS-ADD Checklist scores between T2 and T3 were found to be independently predicted by experience of an angry interaction in the past week and number of people the participant trusted with a secret (table 4.6.2).

Changes in total PAS-ADD Checklist scores were significantly higher for: participants who experienced an angry interaction in the past week (4.79 (2.80, 6.79), $p<.001$) compared to those who did not; and participants who trusted 1 person (4.14, (1.60, 6.68), $p=.002$) or anyone (4.63, (2.09, 7.18), $p<.001$) compared to those who trusted 2-5 people with a secret.

Table 4.6.2 Increase in total PAS-ADD Checklist score between T2 and T3

Factor		**Multivariate Associations**		
		Parameter Estimate (95% CI)	**p-value**	
Group 3: Social Networks & Activities at T2				
Angry interaction in the past week	No	Referent		
	Yes	4.79 (2.80, 6.79)		.000
People trusted with a secret	2-5	Referent		
	Anyone	4.63 (2.09, 7.18)	.000	.000
	>5	0.49 (-2.32, 1.35)	.601	
	1	4.14 (1.60, 6.68)	.002	
	No-one	1.32 (-1.26, 3.89)	.311	
Total PAS-ADD Checklist score at T2		-0.28 (-0.65, 0.09)		.132

4.6.3 Summary of findings on factors predicting deterioration in mental ill-health over time (research question 5)

The only factor found to be associated with change in total PAS-ADD Checklist score between T1 and T3 was age. However, although age was significant at the univariate level of ≤.1, it approached, but did not reach a significance level of ≤.05. The factors found to predict the greatest increase in total PAS-ADD Checklist scores between T2 and T3 were

both from group 3 regarding social networks and activities at T2 – experiencing an angry interaction and trusting others with a secret.

Hypothesis 5: Deterioration of mental health, in terms of increase in total PAS-ADD Checklist scores will be predicted by a range of factors, such as level of ID, gender, living arrangement, experience of life events and presence of urinary incontinence – **rejected.**

4.6.4 Factors predicting mental ill-health relapse between T1 and T3

Of the 41 participants who had mental ill-health at T1, 28 were in remission at T2. Of these 28, 26 experienced a relapse of mental ill-health at T3.

Univariate analyses of factors associated with relapse of mental ill-health between T1 and T3 are detailed in Appendix C, tables C10-14. The 26 people who relapsed were compared with the 21 people who were resilient to mental ill-health at all 3 time points. Significant associations were found between relapse of mental ill-health between T1 and T3 and: gender (x^2 (1) = 4.56, p=.043); life events experienced prior to T1 (x^2 (1) = 7.42, p=.009) and life events experienced prior to T3 (Fisher's exact test 2-sided p =.035), with those experiencing life events being more likely to have relapse of mental ill-health than those who did not experience life events (62.5% vs. 14.3%).

At the second stage of analyses, these variables were entered into the regression and it was found that being female (Odds Ratio .213, 95% CI .051-.883, p= .033) and experiencing life events prior to T1 (Odds Ratio 4.94, 95% CI 1.19-20.53, p= .028) independently predicted relapse of mental ill-health between T1 and T3 (table 4.6.4).

Table 4.6.4 Mental ill-health relapse between T1 and T3: logistic regression results

Factors	OR	95% C.I. for OR Lower	Upper	*p*
Group 1: Personal **Gender**	.213	.051	.883	.033
Group 4: Past experiences **Experience of life events prior to T1**	4.94	1.19	20.53	.028

4.6.4.1 Post hoc analysis: gender and mental ill-health at T3

In view of the finding that female gender was independently predictive of relapse of mental ill-health between T1 and T3, post hoc analyses were conducted to determine whether female gender was also independently predictive of mental ill-health at T3.

Univariate analysis revealed no significant association between gender and mental ill-health at T3 (x^2 (1) = 1.33, p=.37). Thus no further analysis was required.

4.6.5 Factors predicting onset of new mental ill-health at T3

Of the 59 participants who were healthy at T1, 53 remained free from mental ill-health at T2. Of these 53, 32 experienced onset of new mental ill-health at T3.

Univariate analyses of factors associated with the onset of new mental ill-health at T3 are detailed in Appendix C, tables C15-19. The 32 people who experienced onset of new mental ill-health were compared with the 21 people who were resilient to mental ill-health at all 3 time points. Significant associations were found between new onset of mental ill-health at T3 and life events experienced prior to T3 (Fisher's exact test 2-sided p =.047), with those experiencing life events being more likely to have onset of a new mental ill-health at T3 than those who did not experience life events (66.7% vs. 25.0%).

As this was the only significant finding, a second stage of analysis was not required.

4.6.6 Factors predicting resilience to mental ill-health

Twenty-one participants were resilient to mental ill-health at all 3 time points.

Univariate analyses of factors associated with resilience to mental ill-health are detailed in Appendix C, tables C20-24. The 21 participants who were resilient to mental ill-health at all 3 time points were compared with the remaining 79 participants who had all experienced mental ill-health at least once over the 3 time points. Significant associations were found between resilience to mental ill-health and: life events experienced prior to T3 (Fisher's exact test 2-sided p=.069) and urinary incontinence (x^2 (1) = 3.38, p=.066).

At the second stage of analyses, these variables were entered into the regression model and standard residuals were checked for outliers (those greater than +2.58 or less than -2.58). Identified outliers (n=1) were removed from the model and the regression was rerun.

Both variables entered into the regression model were found to be independently significant, with not experiencing life events prior to T3 (Odds Ratio .049, 95% CI .006-.430, *p*= .006) and not having urinary incontinence (Odds Ratio .042, 95% CI .004-.450, *p*= .009) independently predicting resilience to mental ill-health (see table 4.6.6).

Table 4.6.6 Resilience to mental ill-health: logistic regression results

Factors	OR	95% C.I. for OR Lower	Upper	*p*
Group 4: Past experiences **Experience of life events prior to T3**	.049	.006	.430	.006
Group 5: Health & disabilities **Urinary incontinence**	.042	.004	.450	.009

4.6.7 Summary of findings on factors predicting mental ill-health outcomes over time (research question 6)

Relapse of mental ill-health at T3 was found to be predicted by female gender and experience of life events prior to T1. The only factor significantly associated with onset of new mental ill-health at T3 was experience of life events prior to T3, with those who experienced life events being more likely to have an onset of new mental ill-health than those who did not experience life events. Resilience to mental ill-health at all 3 time points was predicted by not experiencing life events prior to T3 and not have urinary incontinence.

Hypothesis 6: Mental ill-health outcomes will be predicted by a range of factors, such as level of ID, gender, living arrangement, experience of life events and presence of urinary incontinence – **partially accepted.**

4.7 Longitudinal findings: factors predicting DC-LD problem behaviour outcomes over time

4.7.1 Factors predicting onset of new DC-LD problem behaviour at T3

Of the 86 participants who were healthy at T1, 81 remained free from problem behaviour at T2. Of these 81, 20 experienced onset of new problem behaviour at T3.

Univariate analyses of factors associated with the onset of new problem behaviour at T3 are detailed in Appendix C, tables C25-29. The 32 people who experienced onset of new problem behaviour were compared with the 61 people who were resilient to problem behaviour at all 3 time points. A significant association was found between onset of new problem behaviour at T3 and life events experienced prior to T1 (x^2 (1) = 5.12, p=.038), with those not experiencing life events being more likely to have onset of a new problem behaviour at T3 than those who experienced life events (34.9% vs. 13.2%).

As this was the only significant finding, a second stage of analysis was not required.

4.7.2 Factors predicting resilience to DC-LD problem behaviour

Sixty-one participants were resilient to problem behaviour at all 3 time points.

Univariate analyses of factors associated with the resilience to problem behaviour are detailed in Appendix C, tables C30-34. The 61 participants who were resilient to problem behaviour at all 3 time points were compared with the remaining 39 participants who had all experienced problem behaviour at least once over the 3 time points. As described in the method (page 117), the first stage of analyses investigated the individual associations of factors with outcomes. Factors found to be associated were selected for further investigation of how independent of other factors they were, in the subsequent regression analysis, if the association was p<.1 at the univariate analysis stage. Significant associations were found between resilience to problem behaviour and: age (x^2 (2) = 3.56, p=.065); level of ID (x^2 (3) = 8.06, p=.005); T1 type of accommodation (x^2 (2) = 11.15, p<.001); T2 type of accommodation (x^2 (2) = 12.97, p<.001); T2 experience of an angry

exchange in the past week (x^2 (1) = 5.34, p=.025); T2 experience of a minor disagreement in the past week (x^2 (1) = 5.45, p=.025); T2 status of having a close relationship (x^2 (2) = 7.84, p=.003); and urinary incontinence (x^2 (1) = 5.89, p=.018).

At the second stage of analyses, these variables were entered into the regression model and standard residuals were checked for outliers (those greater than +2.58 or less than -2.58). Identified outliers (n=4) were removed from the model and the regression was rerun. It was found that resilience to problem behaviour was independently predicted by having mild compared with moderate (Odds Ratio .071, 95% CI .015-.337, p=.001), severe (Odds Ratio .157, 95% CI .030-.828, p=.029) or profound ID (Odds Ratio .058, 95% CI .008-.398, p= .004); not experiencing an angry interaction in the past week compared with experiencing an angry interaction (Odds Ratio .044, 95% CI .008-.245, p<.001), and having more than one close relationship compared with having no close relationships (Odds Ratio 15.28, 95% CI 2.78 -84.07, p=.002) (see table 4.7.2).

Table 4.7.2 Resilience to problem behaviour at all 3 time points: logistic regression results

Factors	OR	95% C.I. for OR Lower	Upper	*p*
Group 1: Personal Factors				
Level of ID (vs. Mild)				
Moderate	.071	.015	.337	.001
Severe	.157	.030	.828	.029
Profound	.058	.008	.398	.004
Group 3: Social networks & activities at T2				
Angry interaction in past week	.044	.008	.245	.000
Having a close relationship (vs. No)				
Yes, 1	3.59	.575	22.37	.171
Yes, >1	15.28	2.78	84.07	.002

4.7.3 Summary of findings on factors predicting problem behaviour outcomes over time (research question 7)

The only factor significantly associated with onset of new problem behaviour at T3 was experience of life events prior to T1, with those who did not experience life events being more likely to have an onset of new problem behaviour than those who did experience life events. Resilience to problem behaviour was predicted by having mild, compared with more severe ID and not experiencing an angry interaction.

Hypothesis 7: Problem behaviour outcomes will be predicted by a range of factors, such as level of ID, gender, living arrangement, experience of life events and presence of urinary incontinence – **partially accepted.**

4.8 Cross-sectional findings: associations between total PAS-ADD Checklist score and lifestyle factors

Throughout the following two sections investigating factors associated with mental ill-health, analysis of each individual predictor is presented in the appendices. The subsequent analyses focus on only those factors which were significantly correlated with mental ill-health.

4.8.1 Correlations between T3 mental ill-health severity and participation in daily, domestic and social activities

Spearman's rank order correlations were performed in order to determine the relationship between total PAS-ADD Checklist scores at T3 and measures of participation in daily, domestic and social activities (see appendix C, table C35). The type and number of activities, as well as frequency and type of accompaniment of participation were also investigated. Significant but weak negative correlations were found between total PAS-ADD Checklist score and: total number of activities with peers ($r_s(98) = -.245$, $p=.014$); total number of frequent outdoor leisure activities ($r_s(98) = -.225$, $p=.025$); total number of social activities ($r_s(98) = -.202$, $p=.043$); total number of social activities with peers ($r_s(98) = -.219$, $p=.029$); and total number of combined leisure activities with peers ($r_s(98) = -.241$, $p=.016$). These relationships are displayed figures 4.8.1 – 4.8.5.

Figure 4.8.1 Relationship between total PAS-ADD Checklist score and total number of activities with peers

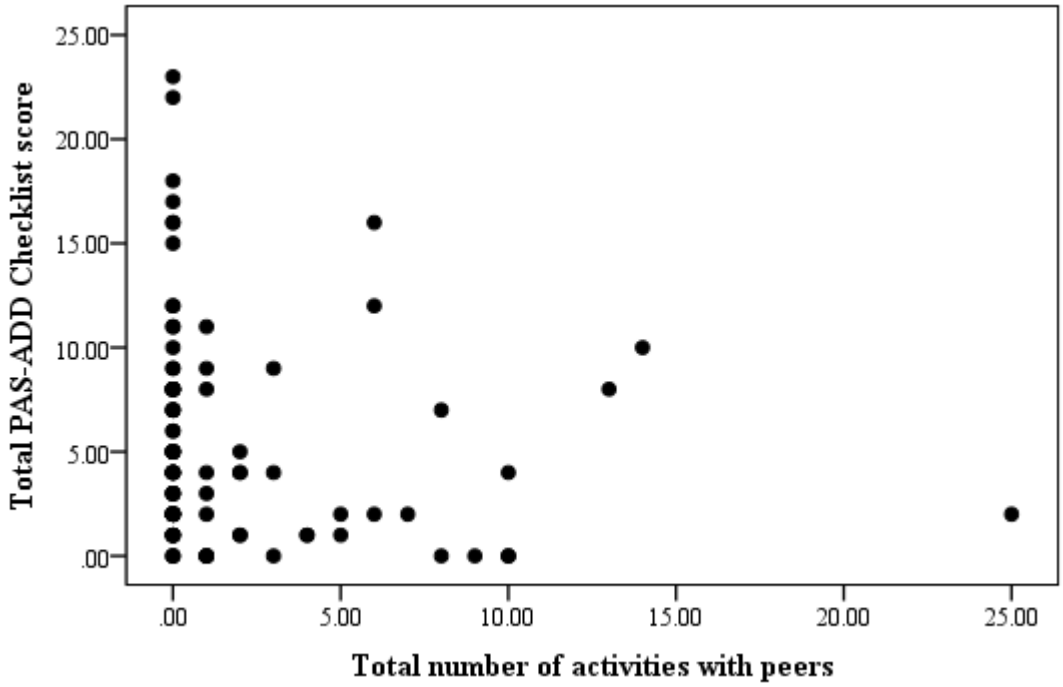


Figure 4.8.2 Relationship between total PAS-ADD Checklist scores and total number of frequent outdoor leisure activities

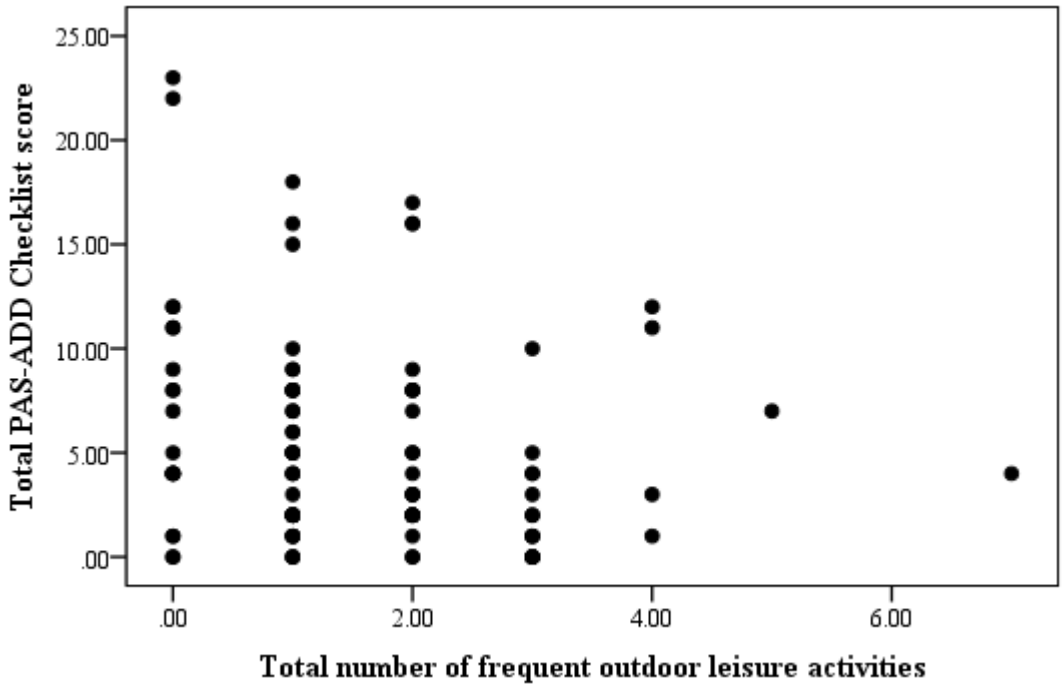


Figure 4.8.3 Relationship between total PAS-ADD Checklist scores and total number of social activities

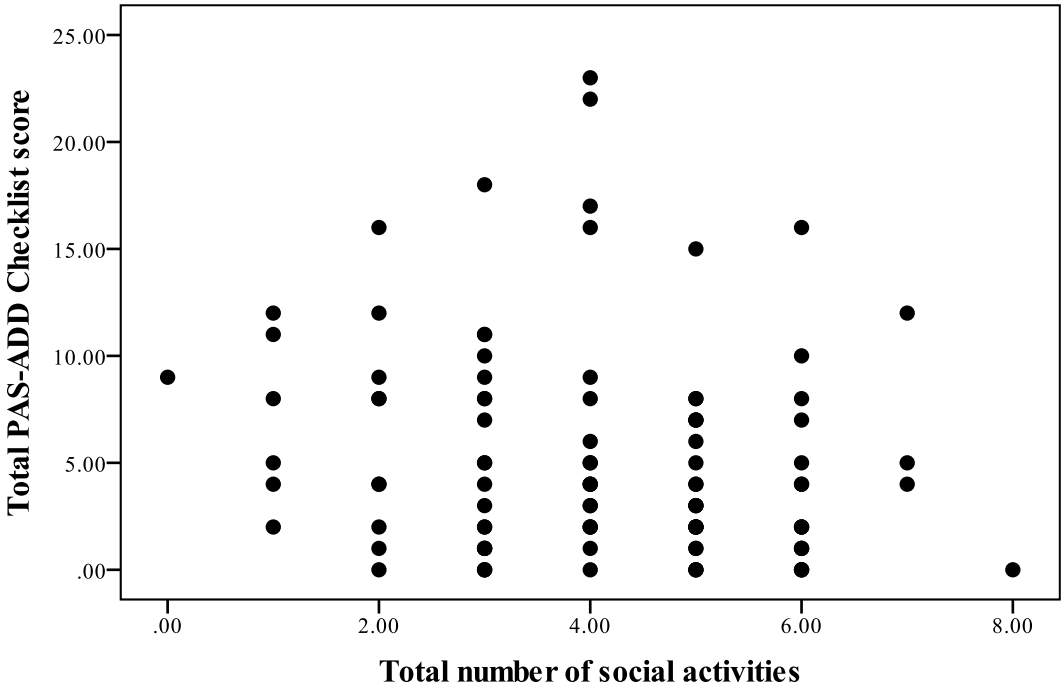


Figure 4.8.4 Relationship between total PAS-ADD Checklist scores and total number of social activities with peers

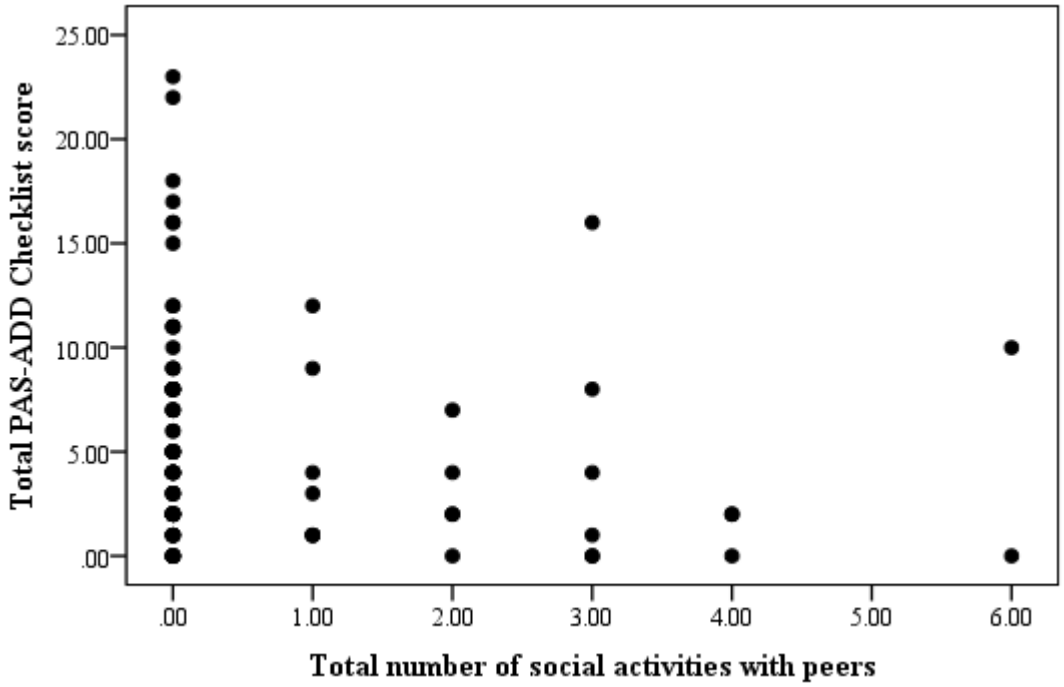
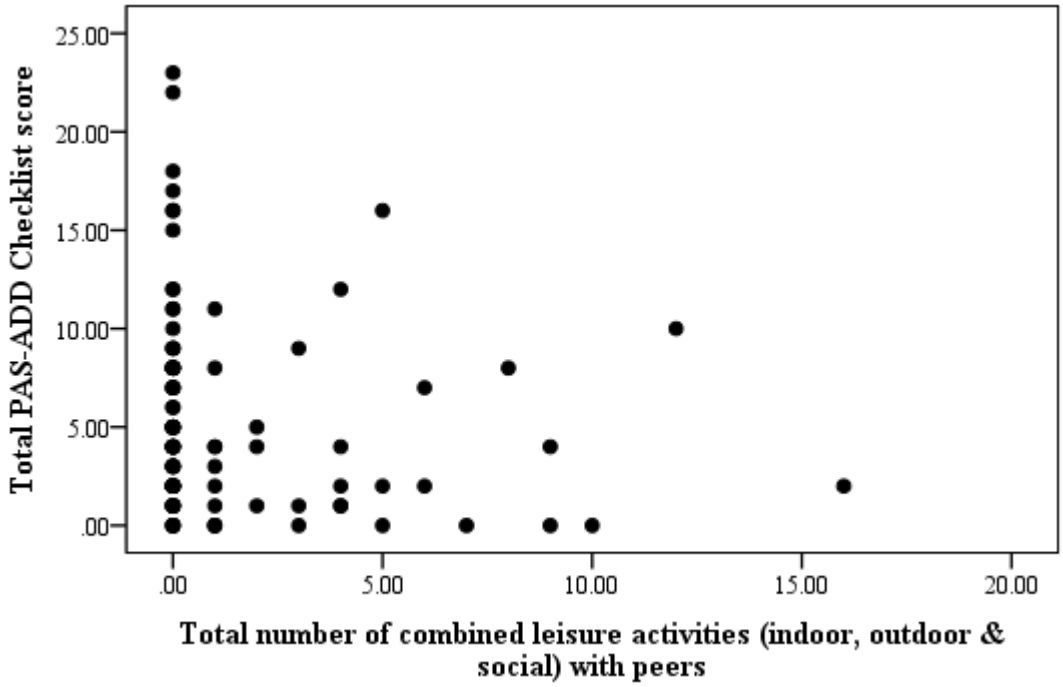


Figure 4.8.5 Relationship between total PAS-ADD Checklist scores and total number of combined leisure activities with peers



4.8.2 Summary of findings on the relationship between total PAS-ADD Checklist scores and lifestyles (research question 8)

Significant but weak correlations were found between total PAS-ADD Checklist scores and 5 subscales of the GCPLA. These correlations were found only for social or leisure activities and/or activities with peers. Thus, those who participated in more of these types of activities had lower total PAS-ADD Checklist scores.

Hypothesis 8: Severity of psychopathology, in terms of higher total PAS-ADD Checklist scores, will be associated with less frequent participation in social activities with peers – **accepted.**

4.9 Cross-sectional findings: associations between total PAS-ADD Checklist score and perceived social support

4.9.1 Correlations between T3 mental ill-health severity and social support

Spearman's rank order correlations were performed in order to determine the relationship between total PAS-ADD Checklist scores at T3 and modified perceived social support total scores (see appendix C, table C35). Only 46 participants were able to answer the perceived social support questions. No relationship was found between total PAS-ADD Checklist scores at T3 and perceived social support ($r_s(44) = -.202$, $p=.178$).

4.9.2 Summary of findings on the relationship between total PAS-ADD Checklist scores and social support (research question 9)

No correlation was found between severity of mental ill-health and perceived social support in those participants who were able to answer the questions.

Hypothesis 9: Severity of psychopathology, in terms of higher total PAS-ADD Checklist scores, will be associated with lower levels of perceived social support – **rejected.**

CHAPTER 5: DISCUSSION

5.1 Principal findings on trajectories and their interpretation

This thesis investigated the trajectories of mental ill-health and problem behaviour over a 10-year time period. A post hoc power calculation revealed the study to be highly powered and therefore able to address the following hypothesis at a clinically significant level. It was hypothesised that distributions would be similar across time points, with the majority of those with mental ill-health and problem behaviour at T1 experiencing persistent illness over the 10-year period. However, distributions of mental ill-health were not similar, with total PAS-ADD Checklist scores showing a significant increase at T3 compared with both T1 and T2. At T3, of the 75% of the cohort meeting criteria for mental ill-health, 32% experienced an onset of new mental ill-health, 26% had experienced a relapse of mental ill-health, 13% experienced persistent problem behaviour, and the remaining participants experienced mental ill-health which had also been present at T2 (but not T1). Of the 41 people with mental ill-health at T1, 31.7% experienced persistent mental ill-health over the 10-year period. Thus, mental ill-health showed greater severity over time, and for the majority of participants followed a remitting-relapsing course. Despite the high number of individuals experiencing symptoms of psychopathology at T3, only 26 were in receipt of clinical services, of which 21 were in contact with a psychiatrist; 2 were in contact with a psychologist; and 3 were in contact with both. Seventeen individuals were currently taking antidepressants, and 17 were also taking antipsychotics. Thirty-three individuals were taking anti-epileptics.

Similarly, distributions of problem behaviour were different across time points, with more at T3 than T1 or T2. Of the 34% meeting DC-LD criteria at T3, 20% had experienced an onset of new problem behaviour, 7% experienced persistent problem behaviour, 5% experienced problem behaviour which had also been present at T2 (but not T1), and the remaining participants had experienced a relapse of problem behaviour. Of the 14 people with problem behaviour at T1, 50% experienced persistent problem behaviour over the 10-year period. Thus, problem behaviour followed a remitting-relapsing course for half of the participants meeting criteria at T1, and was persistent for the other half. Similar patterns

were found for aggressive problem behaviour and self-injurious behaviour, with criteria for aggressive problem behaviour being met by 7% of the cohort at T1, 8% at T2 and 18% at T3. Criteria for self-injurious behaviour were met by 5% of the cohort at T1, 5% at T2 and 12% at T3. Aggressive problem behaviour was persistent for 42.9% of those who met criteria at T1, and self-injurious behaviour showed the highest rate of persistence with 80% of those who met criteria at T1 also meeting criteria at T2 and T3. As with mental ill-health, despite the high number of individuals displaying problem behaviour at T3, only 14 were in receipt of clinical services, of which 12 were in contact with a psychiatrist; and 2 were in contact with a psychologist. Ten individuals were currently taking antipsychotics and 8 were taking antidepressants. Seventeen individuals were taking anti-epileptics.

In comparison with previous literature reporting prevalence rates of mental ill-health, the rate of 75% found at T3 is high. However, based on T1 data, it is expected that had the 75% received full psychiatric assessment, 47% would have been found to have a psychiatric disorder according to clinical diagnoses. This is still relatively high, in comparison with recent population-based studies which have reported prevalence rates of mental ill-health and problem behaviour ranging from 30-50% (Cooper & Bailey 2001; Cooper et al 2007a; Morgan et al 2008). Reported rates of problem behaviour have varied much more than mental ill-health, ranging from 15-60% (Cooper & Bailey 2001; Deb et al 2001b). The rate of 34% found at T3 falls in the middle of these ranges and is similar to the rate of 33.9% reported by Bailey (2007). However, the aforementioned study included only adults with moderate-profound ID and so is not directly comparable with the present study. Comparison with rates of aggressive problem behaviour is problematic given that most studies have reported separate rates for physical, verbal and destructive aggression. However, the majority of studies (Deb et al 2001b; Joyce et al 2001; Lowe et al 2007) reported higher rates for these individual subtypes than the rate of 18% found for overall aggressive problem behaviour at T3. One study did report an overall rate of aggressive problem behaviour, but this was also much higher (51.8%) than reported in the present study (Crocker et al 2006). Similarly, self-injurious behaviour was also found at a much lower rate (12%) at T3 than reported in previous studies (Deb et al 2001b; Joyce et al 2001; Crocker et al 2006; Lowe et al 2007). In comparison with the same literature, the T1 prevalence study also reported lower rates of aggressive problem behaviour and self-injurious behaviour. At each time point in the present study, any problem behaviour

occurring secondary to mental or physical illness were excluded from the rates reported. The implementation of such criteria may in part explain why rates were lower in the present study compared with previous literature.

There are several possibilities which may explain the proportion of patients experiencing psychopathology across the 3 time points. First, it is possible that interventions from clinical services brought about improvements in mental health in the interval between T1 and T2, leading to reduced rates of psychopathology at T2. At both T1 and T2, any participant found to have mental ill-health or problem behaviour were offered a referral to clinical services. Given the relatively short time period (2 years) between T1 and T2, it is likely that those who received such referrals at T1 were either still in contact with services at T2, or had been recently discharged from services due to improvement. In contrast, the interval between T2 and T3 was comparably longer meaning that some of the participants may have disengaged from clinical services (due to for example, personal circumstances such as moving home) or failed to re-engage if there was a relapse in mental-ill health. Failure to re-enter services may have been due to a number of factors i.e. because services failed to follow-up such individuals, or because such individuals were dependent on their carers reporting symptoms to primary care, and this did not happen. Also, given this time period, it is possible that individuals had different carers, who were not aware of the previous contact with services and so did not seek to renew it.

Alternatively, a further possibility to explain the increase in psychopathology over time is the finding that older adults with ID experience higher rates of mental ill-health and problem behaviour than younger adults with ID (Cooper 1997). An existing learning disabilities register was used to recruit 107 adults with all levels of ID from the same geographical area. The sample consisted of 165 adults aged over 65 years, and a comparison group of 75 adults aged 20-65 years. Face-to-face interviews were conducted with the individual and their main carer using the PPS-LD to assess psychiatric disorder, which was found to be higher in the older group than the younger group (68.7% vs. 47.9%, respectively). Although not directly comparable given its cross-sectional design and comparison of two separate groups of people, the Cooper (1997) study provides evidence to suggest that psychopathology in adults with ID either increases with age, or is more prevalent in older birth cohorts; thus supporting the present finding.

With regards to comparisons of longitudinal studies, only 2 investigated mental ill-health and problem behaviour outcomes in a cohort of adults with ID over a 10-year period. One of these studies investigated both mental ill-health and problem behaviour (Reid et al 1978; Reid & Ballinger 1995; Thompson & Reid 2002) and one investigated only problem behaviour (Totsika et al 2008).

The study carried out by Reid et al (1978; 1995; Thompson & Reid 2002) found psychiatric disorder to be persistent between baseline and 16-18 year follow-up. However, between baseline and 26 year follow-up the authors reported a significant decrease in the severity of psychiatric ratings. Such findings are contradictory to the increase in severity of psychopathology reported in the present study. However, it is not possible to directly compare these studies given their methodological differences. For example, the Reid et al (1978) study consisted of a sample of long-stay hospital residents with severe or profound ID, whereas the present study included a population-based sample of adults with mild to profound ID. It is feasible that the long-stay hospital residents would have had a greater severity of psychopathology at baseline than the population-based sample. Thus the hospital residents would be more likely to show a general decrease in severity over time, reflecting regression to the mean. Also, given that the sample were long-stay hospital residents, they may have received treatment or interventions over the course of the study which could have contributed to their improvement. In their original paper the authors alluded to 'treatment procedures' but did not elaborate any further on what this was or whom it was for. In their final paper, Thompson and Reid (2002) reported that individuals aged over 60 received less severe ratings of psychiatric disorder, and claimed that this was not surprising given the increase in mobility problems. At the time of their 26-year follow-up, participants were aged 57.6 on average, with a range of 42-92. In comparison with the T3 follow-up, participants were aged 49.4 on average, with a range of 26.6-79.7. Mobility problems due to age would therefore be less likely to occur in the present sample, contributing to the difference in findings. Also, given that the Reid et al (1978) study did not carry out any intermediate investigations between baseline and 18-16 year follow-up, it is not possible to compare trajectories of mental ill-health over a 10-year period. Finally, the outcomes in the Reid et al (1978) study were reported at the group level and not the individual level, therefore the findings cannot be directly compared because it is not clear whether severity of psychopathology did in fact decrease in the same individuals over time.

The Reid et al (1978) study also investigated self-injurious behaviour and pica, both of which were reported to be highly persistent over time. It is not possible to directly compare these findings with the present study, due to the methodological differences described. Also, given that the authors did not compare the same participants at baseline and follow-up, it is not possible to say whether self-injurious behaviour and pica were in fact persistent over time. However, the authors reported self-injurious behaviour to be displayed in 5.7% at baseline and 11.3% at follow-up. The present study reported a similar finding with self-injurious behaviour displayed in 5% of the sample at baseline and 12% at follow-up. Self-injurious behaviour was also found to be the most persistent problem behaviour investigated, with 80% of those displaying self-injurious behaviour at T1 also displaying self-injurious behaviour at T3. Kiernan and Alborz (1996) also found self-injurious behaviour to be highly persistent, with 75% of those displaying self-injurious behaviour at baseline also displaying it at 5-year follow-up. The sample in this study consisted of young adults aged 19-26 years with unspecified levels of ID, residing with their families. Thus, the sample is not directly comparable with the present study. Also, the duration of follow-up is too short to allow longer term outcomes of problem behaviour to be compared. However, given that the same individuals were compared` over time, the study supports the present finding that self-injurious behaviour is highly persistent over time.

Totsika et al (2008) carried out the only other study to investigate problem behaviour in an adult ID cohort over a 10-year period. In comparison with the present study, they reported a much lower persistence rate of 47% (vs. 80%) for self-injurious behaviour and a higher persistence rate of 79% (vs. 50%) for overall 'serious controlled' problem behaviour. Their sample consisted of adults living in small villas on a long-term residential facility, the majority of whom had severe ID and were older than the adults in the present study. The differences between the two samples, particularly the level of ID, may explain some of the difference between the persistence rates reported by Totsika et al (2008) and those of the present study. The higher rate of persistent problem behaviour may be further explained by the lack of intermediate investigation between baseline and 11-year follow-up. Given that the authors did not conduct intermediate investigations, they would not be aware of any episodes of relapse and remission that may have occurred, and thus may have reported a false rate of persistence.

5.2 Principal findings on predictive factors and their interpretation

The present study has reported factors found to be independently predictive of mental ill-health and problem behaviour. However, this does not necessarily mean that they are causally related, and it is not possible for the findings to meet all of the Howick et al (2009) criteria (outlined on page 79). Firstly, although other factors were controlled for, and the predictors were independent, there may have been other contributing factors which were not assessed or controlled. Each of the outcomes investigated were preceded by the predictive factors. However the time interval (particularly between T1 and T3) was long enough for potential unknown confounders to have an effect on the outcomes. This study is not a replication and there are few existing longitudinal studies with which to compare the findings. Therefore, for each of the outcomes below any similar existing studies will be discussed, as will the mechanistic evidence which may explain the findings. It should also be noted that the study may have been underpowered at T3 to detect some genuinely predictive factors. This is discussed more fully in section 5.5.3.

5.2.1 Personal Factors

Gender

Female gender was found to independently predict mental ill-health relapse between T1 and T3, with over twice as many females than males experiencing relapse. There are no other studies investigating risk factors associated with the relapse of mental ill-health with which to compare this finding. However, female gender has previously been associated with mental ill-health of any type (excluding autistic spectrum disorder and specific phobia) in this cohort at T1 (Cooper et al 2007a). It did not however, predict new episodes of mental ill-health at T2 (Smiley et al 2007). Similarly, there was no relationship between gender and new onset of mental ill-health at T3, nor in change of PAS-ADD Checklist score over time, new onset of problem behaviour, nor resilience to problem behaviour. At T1, first episodes and recurrent episodes of mental ill-health were not distinguished, so the association with female gender could reflect a relationship between recurrent mental ill-

health and female gender, as found at T3. The three other previous prevalence studies found no association between gender and mental ill-health (Deb et al 2001a; Thompson & Reid 2002; Bailey 2007). These studies consisted of smaller sample sizes of 90, 165, and 53 respectively, whereas the T1 study included 1023 participants. It could be that within smaller studies, the numbers of recurrent episodes contributing to the overall prevalence rate were too small to show a significant association with being female. Also, the participants within these studies were on average over 10 years younger than the participants in the T1 prevalence study. Younger adults are less likely to have experienced recurrent mental ill-health than older adults. Therefore the prevalence rate explained by recurrent episodes may have been smaller in these studies, further explaining why no association was found with female gender. In order to test this theory, post hoc analyses were performed to determine whether female gender was also independently predictive of mental ill-health at T3. Univariate analysis revealed no such association, thus supporting the theory that female gender is associated with relapse, and not first episode of mental ill-health. These findings suggest that females may be more vulnerable to recurrent mental ill-health than males.

Alternatively, it may be that the PAS-ADD Checklist screens for psychopathology which is more prevalent in females than males. The majority of items on the PAS-ADD Checklist refer to affective and neurotic disorders. In the general population, comorbid diagnoses of depression and anxiety are higher in females than males for both lifetime and 12 month comorbidity (World Health Organization 2013c). Similarly, an association was found between female gender and depression in the T1 prevalence study (Cooper et al 2007c); however in this study the PAS-ADD Checklist was only used as a screening tool and diagnoses were made based on clinical interviews. Other research has reported that people with ID have a four-fold increased risk of affective disorder; and that this relationship is not attenuated by gender (Richards, Maughan, Hardy, Hall, Strydom and Wadsworth, 2001). Also, Deb et al (2001a) found no associations with female gender when using the mini PAS-ADD, but this may in part be due to the smaller sample size used in their study.

Some research, attempting to explain the aforementioned general population gender disparity in depression, has focussed on gender differences in “biological responses to

stressors, self-concepts, or coping styles" (Nolen-Hoeksema 2001). Such research suggests that even when both genders have been exposed to the same stressors, females may be more likely to develop depression than males. In a review of the literature, the author suggested that frequent exposure to stressful events, and reactivity to such stress, can impact the response of biological and psychological systems to future stress; thus sensitizing these systems and making it more likely that exposure to future stress will result in depression.

Research investigating biological responses has examined gender differences in the hypothalamic-pituitary-adrenal (HPA) axis response to stress. The HPA axis is a major part of the neuroendocrine system which controls responses to stress and regulates many bodily processes, including moods and emotions. A recent review reported that most psychological stress studies found either no significant gender difference, or higher cortisol responses in young males compared with young females, after exposure to controlled-laboratory or real-life psychological stress (Kudielka and Kirschbaum 2004). However, other research has suggested that stress-induced dysregulation of the HPA axis might contribute to increased vulnerability to depression, and that females may be more susceptible to such dysregulation (Weiss, Longhurst, & Mazure 1999). The authors suggested that life stressors such as childhood sexual abuse could result in long-term dysregulation of the HPA axis, similar to that in depressed patients. They reported the female HPA axis to be more susceptible to such stressors and thus more vulnerable to depression. In comparison with healthy general population adults, a recent study found no difference in HPA axis activity in adults with ID (Presland, Clare, Broughton, Luke, Wheeler, Fairchild, Watson, Chan, Kearns, & Ring 2013). Therefore, it is feasible that females with ID may also be more susceptible to dysregulation of the HPA axis, and thus more vulnerable to depression. Such a mechanism could explain why both female gender and experience of life events prior to T1 were found to be predictive of relapse of mental ill-health.

Although the studies discussed did not investigate relapse, they do provide a form of parallel evidence through showing an association between female gender and prevalence of mental ill-health. It is therefore plausible that female gender is also causally predictive of relapse of mental ill-health. Research showing that exposure to stressful events can alter

the way in which females respond to future stressors provides mechanistic evidence, suggesting that the finding is not spurious. Although this finding adds to the research that females have poorer mental ill-health outcomes, this is the first longitudinal study of adults with ID to investigate relapse of mental ill-health over time. Therefore this finding requires further investigation.

Level of ID

Having moderate-profound ID compared with mild ID independently predicted poorer resilience to problem behaviour at all 3 time points. Previous cross-sectional research has reported that both mental ill-health (Cooper et al 2007a) and problem behaviour (Moss et al 2000; Deb et al 2001a; Jones et al 2008; Cooper et al 2009a; Cooper et al 2009b) is associated with more severe levels of ID, although Thompson and Reid (2002) found no such association. However, the latter study consisted of a small sample of adults with only severe or profound ID, which may explain why no such association was found. At T2, moderate rather than mild ID predicted 2-year incidence of mental ill-health, and lower ability predicted 2-year incidence of problem behaviour (Smiley et al 2007). Whilst these studies did not report on resilience, given their cross-sectional designs, they do provide a degree of parallel evidence to suggest the finding is not a spurious one. The finding is also in keeping with cognitive epidemiological studies with the general population, which demonstrate that there is a gradient across level of intelligence with extent of mental ill-health for adults who do not have ID (Aylward, Walker, & Bettes 1984; Chen, Denney, & Breakefield 1995; Purcell, Maruff, Kyrios, & Pantelis 1997; Russell, Munro, Jones, Hemsley, & Murray 1997; van Os, Jones, Lewis, Wadsworth, & Murray 1997). Similarly, research has shown that adults with borderline ID have greater mental ill-health than adults with higher intelligence (Hassiotis et al 2008).

It has been suggested that this may be due to adverse experiences and socioeconomic factors which are more prevalent in persons with lower intelligence (Kaplan, Turrell, Lynch, Everson, Helkala, & Salonen 2001). Such "stress" factors can impact on neural development, both at developmentally sensitive periods, and also through cumulative physiological wear and tear (allostatic load) rendering a greater susceptibility to mental ill-health and problem behaviour (McEwen and Gianaros 2010). Adults with ID have higher

levels of inflammatory cytokines, and increased levels of oxidative stress (Carmeli, Imam, Bachar, & Merrick 2012), suggesting this explanation is a plausible mechanism between extent of ID and problem behaviour outcome.

Other potential mechanisms can be drawn from a neurocognitive development psychological perspective. Emotional regulation and attentional control have been shown to predict risk for psychopathology (Bishop, 2008; Herrman et al 2011), and are more problematic at more severe levels of ID.

Another consideration is that some problem behaviour occurs as a direct consequence of physical pain or other distress (Tonge 2007). Individuals with more severe ID may not be able to communicate the experience of pain and thus rely on their carers to notice their distress and seek help on their behalf. People with mild ID have better communication skills allowing them to both ask for help and describe their pain so that they can receive treatment. Although problem behaviour due to pain or other disorders were excluded, it may take much longer for the cause of pain to be identified in adults with more severe ID and thus they are likely to be in distress for longer. This may explain why adults with mild ID were found to be the most resilient to problem behaviour, given that in the general population chronic pain has been identified as a risk factor for mental illness (World Health Organization 2013b).

Another theory is that adults with mild ID could be less vulnerable to risk factors, and more receptive to protective factors, than are adults with more severe ID. In the general population, factors such as 'autonomy', 'social support and community networks' and 'social participation' have been found to be protective against mental illness (World Health Organization 2013b). Adults with mild ID are more likely to exercise autonomy over their lives (Stalker and Harris 1998) and engage in community opportunities than those with more severe ID, given their better communication and adaptive skills. Whilst the study attempted to collect such data, this was only done at T3 and therefore the predictive value of these factors could not be tested out in this cohort of adults with ID. Physiological factors such as urinary incontinence have also been found to be independently associated with prevalence of problem behaviour (Jones et al 2008). However, in this T3 analysis,

whilst urinary incontinence was related to resilience, it was not independently predictive when entered into the regression with ability level and other factors.

Interestingly, level of ID was not found to be predictive of new onset of problem behaviour nor resilience to mental ill-health. However, it is likely that this is due to the small number of people experiencing onset of problem behaviour and resilience to mental ill-health, rather than a true finding.

It seems apparent that people with mild ID are more resilient to developing problem behaviour than people with more severe ID. Although it is not clear why this happens, general population research on cognitive epidemiology corroborates this finding, and research and theories regarding allostatic load provide plausible mechanistic evidence. Cross-sectional research showing more severe levels of ID to be associated with mental ill-health and problem behaviour also provides a degree of parallel evidence. Thus it is possible that more severe levels of ID causally predict poorer resilience to problem behaviour. However, further investigation is needed to provide clarification.

5.2.2 Social networks and activities

Three variables from the social networks and activities group were found to independently predict several mental ill-health and problem behaviour outcomes. Although these variables were predictive of different outcomes, they may reflect similar constructs found to be risk factors for, and protective factors against mental ill-health in the general population. There is no existing longitudinal research investigating the role of social networks and activities in mental ill-health and problem behaviour outcomes in the adult ID population with which to directly compare the findings.

Angry interactions

Experiencing an angry interaction in the past week prior to the T2 interview was found to predict a greater increase in total PAS-ADD Checklist scores between T2 and T3, compared with not experiencing an angry interaction. Not experiencing an angry interaction in the past week prior to the T2 interview was found to independently predict

resilience to problem behaviour between T2 and T3, for those individuals who had not previously had problem behaviour at T1, compared to the rest of the cohort.

Experiencing a recent angry interaction may reflect other circumstances which are risk factors for mental ill-health. For example, 'racial injustice and discrimination' and 'exposure to aggression, violence and trauma' have all been identified as risk factors for mental ill-health in the general population (World Health Organization 2013b). People with ID are known to experience high rates of discrimination and violence compared to the general population (Hughes, Bellis, Jones, Wood, Bates, Eckley, McCoy, Mikton, Shakespear, & Officer 2012). They also lack opportunity to make decisions for themselves, the extent to which varies by a range of factors including living arrangement and level of ability (Jenkinson, Copeland, Drivas, Scoon, & Yap 1992; Wehmeyer and Bolding 2001; Stalker & Harris 1998). It is feasible therefore, that some individuals will have limited choice regarding where they live, who they live with and who they spend their time with. All these factors could conceivably lead to angry interactions and thus increased vulnerability to mental ill-health. Equally, a lack of angry interaction may reflect a safe, threat free environment where individuals feel supported and have positive relationships with those around them.

Alternatively, it may be that adults who engage in angry interactions are more likely to make negative attributions about themselves, which in turn make them more vulnerable to mental ill-health. For example, after an angry interaction, such an individual may feel that they are unlikeable or unlovable which may cause them to feel sad or angry. However, it is equally possible that presence of mental ill-health could lead to an angry interaction. For example, psychopathology symptoms such as irritability and reduced tolerance could cause an individual to be more reactive to stressors and thus more likely to engage in an altercation.

Given that no existing longitudinal research has investigated the relationship between experience of angry interactions and mental ill-health, it is not possible to make parallel comparisons. However, research in the general population provides some support of a possible relationship between angry interactions and mental ill-health. Two feasible hypotheses have been proposed which explain the mechanism between these factors. The

first hypothesis suggests an angry interaction to be causal of mental ill-health, but the second hypothesis implies reverse causality. Therefore, there is not enough evidence to conclude that experience of an angry interaction prior to T2 interview is causally related to increased severity of psychopathology, nor that not experiencing an angry interaction prior to T2 interview is causally related to resilience to mental ill-health. However, these findings are of interest and could be relevant to new treatments and interventions. Thus further research is warranted.

Close relationships

Having more than 1 close relationship compared with having no close relationships at T2 was found to independently predict resilience to problem behaviour between T2 and T3, for the adults who had been free from problem behaviour at T1, compared with the rest of the cohort. The confidence interval of the odds ratio was however wide, in view of the sample size. Gregory et al (2001) stated that although important, proximity to, and frequent interaction with others was not sufficient for the formation of deeper friendships, only superficial acquaintances. Instead, they reported structural and process factors to be more important. Structural factors included physical attractiveness, similarity in appearance, personal characteristic and attitudes. Process factors included displaying reciprocity, gradually increasing self-disclosure over time, and both verbal and non-verbal communication indicating a liking for the other person. Considering the process and structural factors necessary to develop deep friendships, having more than 1 close relationship could imply a great deal about an individual's life. It suggests such individuals have had the opportunity to meet and engage with like-minded others, in an environment which allows the gradual self-disclosure and display of reciprocity. This may reflect similar constructs found to be protective factors for mental ill-health in the general population, such as 'social support and community networks' and 'positive interpersonal interactions' (World Health Organization 2013b). Not having any close relationships may mean that individuals have not had the opportunity to spend time with others who have similar attitudes and indicate a liking for them. Alternatively, it could mean that individuals who state that they do not have any close relationships hold negative attributes about themselves and believe that they are not liked by others. Either of these could reflect similar constructs found to be risk factors for mental ill-health in the general population,

such as ‘peer rejection’, and ‘isolation and alienation’ (World Health Organization 2013b). This finding was independent of level of ability, demonstrating that it is not just reflecting ability level.

However, it is possible that close relationships are not a protective factor against problem behaviour. Although the analysis considered resilience between T2 and T3 using data collected at T2 in people who had also been free from problem behaviour at T1, the comparators in the cohort were the adults who had experienced problem behaviour at any time. This included 14 who had displayed problem behaviour at T1. The small numbers are such that it was not possible to exclude these individuals. The presence of problem behaviour for these 14 people may cause the absence of close relationships. For example, it may be that people with problem behaviour have their activities restricted due to their behaviour and so do not get the chance to develop close relationships, or it may be that others do not wish to be friends with them because of their problem behaviour. This may have therefore contaminated the data collection at T2. However, this seems unlikely given that of those identified as having DC-LD problem behaviour at T2, less than a quarter reported not having any close relationships at both T2 and T3. It is however possible that the presence of problem behaviour prevents individuals from developing several close relationships, given that of those identified as having DC-LD problem behaviour at T2, only 50% at T2 and 37.5% at T3 reported having more than 1 close relationship.

Although the role played by ‘close relationships’ in resilience to problem behaviour is unclear, further investigation is warranted. Adults in the general population are significantly more likely to have 6 or more friends or relatives with whom they have regular contact (Hall; Strydom; Richards; Hardy; Bernal & Wadsworth, 2005). They are also known to experience a lower prevalence of mental ill-health than adults with ID. The general population literature suggests that multiple factor may play a role in maintaining mental health. It is plausible that ‘close relationships’ is such a factor and as such should be investigated further.

Trusting others with a secret

At T2, trusting to share a secret with 1 person, or with anyone, was found to be associated with a greater increase in total PAS-ADD Checklist scores between T2 and T3, compared with trusting to share a secret with 2-5 people. People tend to trust their close friends with secrets. Therefore, trusting only 1 person and trusting anyone could reflect very different social networks and relationships, i.e. someone who has a limited social network compared with someone who has an extensive social network. Alternatively, it could reflect very similar social relationships. For example, someone who trusts only 1 person with a secret might do so because they have no other close friends, and someone who trusts anyone might do so because, although they have numerous acquaintances, they do not have any close friends and are indiscriminate about who they trust, or do not understand the concept of trust. Therefore, trusting 1 person and trusting anyone with a secret might also reflect the same risk factors hypothesised to be associated with having no close friends, such as 'peer rejection', 'isolation and alienation'. Trusting 2-5 people with a secret could reflect the same protective factors hypothesised to be associated with having more than 1 close friend, i.e. 'social support and community networks' and 'positive interpersonal interactions'. This could explain why such individuals had a smaller increase in their total PAS-ADD Checklist scores between T2 and T3. Furthermore, trusting 2-5 people with a secret suggests knowing that support is available and having the opportunity to choose the best person to confide in. The knowledge of being able to choose a confidant could reflect several other constructs found to be protective against mental ill-health in the general population. For example, 'empowerment', the 'ability to cope with stress', 'feelings of security', 'feelings of mastery and control' and 'social support of family and friends'(World Health Organization 2013b).

Alternatively, it is possible that the number of people trusted with a secret reflects individual's attachment styles. Given that a link has been established between attachment style and mental health in the general population (Mikulincer and Shaver 2007), this could explain why increased severity of psychopathology was predicted by trusting anyone or one person to share a secret with, compared with trusting 2-5 people. Attachment styles are thought to develop when a child is approximately 9 months of age; however during the first 3-6 months of life, babies are said to develop 'indiscriminate attachments' (Schaffer

and Emerson 1964). That is, they will seek comfort from and attach themselves to anyone, be it family or stranger. The attachment styles that develop after this phase are described as: secure, anxious or avoidant. Secure attachment is thought to provide the foundation for good mental health (Mikulincer, Shaver, & Pereg 2003). Anxious styles are characterised by a strong need for closeness, fear of rejection and worry, and avoidant styles are characterised by independence and a desire for emotional distance from others (Mikulincer et al 2003). It is therefore conceivable that trusting 2-5 people with a secret could be indicative of secure attachment; whereas trusting anyone could be indicative of indiscriminate attachment (which has not developed into another style). Similarly, trusting only one person could be indicative of avoidant attachment. Research in the general population investigating attachment has found that higher avoidant scores at baseline predict worse mental health 7-years later (Berant, Mikulincer, & Shaver 2008). Other general population research investigating resilience has suggested that secure attachments in childhood are associated with fewer behaviour problems and better psychological wellbeing (Herrman et al 2011). This research provides further evidence to support this theory that attachment styles can affect future psychopathology.

Interestingly, no predictions were found between resilience and any of the variables collected by the past and personal history questionnaire (Appendix C tables C23 and C33) such as parental divorce in childhood or former ex-long-stay hospital resident. This may be because these factors do not play an important role in resilience in the ID population, or may be a result of the small sample size. The suppositions about the role of social networks are based on general population findings. It is feasible that the same constructs which are risk and protective factors in the general population could also be risk and protective factors in the ID population. However, parallel comparisons cannot be draw, given that no existing longitudinal research has investigated the role of social networks for mental ill-health and problem behaviour outcomes in adults with ID. Attachment theory may provide a feasible explanation of the mechanism between trusting others and increase in severity of psychopathology, but causal direction cannot be determined. This area has been largely neglected in studies investigating psychopathology in the ID population, and the findings suggest more research is warranted.

5.2.3 Past experiences

Life events

Life events were found to be the factor most commonly associated with mental ill-health and problem behaviour outcomes over time. Experiencing life events prior to T1 predicted mental ill-health relapse between T1 and T3. Experiencing life events prior to T3 independently predicted new onset of mental ill-health at T3. Not experiencing life events prior to T1 was found to independently predict onset of new problem behaviour at T3. Finally, not experiencing life events prior to T3 was found to independently predict resilience to mental ill-health between T2 and T3, for people free from mental ill-health at T1, compared with the rest of the cohort.

Several authors have used cross-sectional data to report associations between experiencing life events and presence of mental ill-health (Hastings et al 2004; Esbensen & Benson 2006; Cooper et al 2007a; Cooper et al 2007c; Hulbert-Williams et al 2008; Reid et al 2011) and problem behaviour (Esbensen & Benson 2006). In this cohort at T2, life events were found to predict subsequent mental ill-health and problem behaviour (Smiley et al 2007). The finding that not experiencing life events predicted resilience to mental ill-health, and that life events predicted new onset and relapse of mental ill-health is broadly in keeping with existing literature. Using the PAS-ADD Checklist, Hastings et al (2004) found exposure to one or more life events in the past 12 months significantly increased the odds of participants scoring above cut-off on the affective disorder subscale. Esbensen & Benson (2006) found that both frequency counts of life events, and life events perceived as being negative, predicted depressive symptoms 4 months later.

However, this T3 data and previous reports are extremely difficult to interpret. Whilst the life event data prior to T3 covers the one year period prior to T3, it is not known at which point the new episode or relapse of mental ill-health occurred i.e. it could have been more than 12 months before T3. It is conceivable that having mental ill-health puts a person at greater risk of experiencing life events, so there could be reverse causality accounting for these findings. This possibility is also present in all those previously reported studies

except for that of Smiley et al (2007). The finding that life events experienced 9-10 years ago predicted subsequent relapse of mental ill-health at some point 2-9 years later (i.e. between T2 and T3) cannot simply be taken at face value, and it is also the opposite finding to that of problem behaviour. This latter finding is also compounded by the very small number who experienced new problem behaviour (with respect to the cohort size at T3).

During the T1 (2002-2004) investigations, the government was working towards its commitment to close all long-stay hospitals by 2005 (Scottish Executive 2000). At this time, many people experienced a great deal of change. For example, residents of long-stay hospitals were moved into the community. As such, people already residing in the community also experienced change, as new people moved into their homes or attended their day centre. Such changes, particularly moving out of hospital could potentially impact mental health. Although possible, it seems unlikely that events which took place up to 10 years ago would impact present mental health and problem behaviour. A more feasible explanation is that these findings – both experiencing and not experiencing life events at T1 - may be spurious, due to limitations such as multiple comparisons and small group sizes (see limitations section). However, evidence from research of the HPA axis has suggested that stress-induced dysregulation can contribute to increased vulnerability to future stressors (Weiss et al 1999). Therefore, although unlikely, it is possible that events experienced up to 10 years ago could impact present mental health and problem behaviour.

Parallel evidence exists supporting the finding that experience of life events are related to mental ill-health and problem behaviour outcomes. Mechanistic evidence also exists, but the direction of causality is complicated and difficult to determine. Therefore, further research is necessary to determine causality.

5.2.4 Health and disabilities

Urinary incontinence

Not having urinary incontinence was found to independently predict resilience to mental ill-health, compared with having urinary incontinence. Urinary incontinence has been found to be associated with mental ill-health in previous investigations of this cohort, as well as in the general population (Coyne, Kvasz, Ireland, Milsom, Kopp, & Chapple 2012). In this cohort, urinary incontinence was found to be associated with both prevalence (Cooper et al 2007a) and incidence (Smiley et al 2007) of mental ill-health, as well as prevalence of problem behaviour of any type (Jones et al 2008) and aggressive problem behaviour (Cooper et al 2009a). In the general population, urinary incontinence has for some time been linked to mental illness. A recent study found significant associations between urinary incontinence and depression and anxiety in both men and women (Coyne et al 2012). Rates of depression and anxiety varied across type of urinary incontinence, but were generally higher in females than males. The authors concluded that the relationship between urinary incontinence and mental health was unclear. They hypothesised that anxiety or depression could lead to urinary incontinence, but equally, stigma associated with urinary incontinence could lead to anxiety, and avoidance of social situations could lead to depression. Analogous to this theory, other researchers have found that the same circuitry linking the bladder and the brain 'enables pathological processes in one target of the circuit to be expressed in the other' (Valentino, Wood, Wein, & Zderic 2010). In other words, the presence of urinary incontinence can affect this circuit, consequently impacting on cognitive and behavioural functions; just as psychosocial stressors can affect the circuit, resulting in urology dysfunction.

There is clear mechanistic evidence to explain the relationship between urinary incontinence and mental ill-health; however, given the bi-directional relationship of the brain/bladder circuitry, the direction of causality is unknown. Nevertheless, it is clear that the presence of urinary incontinence is a risk factor for mental ill-health in both the general and ID population. Therefore, screening for urinary incontinence could allow a high-risk group to be identified early, for preventative measures and to alert carers to risk. Research

on continence management should also measure mental ill-health as an outcome of the intervention.

5.3 Cross-sectional findings

5.3.1 Associations between total PAS-ADD Checklist score and activity participation

Cross-sectional analysis revealed no significant relationship between total PAS-ADD Checklist scores and total scores on the ICI and IPDL. However, significant negative correlations were found between total PAS-ADD Checklist scores and a range of subscales from the GCPLA. These were: total number of activities with peers; total number of frequent outdoor leisure activities; total number of social activities; total number of social activities with peers; and total number of combined leisure activities with peers. These negative relationships suggest that psychopathology was indeed more severe for those who participated in less frequent activities. However, the correlations found were weak, suggesting that although the hypothesised relationships exist, they are not very robust. As the data is cross-sectional, no definite statement can be given regarding causation.

However, several important inferences can be made from the findings. Firstly, of the 5 relationships identified, 3 regarded the type of support, with which people participated in activities. All of these were activities participated with peers. People who participate in activities with their peers (without an accompanying carer) are likely to have milder ID. People who participate in activities by themselves are also likely to have milder ID. However, no relationship was found between participating in activities alone and total PAS-ADD Checklist scores. This would suggest that the relationship between participating in any activities with peers, and total PAS-ADD Checklist scores cannot be fully explained by level of ID.

Similarly, participating in both social activities and leisure activities with peers, but not alone, had significant negative correlations with total PAS-ADD Checklist scores. Participating in activities alone may differ from participating in activities with friends in several ways. Individuals participating in activities alone might feel independent,

confident and empowered. However, the social activities measured included going to discos and parties. It could be a very unpleasant or daunting experience for an individual to attend such events alone, and may result in feelings of isolation, alienation and rejection. Individuals participating in activities with friends are equally likely to feel independent and confident, but much less likely to feel isolated and alone. Such individuals are more likely to experience feelings of belonging and camaraderie, which may lead to social support. It can be hypothesised that the relationship between activities with peers and mental ill-health is explained by social support; however, given the cross-sectional nature of this investigation, it cannot be said whether a causal relationship exists. It is possible that, similar to the general population, social support is a protective factor against mental ill-health. Alternatively, it may be that the presence of mental ill-health prevents people from socialising with their peers. For example, someone who is depressed could experience symptoms such as social withdrawal (which would prevent them from spending time with friends), or low self-esteem (which could distort their perceptions and cause them to report that they do not interact with friends).

Further supporting the theory that the relationship with psychopathology is not due to level of ID, is the finding that no relationship exists between total PAS-ADD Checklist scores and total IPDL scores. Each item on the IPDL receives a score from 0-3. Activities which individuals participate in alone, without the support of a carer, receive a score of 3. Activities which individuals are unable to participate in receive a score of 0. Therefore, individuals with mild ID are more likely to have higher total scores than individuals with more severe ID. Thus, if mild ID was associated with psychopathology, a relationship would exist between IPDL total score and total PAS-ADD Checklist score.

Secondly, relationships were found between psychopathology and social and leisure activities, but not services, public transport or facilities/amenities. This would suggest that type of activity is an important factor. The fact that no relationship was found between mental ill-health and total score on the ICI or the IPDL further supports the finding that type of activity is important. Although some of the same activities are measured in the ICI and GCPLA, the GCPLA measures a much wider variety of activities, which it categories into different types. The ICI does not categorize its items into different types of activities, which may explain why no relationship was found. Examples of some items from the

social and leisure activity sections of the GCPLA are: going to parties, cafés, playing games, sports and going to the cinema. Examples of some items from the services, public transport and facilities/amenities sections are: using the bus, going to the bank, library, shops, and going to see the doctor. It could be argued that an important difference between these groups of activities is active participation. Most of the social and leisure activities require individuals to actively participate or interact with others, whereas most of the services, public transport and facilities/amenities only require individuals to be present. It is therefore possible that, in terms of mental ill-health, using local facilities such as shops is of less importance to people with ID than taking part in activities with their peers. Such a finding would be consistent with Bigby's (2012) theory that, with regards to social inclusion, presence in the community is of little value unless it is the individual's preference.

Thirdly, of the 5 relationships identified, 4 concerned regular activities (i.e. quarterly or more often) and only 1 concerned frequent activities (i.e. weekly or more often). This could mean that the frequency of outdoor leisure activities in particular, is of high importance to people with ID, in terms of mental health. It could be argued that people who are free from mental ill-health are more likely to participate in more frequent activities, thus explaining this relationship. However, if that was the case the same relationship would be expected between all other frequent activities and total PAS-ADD Checklist scores. This further supports the idea that type of activity is an important factor with regards to mental health, and suggests that participating in a high frequency of activities is less important.

These findings are of importance, given the lack of clarity regarding whether a relationship exists between social factors and mental health. Gregory et al (2001) found that greater satisfaction with friendships was reported by those with a greater number of people with ID in their social networks. They also highlighted some of the processes necessary for developing close friendships, such as similarity in appearance and attitudes. It is reasonable then, that attending regular activities would increase an individual's chances of developing friendships, and thus receiving social support. However, Bigby (2012) concluded that number of activities does not equate to social support, and argued that '*Research must move beyond an approach that tends to equate social inclusion with simple*

counts of how many times a person goes out their front door to visit the community'. It is clear from the findings that the relationship between mental health and participation in activities is complex. A linear relationship was not found between mental ill-health and total number of regular or frequent activities. If social support and social inclusion are protective against mental ill-health, the findings support Bigby's theory that these constructs cannot be achieved simply through participating in a greater number of activities. The relationships identified with mental ill-health depended on the type of activity, and the type of support for the activity. This finding could suggests that it is not the frequency or number of activities that an individual takes part in that is important, but the amount of participation and interaction the type of activity allows, and with whom this occurs.

Given the cross-sectional nature of this element of the study, and lack of other research with which to compare the findings, several speculations have been made, which highlight the need for further research. This is particularly important, so that policies and services for people with ID can understand the relationship between mental ill-health and social inclusion and social support. Only when this understanding is gained, can policies and services provide the resources necessary to support people to live their lives in a manner that is both fulfilling, and protective of mental health.

5.3.2 Associations between total PAS-ADD Checklist score and social support

Despite the hypothesis that greater severity of psychopathology would be associated with lower perceived social support, no such relationship was found. Similarly, in their study investigating whether social support has a moderating effect on mental ill-health, Hulbert-Williams et al (2011) found no evidence of a relationship. To explain this, the authors suggested that either social support may not moderate the relationship between life events and psychological problems in adults with ID, or the measure they used may not have had the sensitivity necessary to measure the aspects of social support which are important to people with ID. Likewise, it seems the most likely reasons to explain the lack of finding are: 1) no relationship exists between social support and psychopathology in adults with ID; or 2) the modified Index of Perceived Social Support is not an adequate measure of

social support in the ID population. The latter theory is much more probable, given that a) social support has been successfully measured in the ID population, albeit not in relation to mental health (Gregory et al 2001; Miller and Chan 2008) ; and b) social support has been found to be a protective factor against mental ill-health in the general population (World Health Organization 2013b). Some form of social support may therefore moderate mental health in the ID population, particularly those with more mild levels of ID.

It is possible that the concepts in the modified Index of Perceived Social Support were too abstract for some individuals to fully understand, given that before its minor modification, it was intended for use in the general population. However, Miller and Chan (2008) also used a measure intended for use in the general population, the PRQ-85 (Brandt and Weinert 1981). Although they altered the scoring method from a 7-point scale to a 4-point scale, no other modifications were made. As such, their questionnaire also contained abstract concepts. However, their participants were described as 'having a relatively high level of adaptive functioning' and all were in paid employment. Their level of ID was unknown, but the latter information suggests that they had mild or borderline ID. Another factor might be the number of items used to measure perceived social support. The PRQ-85 consisted of 25 items, measuring 5 concepts, whereas the modified Index of Perceived Social Support consisted of only 7 items. It is possible therefore, that the measure had insufficient sensitivity to gauge perceived support in the adult ID population. This may explain why no correlation was found between mental ill-health and perceived social support. Therefore it is possible that the present finding is not an accurate indication of this relationship. Akin to the general population, social support may play an important role in the mediation of mental ill-health and thus further efforts should be made to investigate this relationship.

5.4 Strengths

The principal strengths of the study are its population-based sample, longitudinal design, sample size, reporting of outcomes at both a group and individual level, clear definition of mental ill-health and use of a psychiatrist specialising in ID.

5.4.1 Population-based sample

During the baseline investigation, a database of adults with ID living in the Greater Glasgow Health Board Area was constructed through multiple sources. All general practitioners in the Greater Glasgow Health Board Area worked with the project, to identify adults with ID. They were paid a fee per adult with ID whom they identified as being registered with them. Therefore, it is unlikely that a significant number of adults with ID were missed, and highly unlikely that any adults with moderate to profound ID were missed. Thus, it is probable that the sample was representative of the wider population of adults with ID; and in fact, compared with other prevalence studies, independent researchers rated it as having the most rigorous assessment procedure (Buckles et al 2013). Furthermore, the review revealed that of the two studies to investigate the natural history of mental ill-health and problem behaviour in a cohort of adults over a 10-year period, neither included adults with all levels of ID. Thus, compared with other longitudinal research, the findings are the most representative of the wider population of adults with ID.

5.4.2 Longitudinal design

The longitudinal design allowed identification of the trajectory of mental ill-health and problem behaviour outcomes over time, as well as risk and protective factors associated with such outcomes. A review revealed only 2 longitudinal studies investigating mental ill-health and problem behaviour in the adult ID population over a 10-year time period (Reid et al 1978; Reid & Ballinger 1995; Thompson & Reid 2002; Totsika et al 2008). Neither of these conducted intermediate investigations between baseline and 10-year follow-up. Furthermore, these studies conducted their baseline investigations in the 70s, and 90s; at a time when many adults with ID were living in long-stay hospitals or

residential facilities. Thus, the findings are the most representative of current UK living situations of adults with ID. Also, given the 2 follow-up investigations over the 10 years, the findings are the most likely to provide an accurate portrayal of the trajectory of mental ill-health and problem behaviour outcomes, in terms of persistence, new onset, relapse and remission.

5.4.3 Sample size

Although the significant reduction in the sample size between T2 and T3 led to several limitations (see section 5.9.2), the retention of 100 adults over a 10-year period is a major strength of the study. Of the two studies identified as investigating the natural history of mental ill-health and problem behaviour in an adult ID population (Reid et al 1978; Reid & Ballinger 1995; Thompson & Reid 2002; Totsika et al 2008), both retained less than 100 adults (53 and 58 respectively) over a 10-year period. Therefore, the findings are based on the largest existing cohort of adults with ID, retained over a 10-year time period.

5.4.4 Reporting outcomes at both a group and individual level

In the review of studies investigating the long term outcomes of mental ill-health and problem behaviour in adults with ID, a common limitation was identified in the manner in which outcomes were reported. Many studies only reported outcomes at a group level. By doing so, although these studies gave an indication of trends in the population, they failed to show whether psychopathology persists or changes within the same individuals over time. Thus, it was found that some studies reported high rates of persistent psychopathology, based on the finding that the same number of people displayed the same behaviour at both baseline and follow-up. However, it was not the same individuals displaying the same behaviour at both baseline and follow-up. Therefore, such studies may provide a misleading indication of persistence. The present study has avoided such a possibility by reporting outcomes at both the group and individual level. This gives an indication of change over time at a population level, but also clearly shows the trajectory of mental ill-health and problem behaviour outcomes for each of the 100 participants over the 10-year period. This is the only way to accurately indicate whether or not

psychopathology is persistent in the ID population, and thus is a major strength of the present study.

5.4.5 Clear definition of mental ill-health

A further major strength of the study is the clear and concise manner in which mental ill-health has been defined. A clear illustration of the modifications made to the PAS-ADD Checklist, the cut-off threshold used and the reasons for making such changes has also been provided. This ensures that the methods used can be easily replicated by other researchers, allowing the findings to be further validated.

Another common limitation in studies investigating the long term outcomes of mental ill-health and problem behaviour in adults with ID is that many studies using psychopathology instruments fail to clarify whether a change in score, severity or frequency leads to a change in mental ill-health or problem behaviour status. As a result, it is not clear whether studies reporting a significant increase in psychopathology scores found that participants experienced a new onset of illness, or an increased severity of existing illness. Similarly, for those reporting a significant decrease in psychopathology scores, it is not clear whether this was indicative of remission of illness or merely a reduction in severity. For those who reported no significant change in psychopathology scores and therefore concluded persistence, it is not clear whether this indicated persistent illness or health, or both.

The cut-off threshold used to indicate those with mental ill-health and those deemed healthy has been clearly reported, as has the rationale for using the threshold. Furthermore, the fact that mental ill-health has been reported at an individual level quite clearly shows which individuals experienced which mental ill-health outcome in terms of persistence, new onset, remission, and resilience.

5.4.6 Use of a psychiatrist specialising in learning disabilities

The accurate identification of mental ill-health and problem behaviour in the adult ID population is a difficult process; confounded by issues such as diagnostic overshadowing,

polypharmacy, and the pathoplastic effects of ID. The limitation of using the modified PAS-ADD Checklist to indicate mental ill-health rather than clinical diagnosis by a psychiatrist specialising in ID has been recognised (see section 5.9.8). However, every modified PAS-ADD Checklist and Problem Behaviour Checklist was reviewed by the same psychiatrist, specialised in working with people with ID. This psychiatrist also reviewed all participant medications, recorded during the T3 interviews. Where further information was required, the psychiatrist consulted clinical case notes and visited some participants herself to gather additional information. Although not the gold standard of psychiatric diagnosis, it is believed that this process led to an accurate identification of mental ill-health and problem behaviour within the sample. Furthermore, the same psychiatrist worked on the project during all 3 time points, potentially reducing some of the interviewer bias.

5.4.7 Generalizability

The results can be generalised to other populations with ID in high income countries, in view of the original construction of the cohort, that T3 participants do not differ from non-participants on key characteristics, and that the T3 participants were assessed at all three time points in clearly described ways. It is unknown whether the results can also be generalized to other populations of adults with ID in low and middle income countries. However this is unlikely, particularly for lower income countries given that the availability of health services for people with ID tends to increase with income level (World Health Organization 2007).

5.5 Limitations

The study is limited by issues common to longitudinal research, such as attrition rate, interview bias, sample size and causality. Other limitations include use of the modified PAS-ADD Checklist to diagnose mental ill-health; the use of some assessment measures with unknown psychometric properties; the time gap between T2 and T3 investigations; volunteer bias and reliance on quantitative measures of lifestyle factors and social support.

5.5.1 Attrition

Attrition is an inherent problem in longitudinal research, and particularly so in research investigating the ID population. In the T3 investigation, 9.78% of the original T1 sample was followed-up. However, given that the aim of the study was to investigate mental ill-health and problem behaviour outcomes at several time points over a 10 year period, attempts were made to recruit only the 651 adults who also participated in the T2 investigations. Of these 651 adults, 97 had died, resulting in a potential cohort of 554 participants. Thus, 18% of the potential cohort was followed-up at T3.

It was not possible to trace all of the participants and this may have biased the sample. It is possible that the 100 adults who were followed over the 10 year period had worse mental ill-health than those who were not traced, thus resulting in the high rate of illness at T3. However, analysis of T2 demographics showed no statistical difference between T3 participants and non-participants, with the exception of deprivation index. This showed a non-linear effect, suggesting that the finding may be spurious.

Although only a small percentage of the original cohort was retained over the 10 year period, there are no other longitudinal studies following adults with ID, which have retained as large a sample as the current study.

5.5.2 Sample size

As a result of low cohort retention the sample size was significantly reduced, in comparison with the previous investigations. As stated on page 92, 2 issues prevented the recruitment of more participants: 1) the aim of the study was to investigate the trajectory of mental ill-health and problem behaviour at several time points over a 10-year period – as such it was not desirable to attempt to recruit individuals who had participated at T1, but not at T2 – furthermore, such a methodology would have led to additional limitations (as highlighted in the literature review) and would not have allowed conclusions to be made regarding longitudinal patterns of psychopathology; 2) the present research was conducted to fulfil the requirements of a 3-year PhD and as such only 1 year could be spent on tracing, recruiting and interviewing potential participants: the reported sample size reflects

the maximum number of participants who could be recruited within the given time constraints. The small sample size presents several issues which must be taken into consideration. Firstly, due to the lack of previous research it was not possible to perform a power calculation, and therefore it was unknown whether analysis of the recruited sample size would yield clinically significant findings. However, the confidence intervals of all odds ratios are reported in the results, so showing the degree of un/certainty of the findings. Post hoc power calculations were also performed, suggesting the increase in psychopathology between T1-T3 and T2-T3 to be clinically significant. It should be noted that these calculations were performed with the total sample size of 100 participants, and that no further post hoc power calculations were performed. As such the analysis of factors predictive of mental ill-health and problem behaviour outcomes - which involved comparison of smaller group sizes - should be interpreted with caution. Secondly, due to small numbers it was not possible to investigate all outcomes of interest, such as relapse of problem behaviour, and further analysis of aggressive problem behaviour and self-injurious behaviour. The investigation of relapse of mental ill-health and onset of new problem behaviour consisted of small group sizes, which may have increased the probability of type II statistical errors (i.e. false-negatives). Likewise, due to small numbers, several 'social networks & activities' factors which approached significance in the univariate analysis could not be investigated further. As a consequence, the study may have failed to identify several important risk and protective factors, predictive of various outcomes.

5.5.3 Causality

Determining causality of mental ill-health and problem behaviour outcomes in adults with ID is extremely complicated. Factors found to independently predict mental ill-health and problem behaviour outcomes have been reported; however, this does not necessarily mean that they are causal. Temporal sequence was met by all predictor variables, but unknown confounding factors may have caused the outcomes investigated. A cause and effect relationship cannot be accurately inferred from a single study, and there is limited longitudinal data with which to compare the findings.

5.5.4 Case ascertainment

Use of a population-based sample has been reported to be a main strength of the study (see section 5.4.1); however, this approach also has limitations. Although the baseline method of case ascertainment was extremely robust; multiple sources were used to identify adults with ID, rather than screening the whole population. Therefore, the sample is technically administrative, rather than a true population-based sample. However, the procedure, including paying general practitioners to identify individuals with ID, ensured a reasonable ascertainment rate. As reported in section 5.4.1, given that all general practitioners in the Greater Glasgow Health Board Area worked with the project, it is extremely unlikely that any adults with moderate to profound ID were missed. However, it is likely that the procedure failed to identify all adults with IQ <70, given that many are unknown to their general practitioner and are not in receipt of any services for people with ID. This is an issue common to most ID research, and it certainly limits the findings. However, in terms of those adults with ID known to, and in receipt of services, the sample is thought to be representative of the wider population.

5.5.5 Volunteer bias

It is possible that the findings may be subject to volunteer bias. Given the nature of the study, all participants from the T2 investigations were invited to take part. In the general population, volunteers have been found to be more educated, more intelligent, more sociable, more approval-motivated and more likely to come from a higher social class than non-volunteers (Rosenthal and Ralph 1975). It is not known whether these differences are the same for the ID population, whose carers usually reply on their behalf. However, no statistical difference was found between the participants and non-participants, in terms of a range of demographics, including level of ID. Although a difference was found for deprivation index, the difference was non-linear, suggesting the finding may be spurious. Regardless, it is unlikely that this represents a difference in socio-economic status, given that many adults with ID live in congregate or supported living, in areas which are determined by service providers. Also, many adults with ID will rely on their paid or family carers to help them decide whether or not to participate in research. Thus any

volunteer bias may be more of a reflection of differences in the carers of the adults with ID, rather than the adults themselves.

5.5.6 Lack of physical health check

At both T1 and T2 investigations, participants had their physical health assessed in order to exclude any possible physical causes of psychiatric symptoms. No such checks were carried out in the T3 study. However, both the PAS-ADD Checklist and the Problem Behaviour Checklist ask responders to ensure that any symptoms are not the result of physical illness. Furthermore, all medications taken by participants were recorded, which would also help to rule out any physical causes of mental ill-health. Regardless of these precautions, it is possible that the lack of physical health check may have increased the number of false-positive cases of mental ill-health and problem behaviour, thus biasing the findings.

5.5.7 Interview bias

During the T1 investigations, all interviews were conducted by a team of 9 general practitioners and nurses, specialising in working with people with ID. During the T2 investigations, all interviews were conducted by research assistants, trained to work with adults with ID. During the present T3 investigation, all interviews were conducted by a research student, also trained to work with people with ID. Although all interviewers were trained to work with people with ID, and the same assessments were used, their interviewing styles may have varied. Although it is unlikely that this would have had a significant impact on participant responses, it is possible that some interviewers may have deemed some symptoms as important, while other interviewers would not. Thus, some interviewers may have recorded symptoms which others ignored.

Similarly, it was not possible for the same family or paid carer to be present at each investigation over the 10 years. Also, although the presence of an informant who knew the participant well was requested, it is possible that some carers rated symptoms as problematic which others viewed as traits of the individual.

5.5.8 Time gap between T2 and T3 investigations

The primary aim of the study was to identify the trajectory of mental ill-health and problem behaviour over time, with a particular focus on identifying whether people with ID experience persistent illness or episodes of relapse and remission. The T2 investigations attempted to measure any episodes of mental ill-health which had occurred in the 2 years since the T1 investigations, making it unlikely that any new episode of mental ill-health were missed. However, a much longer time gap of 6-8 years passed between the T2 and T3 investigations, with no such attempt to identify intermediate episodes of mental ill-health. Therefore, it is possible that unknown episodes of relapse and remission occurred between the current and previous investigation. Thus, although 13 people were identified as having persistent mental ill-health over the 10 year period, it is possible that they experienced some remission over the last 10 years. Regardless, this is currently the only longitudinal study to follow a cohort of adults with ID over a 10 year period, which has conducted intermediate investigations.

5.5.9 Use of the modified PAS-ADD Checklist to diagnose mental ill-health

There are two limitations to using the modified PAS-ADD Checklist to diagnose mental ill-health. Firstly, the gold standard method for assessing psychopathology is clinical assessment by psychiatrists specialising in learning disabilities. Secondly, due to the modifications made to the PAS-ADD Checklist, its psychometric properties are unknown and were not investigated.

With regards to the former limitation, face-to-face psychiatric assessment was not possible during the T3 investigation. As a result, total PAS-ADD Checklist scores were used to indicate presence of mental ill-health, at each of the 3 time points over the 10-year period. Although the PAS-ADD Checklist has been rated by independent researchers as the best screening assessment available for use in adults with ID, the same researchers have also cautioned against its use as the sole measure for assessing psychopathology (Sturmey et al 2005). The modifications to the PAS-ADD Checklist were made in order to address some of the gaps in coverage identified by Simpson (1998). The cut-off was lowered to a total score of ≥ 2, in accordance with Simpson's findings using ROC curve analysis. Simpson

reported the best cut-off between cases and non-cases in terms of sensitivity and specificity, when using DSM-IV criteria to be ≥1; with a false-positive rate of around 50% until the cut-off reached ≥3. Thus, use of the PAS-ADD Checklist to indicate presence of mental ill-health may have led to an increased false-positive rate in the sample. However, in order to reduce the false-positive rate and increase specificity, the item referring to specific phobia was excluded from the cut-off criteria. Examination of the T1 data showed that 61.7% of those meeting the modified PAS-ADD Checklist criteria for mental ill-health also received a clinical diagnosis, according to psychiatric assessment. This would suggest that the modifications made to the PAS-ADD Checklist did in fact lower the false-positive rate reported by Simpson.

With regards to the latter limitation, it cannot be stated whether the modified PAS-ADD Checklist has reliability and validity. The original PAS-ADD Checklist has had its psychometric properties thoroughly investigated, and its reliability and validity demonstrated by original authors and independent researchers (Moss et al 1998; Sturmey et al 2005; Simpson 1998). Therefore, it cannot be assumed that the psychometric properties of the modified PAS-ADD Checklist are the same as the original version. However, it is not likely that the modifications had a significant impact on the psychometric properties, given that only additional questions were included and the scoring method changed in order to increase its sensitivity.

Although it has been recognised that use of the PAS-ADD Checklist to identify mental ill-health has its limitations, the study is strengthened by its consistent use, with the same modifications and cut-off threshold, at all 3 investigations. Given that a main aim of the study was to identify whether psychopathology remains stable over time, and not to diagnose specific disorders, it is suggested that the modified PAS-ADD Checklist was an appropriate tool with which to do this. Finally, to ensure that symptoms had been rated correctly, every participant's PAS-ADD Checklist questionnaire was discussed with a psychiatrist specialising in learning disabilities.

5.5.10 Use of the Problem Behaviour Checklist to diagnose problem behaviour

Reliability and validity of the Problem Behaviour Checklist were not tested in the current study. However, validity of the DC-LD criteria compared with clinical practice was demonstrated in the field trials (Cooper et al 2003), and the T2 investigation found inter and intra-rater reliability to be high, ranging from 0.72-1.00. In order to enhance reliability and validity in the current study, every checklist was discussed in detail by the research student and psychiatrist specialising in learning disabilities. Consensus was then made regarding whether or not the information recorded met DC-LD criteria. In the event that more information was required, the psychiatrist consulted clinical case-notes to further inform the decision.

5.5.11 Multiple comparisons

One of the primary aims of the study was to identify factors predictive of, and associated with mental ill-health and problem behaviour outcomes over time. In order to achieve this aim, a wide range of factors were investigated, which, according to both research in the ID and general population, are thought to play an important role in mental ill-health. Given that this resulted in the analysis of a large number of variables, it is possible that the process led to an increased probability of false-positives. That is, when multiple comparisons are tested, the likelihood of incorrectly rejecting the null hypothesis increases (i.e. a type I statistical error). There are several methods available to counteract the problem of multiple comparisons, the simplest and most conservative being the Bonferroni correction. However, the Bonferroni correction has a tendency to be overly conservative, leading to an inflated false-negative rate. Given the explorative and novel nature of the study, it was not desirable to increase the probability of false-negatives and so the Bonferroni correction was not used. Thus, interpretation of the findings must be made with some caution.

5.5.12 Use of quantitative measures of lifestyle and social support

A quantitative measure, the GCPLA, was used to assess lifestyles and participation in social activities. This information was then used to make inferences about more complex constructs such as social inclusion and social support. Such 'complex and overlapping concepts' are recognised as being difficult to measure (Nicholson and Cooper 2013), and there are no standard methods for doing so. The GCPLA does not claim to measure social inclusion or social support and the inferences are purely theoretical. Nevertheless, it seems reasonable to make some postulations about such constructs, based on the amount of time spent in the community, and the frequency with which one participates in activities with others. However, the use of quantitative methods to measure social inclusion has limitations. For example, Bigby (2012) noted that measures such as the ICI fail to provide important information regarding the precursor to the activity, the quality of the activity, the nature of the activity, and with whom activities are shared. Without such information it cannot be known whether participation in activities was 'chosen or routine'; 'hostile or convivial'; 'participatory, engaging or passive'; and shared 'as part of a large group or as an individual'. Bigby concluded that without such information, '*qualitatively quite different experiences of community presence* would be *scored similarly*'. This is a valid point and the present study would have benefited from a qualitative component to assess social inclusion and social support. However, such a component would have been feasible to conduct only in adults with mild ID and would have resulted in the exclusion of those with more severe ID. The use of quantitative measures, although admittedly does not capture the subjective experience in a valid way, provides a good indicator of time spent within the community and with others. Even adults with less severe ID may struggle with concepts such as feeling valued by others, or being able to depend on friends and family. The objective measure of time spent with others may be a valid measure of important components of social inclusion and support, and should not be underestimated. That is not to say that a count of the number of times an individual visits the community will tell us whether or not they are included and supported socially, these concepts are clearly much more nuanced than that. However, use of the GCPLA identified the possibility that some types of activities, and types of company to those activities, may be more important than others, with regards to mental ill-health. Thus, the use of a quantitative measure has identified potential future areas for research into social inclusion and social support.

5.6 Clinical implications of findings

The present study is the only longitudinal research to date, which has investigated a cohort of adults with mild to profound ID, at several time points over a 10-year period. Thus, the findings are of much clinical relevance. Rates of both mental ill-health and problem behaviour were found to increase in the cohort over the 10-year period, suggesting that individuals with ID require more support from mental health services over time. Given that life expectancy is increasing in the ID population (Puri, Lekh, Langa, Zaman, & Singh 1995; Bittles, Petterson, Sullivan, Hussain, Glasson, & Montgomery 2002), it is likely that a growing demand will be placed upon mental health services.

Regardless of the limitations of the study, this finding needs to be addressed by government policy, mental health and social services, and care providers for people with ID. These agencies need to address how they can plan and respond to meet the increasing mental ill-health needs; and how they can monitor for changes in mental ill-health better. The authors of the T1 and T2 investigations stated the need for public health strategies and social and health care policies to be aware of the differing epidemiology of mental ill-health, between the ID and general population, in order to avoid further increases in the health inequality between these two populations. The authors highlighted the need for improved methods of screening, identifying and treating mental ill-health in this population. The present findings appear to suggest that such needs have not been met. There are 4 possible ways in which services may have failed to address the deteriorating mental health in this population: 1) carers may not be aware of the symptoms of mental ill-health and thus have not referred individuals to the appropriate services; 2) carers may have noticed the symptoms of mental ill-health but have not known what they should do or whom they should refer individuals to; 3) individuals have not been referred from primary care to specialist services; 4) individuals have received referrals to mental health services, but have not received treatment; or 5) treatment has been received but it has been ineffective, or improvements have been short-lived. Given that only 26 individuals with mental ill-health and 14 individuals with problem behaviour were in contact with a psychiatrist or psychologist, any of the first 4 possibilities are equally likely. However, over 60% of both those with mental ill-health and problem behaviour were taking psychotropic medication, suggesting that they were in contact with primary care services.

In order to improve the detection of mental ill-health, services should ensure that carers of people with ID are trained to identify the symptoms of psychopathology. Carers should also be aware of the appropriate mental health services available for people with ID; with knowledge of how and when to use these services. In order to facilitate this, services should carry out regular mental health screenings.

Services for people with ID should also be aware of the risk factors associated with mental ill-health. Factors such as being of female gender, having more severe ID, experiencing life events and having urinary incontinence have been associated with poorer mental health outcomes in the present study, in previous investigations (Cooper et al 2007a; Cooper et al 2007b; Cooper et al 2007c; Smiley et al 2007; Jones et al 2008; Cooper et al 2009a; Cooper et al 2009b), and from independent research (Moss et al 2000; Deb et al 2001b; McClintock, Hall, & Oliver 2003; Hulbert-Williams et al 2008), and are confirmed to have longer term importance in this T3 study. However, there appears still to be little public awareness of these high risk populations. Service providers and planners should therefore be educated to use these findings to identify 'at risk' groups for mental illness, and provide extra support and early intervention where necessary. They should also be aware that lifestyles and social networks appear to play a role in the maintenance of mental health, and await further clarification which future research may bring.

Adults with ID have a considerable burden of mental ill-health, much of which persists or relapses over time. This is an important message for policy-makers at government.

5.7 Implications for future research

Future longitudinal research is needed to determine whether the findings can be replicated. Such research should include all levels of ID, and take several points into consideration. Firstly, the trajectory of outcomes for mental ill-health and problem behaviour were found to differ over time; with the majority of the cohort experiencing episodic mental ill-health and equal proportions of persistent and episodic problem behaviour. Although problem behaviour occurred at a lower rate than mental ill-health, it was found to be much more persistent than mental ill-health. The highest rates of persistence were found for those with self-injurious behaviour at T1. This suggests that in order to identify the true trajectory of outcomes, future research should investigate mental ill-health and problem behaviour separately.

Secondly, had the T2 follow-up not been conducted, much higher rates of persistence for both mental ill-health and problem behaviour over time would have been incorrectly concluded. Also the difference in the trajectory of mental ill-health and problem behaviour over time would not have been identified. Of the two longitudinal studies identified as investigating mental ill-health and problem behaviour in adults with ID over at least a 10-year period, neither carried out follow-up investigations between baseline and 10 years. As a result, no conclusions could be made from them regarding the persistence of mental ill-health and problem behaviour over time. Therefore, future longitudinal research should carry out several follow-up investigations over time, preferably with less than 5 years between each investigation.

Thirdly, there were limitations in the manner in which many longitudinal studies report their findings. Some studies only report outcomes at a group level, which reflect changes in the population, but does not illustrate whether individuals experience persistent or episodic psychopathology over time. Other studies do not state whether a significant change in score, frequency or severity leads to a change in mental ill-health or problem behaviour status, making findings incomparable. Therefore, future research should make findings as transparent as possible by reporting their outcomes at both the group and individual level. They should also state mental ill-health and problem behaviour status of

participants at baseline, and report whether change in score, frequency or severity at follow-up leads to a change in baseline status.

Finally, both the longitudinal and cross-sectional investigations found relationships between psychopathology, and a number of lifestyle and social factors. Future research should endeavour to investigate these factors in longitudinal studies with larger samples. For this, they should also use instruments which allow several aspects of participation to be measured, including choice to participate, type of activity, support type, and quality of activity participation. This information could be further complemented by a qualitative component investigating the subjective experience of social support and social inclusion.

CHAPTER 6: CONCLUSIONS

This thesis sought to determine the trajectories of mental ill-health and problem behaviour over the course of a 10-year period, in adults with mild to profound ID. An initial review of the literature (section 1.6) revealed a paucity of knowledge on long-term mental ill-health and problem behaviour outcomes in the ID population. The main findings from our empirical work (see table 6.1) were that 75% of the cohort met the lowered criteria for mental ill-health at T3, a higher rate than found at T1 or T2. Analysis of total PAS-ADD Checklist scores found an increase in severity of psychopathology at T3 compared with both T1 and T2. These results suggest that, not only were more people unwell at T3, but many of those already experiencing mental ill-health had deteriorated further. Thirty-four percent of the cohort met DC-LD criteria for at least one type of problem behaviour, and 18% met DC-LD criteria for aggressive problem behaviour. Hence, it can be concluded from this work that mental ill-health and problem behaviour remain a pressing public problem for adults with ID, which has not been solved by the closure of long stay hospitals.

Over the 10-year period, mental ill-health was found to follow a remitting-relapsing trajectory for the majority of the cohort. Conversely, problem behaviour was less variable over time, with equal proportions of the cohort displaying remitting-relapsing and persistent trajectories. Self-injurious behaviour was found to be highly persistent, with 100% of those displaying the behaviour at T1 also displaying it at T2, and a further 80% continuing to show persistent self-injurious behaviour at T3; suggesting this subtype of problem behaviour is highly stable even over a decade-long period.

The lower rates of psychopathology found at T2 compared with T1 may reflect improved levels of clinical management once study participants were identified as experiencing significant levels of psychopathology and referred to services (post-T1). This improvement may, therefore, indicate potential clinical benefits of targeted intervention. However, given the increase in psychopathology between T2 and T3, this also raises a number of issues and possibilities. That is, 1) interventions do not have lasting

Table 6.1 Key findings from thesis

Key aims/research questions	Key thesis findings
Review existing longitudinal research	There is a dearth of high quality studies investigating the long term outcomes of mental ill-health and problem behaviour. Definitive conclusions cannot be made.
Prevalence of psychopathology at T3	Mental ill-health: 75% Problem Behaviour: 34%
Rates of persistence	Mental ill-health is persistent in those with ID: 31.7% Problem behaviour is persistent in those with ID: 50%
Factors predictive of:	
• Increase in psychopathology	Risk factors for T2-T3: experiencing an angry interaction in the last week, trusting only 1 person or anyone with a secret
• Relapse	Risk factors for mental ill-health: female gender, experiencing life events prior to T1
• New onset	Risk factors for mental ill-health: experiencing life events prior to T3 Risk factors for problem behaviour: not experiencing life events prior to T1
• Resilience	Protective factors for mental ill-health: not experiencing life events prior to T3, not having urinary incontinence Protective factors for problem behaviour: mild rather than more severe ID, not experiencing an angry interaction, having more than 1 close relationship

long-term effects, and/or 2) people who experience relapse are not referred back into clinical services. Unfortunately, the data do not permit assessment of these possibilities; however, this area remains ripe for future investigation.

With respect to self-injurious behaviour, the high rate of persistence in the sample suggests that 1) these individuals did not receive any clinical intervention; or 2) treatments were only beneficial in the short-term; or 3) treatments were ineffective. Due to the sample size, risk factors associated with persistent self-injurious behaviour could not be investigated; however, given the high rates of persistence reported in this small group, further research in this area is required.

The high rates of persisting and relapsing psychopathology suggest that strategies for monitoring and consequently referring individuals to specialist mental health services are inadequate in this population. Policy makers and service providers should attempt to address this through ensuring that carers: 1) are trained to recognise the symptoms of mental ill-health; 2) are aware of the mental health services available for people with ID, and 3) understand how and when to access these services. To aid this, service providers should implement regular monitoring of mental health, using assessments specifically tailored to individual needs. Such measures should allow early detection of psychopathology, ensuring that services and interventions can be accessed promptly, thus facilitating the prevention of relapse and new onset of illness.

In order to further facilitate the early detection of psychopathology, services should be aware of the high risk groups which have been identified in this research, and corroborated by findings in existing literature. In particular, those with more severe ID, urinary incontinence, female gender and experience of life events have worse mental ill-health and problem behaviour outcomes. As such, service providers should attempt to identify these individuals and ensure that they are a priority for regular mental health monitoring. Screening for urinary incontinence is thus necessary, and implementation of continence management should be considered as it may have the potential to alleviate psychological distress, given the bi-directional relationship between the brain-bladder circuitry. Support workers and carers should also be aware that females are more vulnerable to experiencing a relapse of mental ill-health. They should use this knowledge to implement appropriate

relapse prevention plans with women who have a history of mental illness. Finally, service providers and support workers should be aware of the potential impacts of life events on adults with ID. They should be vigilant for such occurrences, in order to ensure individuals experiencing adverse events receive appropriate support, both at the time of the event and when required thereafter.

The findings of this work must be viewed within the context of several limitations. Principally our sample was small, potentially resulting in an increased probability of false-negatives, meaning that important risk and protective factors may not have been identified. Also, because of the large time gap between T2 and T3, it is possible that some individuals experienced episodes of relapse and remission that the present study methodology was unable to detect, thus biasing reported trajectories. However, these limitations must be balanced against several strengths. This is the first piece of work to report mental ill-health and problem behaviour outcomes (at both the group and individual level), in a cohort of adults with ID, on several occasions over a 10-year period. In comparison with existing research, it has retained the largest sample than any other longitudinal study. Moreover, collected data are representative of current living situations of adults with ID, and given the comprehensive case ascertainment procedures at T1, is generalizable to other populations of adults with ID living in high income countries. As a result, this body of work provides the most accurate and detailed investigation of long term outcomes of mental ill-health and problem behaviour, and their associated risk and protective factors.

Given the novelty of this research, definitive conclusions cannot be made. However, when considered with existing parallel and mechanistic evidence, this work provides an excellent foundation for future research investigating risk and protective factors of mental ill-health and problem behaviour outcomes.

Ideally, future research should aim to replicate and extend these findings in subsequent longitudinal studies. Ultimately, treatment evaluations are required to determine whether addressing known risk factors - identified in the present body of work - and mental distress directly, may help improve short and long-term mental health and well-being in this population. Such studies and their translation into clinical care may have important benefits to the quality of life of people with ID.

APPENDIX A

Systematic review search strategy

Ovid Medline Search Strategy

In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

Search Number	Search Term	Results
1	mental health/	19400
2	limit 1 to (abstracts and english language and yr="1975 -Current")	10536
3	exp Obsessive-Compulsive Disorder/	10605
4	limit 3 to (abstracts and english language and yr="1975 -Current")	6404
5	(mental disorders or mental* ill* or mental ill-health or psychopathology or psychiatric illness).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	164103
6	limit 5 to (abstracts and full text and yr="1975 -Current")	68295
7	2 OR 4 OR 6 **(MH)**	82750
8	exp Self-Injurious Behavior/	50378
9	limit 8 to (abstracts and english language and yr="1975 -Current")	25211
10	exp Pica/	927
11	limit 10 to (abstracts and english language and yr="1975 -Current")	400
12	(challeng* behavio?r* or problem behavio?r* or maladaptive behavio?r*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	4462
13	9 OR 11 OR 12 **(PB)**	29786
14	7 OR 13 **(MH OR PB)**	108334
15	exp Intellectual Disability/	77340
16	limit 15 to (abstracts and english language and yr="1975 -Current")	38953
17	exp Mentally Disabled Persons/	2110
18	limit 17 to (abstracts and english language and yr="1975 -Current")	790
19	(intellec* disab* or learning disab* or mental* retard* or learning impair* or mental* handicap*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	70612
20	limit 19 to (abstracts and english language and yr="1975 -Current")	38356

21	16 OR 18 OR 20 **(ID)**	54980
22	14 AND 17 **(MH/PB AND ID)**	347
23	exp Retrospective Studies/	437896
24	limit 23 to (abstracts and english language and yr="1975 -Current")	354246
25	exp Epidemiologic Studies/	1480938
26	limit 25 to (abstracts and english language and yr="1975 -Current")	1190227
27	exp Cohort Studies/	1225823
28	limit 27 to (abstracts and english language and yr="1975 -Current")	969599
29	exp Longitudinal Studies/	978846
30	limit 29 to (abstracts and english language and yr="1975 -Current")	620229
31	(prospective or cohort or longitudinal or epidemiolog* or follow*up or retrospective or incidence or prevalence).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	2067495
32	limit 31 to (abstracts and english language and yr="1975 -Current")	1670911
33	24 OR 26 OR 28 OR 30 OR 32 **(ST)**	1981677
34	22 AND 33 **(MH/PB AND ID AND ST)**	**1117**

Key:

MH = Mental health search terms

PB = Problem behaviour search terms

ID = Intellectual disability search terms

ST = Study type search terms

Ovid Embase Search Strategy

Embase Classic+Embase 1947 to 2012 February 17

Search Number	**Search Terms**	**Results**
1	mental disorders/	113843
2	limit 1 to (abstracts and english language and yr="1975 -Current")	51964
3	((((mental disorders or mental*) adj ill*) or mental adj ill-health or psychopathology or psychiatric) adj illness).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	4486
4	limit 3 to (abstracts and english language and yr="1975 -Current")	3782
5	2 OR 4 **(MH)**	54393
6	exp Self-Injurious Behavior/	4337

7	limit 6 to (abstracts and english language and yr="1975 -Current")	3206
8	exp Aggression/	26495
9	limit 8 to (abstracts and english language and yr="1975 -Current")	16032
10	exp Pica/	927
11	limit 10 to (abstracts and english language and yr="1975 -Current")	400
12	(((((challeng* adj behavio?r*) or problem) adj behavio?r*) or maladaptive) adj behavio?r*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	841
13	limit 14 to (abstracts and english language and yr="1975 -Current")	795
14	7 OR 9 OR 11 or 13 OR 15 **(PB)**	20048
15	5 OR 16 **(PB OR MH)**	73088
16	exp Mental Deficiency/	45288
17	limit 18 to (abstracts and english language and yr="1975 -Current")	19566
18	exp learning disorder/	17940
19	limit 20 to (abstracts and english language and yr="1975 -Current")	10810
20	(((((((((intellec* adj disab*) or learning) adj disab*) or mental*) adj retard*) or learning) adj impair*) or mental*) adj handicap*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	2671
21	limit 22 to (abstracts and english language and yr="1975 -Current")	1160
22	19 OR 21 OR 23 **(ID)**	30372
23	17 AND 24 **(PB/MH AND ID)**	2265
24	exp Retrospective Studies/	437896
25	limit 26 to (abstracts and english language and yr="1975 -Current")	354246
26	exp follow-up/	459393
27	limit 28 to (abstracts and english language and yr="1975 -Current")	325912
28	exp Epidemiologic Studies/	1480938
29	limit 30 to (abstracts and english language and yr="1975 -Current")	1190227
30	exp Cohort Studies/	1225823
31	limit 32 to (abstracts and english language and yr="1975 -Current")	969599
32	exp Longitudinal Studies/	798846
33	limit 34 to (abstracts and english language and yr="1975 -Current")	620229
34	(prospective or cohort or longitudinal or epidemiolog* or follow*up or retrospective or incidence or prevalence).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	2067495
35	limit 36 to (abstracts and english language and yr="1975 -Current")	1670911

36	27 OR 29 OR 31 OR 33 OR 35 OR 37 **(ST)**	1981677
37	25 and 38 **(PB/MH AND ID AND ST)**	**694**

Key:

MH = Mental health search terms

PB = Challenging behaviour search terms

ID = Intellectual disability search terms

ST = Study type search terms

PsycINFO Search Strategy

Search Number	**Search Terms**	**Search Options**	**Results**
1	DE "Mental Disorders" OR DE "Affective Disorders" OR DE "Anxiety Disorders" OR DE "Chronic Mental Illness" OR DE "Dementia" OR DE "Dissociative Disorders" OR DE "Personality Disorders" OR DE "Pervasive Developmental Disorders" OR DE "Psychosis" OR DE "Schizoaffective Disorder"	Search modes - Boolean/Phrase	135439
2	AB (mental* disorder* or mental* adj ill*) or mental adj ill-health or (psychopathology) or (psychiatric* adj ill*)	Search modes - Boolean/Phrase	70274
3	S1 or S2 **(MH)**	Search modes - Boolean/Phrase	183759
4	MJ behaviour problems	Search modes - Boolean/Phrase	17959
5	AB (challeng* behavio?r*) or (behavio?r* problems) or (aggressive behavio?r*) or (self-injur*) or (destructive behavio?r*) or (verbal* aggressi*) or (maladaptive behaviour) or (pica)	Search modes - Boolean/Phrase	13468
6	S4 or S5 **(PB)**	Search modes - Boolean/Phrase	29701
7	S3 or S6 **(MH OR PB)**	Search modes - Boolean/Phrase	209862
8	DE "Learning Disabilities" OR DE "Developmental Disabilities"	Search modes - Boolean/Phrase	27696
9	DE "Mental Retardation" OR DE "Down's Syndrome" OR DE "Mild Mental Retardation" OR	Search modes - Boolean/Phrase	4761

	DE "Moderate Mental Retardation" OR DE "Profound Mental Retardation" OR DE "Severe Mental Retardation"		
10	AB (intellect* disab*) or (intellectual* disorder*) or (intellectual* handicap*) or (intellectual* impair*) or (intellectual* deficien*) or (intellectual* subnorma*) or (learning disab*) or (learning disorder*) or (learning impair*) or (learning difficult*) or (developmental* disab*) or (developmental* disorder*) or (developmental* handicap*) or (developmental* impair*) or (development* delay*) or (mental* disab*) or (mental* handicap*) or (mental* impair*) or (mental* deficien*) or (mental* subnorm*) or (mental* retard*) or (education* adj3 subnorm*) or (mental* handicap*)	Search modes - Boolean/Phrase	78625
11	S8 or S9 or S10 **(ID)**	Search modes - Boolean/Phrase	94858
12	S7 and S11 **(ID AND MH/PB)**	Search modes - Boolean/Phrase	14578
13	AB prospective or cohort or longitudinal or epidemiolog* or follow*up or retrospective or incidence or prevalence	Search modes - Boolean/Phrase	216516
14	((((DE "Epidemiology") OR (DE "Longitudinal Studies")) OR (DE "Cohort Analysis")) OR (DE "Followup Studies")) OR (DE "Retrospective Studies")	Search modes - Boolean/Phrase	62379
15	S13 or S14 **(ST)**	Search modes - Boolean/Phrase	242261
16	S12 and S15 **(ST AND ID AND MH/PB)**	Search modes - Boolean/Phrase	2632
17	S12 and S15 **(ST AND ID AND MH/PB)**	Limiters - Publication Year from: 1975-2012; English; Population Group: Human; Methodology: brain imaging, clinical case study, impirical study, -Followup Study, Longitudinal Study,	**1503**

		Prospective Study, Retrospective Study, treatment outcome/clinical trial Search modes - Boolean/Phrase	

Key:

MH = Mental health search terms

PB = Challenging behaviour search terms

ID = Intellectual disability search terms

ST = Study type search terms

CINAHL Search Strategy

Search Number	**Search Terms**	**Results**
1	AB mental health OR AB (anxiety or obsessive-compulsive disorder or panic disorder or phobic disorder or dementia or dissociative disorder or multiple personality disorder or mood disorders or affective disorder or bipolar disorder or depress* or personality disorder or borderline personality disorder or psychotic* or schizophreni* or mental disorders or mental* ill* or mental ill-health or psychopathology or psychiatric illness) **(MH)**	86989
2	AB (challeng* behavio?r*) or (behavio?r* problems) or (aggressive behavio?r*) or (self-injur*) or (destructive behavio?r*) or (verbal* aggressi*) or (maladaptive behaviour) or (pica) **(PB)**	2870
3	1 OR 2 **(MH OR PB)**	88825
4	AB (intellect* disab*) or (intellectual* disorder*) or (intellectual* handicap*) or (intellectual* impair*) or (intellectual* deficien*) or (intellectual* subnorma*) or (learning disab*) or (learning disorder*) or (learning impair*) or (learning difficult*) or (developmental* disab*) or (developmental* disorder*) or (developmental* handicap*) or (developmental* impair*) or (development* delay*) or (mental* disab*) or (mental* handicap*) or (mental* impair*) or (mental* deficien*) or (mental* subnorm*) or (mental* retard*) or (education* adj3 subnorm*) or (mental* handicap*) **(ID)**	13295
5	S3 and S4 **(MH/PB AND ID)**	3033
6	AB prospective or cohort or longitudinal or epidemiolog* or follow*up or retrospective or incidence or prevalence **(ST)**	173315
7	S5 and S6 **(MH/PB AND ID AND ST)**	**639**

Key:

MH = Mental health search terms

PB = Challenging behaviour search terms

ID = Intellectual disability search terms

ST = Study type search terms

Cochrane Search Stategy

Search Number	Search Terms	Results
1	MeSH descriptor **Mental Retardation** explode all trees	924
2	MeSH descriptor **Learning Disorders** explode all trees	2746
3	MeSH descriptor **Mentally Disabled Persons** explode all trees	110
4	(mental* near/6 retard*)	1074
5	(intellect* near/6 disab*)	333
6	(learning near/6 disab*)	639
7	(mental* near/6 handicap*)	163
8	(mental* near/6 deficien*)	326
9	(intellect* near/6 impair*)	187
10	(learn* near/6 disorder*)	650
11	(learning near/6 difficult*)	240
12	((((((((((#1 OR #2) OR #3) OR #4) OR #5) OR #6) OR #7) OR #8) OR #9) OR #10) OR #11) OR #12) **(ID)**	4396
13	(behavioural problems):ti,ab,kw	1760
14	MeSH descriptor **Behavior** explode all trees	34532
15	(BEHAVIOR*)	35837
16	(behaviour*)	12961
17	(behavioural-symptoms*)	372
18	(IMPULSE-CONTROL-DISORDERS)	120
19	MeSH descriptor **Violence** explode all trees	1168
20	(CONDUCT DISORDER)	9895
21	(ATTENTION near DEFICIT*)	2145
22	(conduct)	62006
23	(DISRUPTIVE near DISORDERS*)	228
24	(behaviour-disorders*)	1072
25	(ANGER or ANGRY)	1326
26	(HYPERACTIV*)	2696
27	(VIOLEN*)	1381
28	(AGGRESSI*)	5103

29	((((((((((((#14 OR #15) OR #16) OR #17) OR #18) OR #19) OR #20) OR #21) OR #22) OR #23) OR #24) OR #25) OR #26) OR #27) OR #28) OR #29) **(PB)**	103834
30	MeSH descriptor **Mental Disorders**, this term only	4016
31	MeSH descriptor **Adjustment Disorders** explode all trees	2511
32	MeSH descriptor **Anxiety Disorders** explode all trees	8202
33	MeSH descriptor **Mood Disorders** explode all trees	3925
34	MeSH descriptor **Neurotic Disorders**, this term only	350
35	MeSH descriptor **Affective Symptoms**, this term only	535
36	(anxi* or depress* or melancholi* or neuros* or neurotic or psychoneuro* or stress* or distress* or emotion*)	85479
37	(#31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37) **(MH)**	88386
38	(follow-up studies)	92475
39	(prospective studies)	93565
40	(retrospective studies)	12462
41	Any MeSH descriptor with qualifier: **EP**	38056
42	(#39 OR #40 OR (#41or AND #42)) **(ST)**	185952
43	(#30 OR #38) **(PB OR MH)**	166022
44	(#13 AND #43 AND #44) **(ID AND ST AND PB/MH)**	**1595**

Key:

MH = Mental health search terms

PB = Problem behaviour search terms

ID = Intellectual disability search terms

ST = Study type search terms

APPENDIX B

Ethical approval

NHS
Greater Glasgow and Clyde

Coordinator/Administrator: Dr Erica Packard/Ms Elaine O'Donnell
Telephone Number: 0141 211 6208
E-Mail: erica.packard@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

3 June 2011

Prof Sally-Ann Cooper
Academic Unit of Mental Health & Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH

NHS GG&C Board Approval

Dear Prof Cooper,

Study Title:	**Prospective study of the mental health of adults with intellectual disabilities: underlying mechanisms and outcomes.**
Principal Investigator:	**Prof Sally-Ann Cooper**
GG&C HB site	**Gartnavel Royal Hospital**
Sponsor	**NHS Greater Glasgow and Clyde**
R&D reference:	**GN11LD126**
REC reference:	**11/AL/0178**
Protocol no: (including version and date)	**V1; 14/02/11**

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
   a. During the life span of the study GGHB requires the following information relating to this site
      i. Notification of any potential serious breaches.
      ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

NHS
Greater Glasgow and Clyde

2. **For all studies** the following information is required during their lifespan.
   a. Recruitment Numbers on a quarterly basis
   b. Any change of staff named on the original SSI form
   c. Any amendments – Substantial or Non Substantial
   d. Notification of Trial/study end including final recruitment figures
   e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

EPackard.

Dr Erica Packard
Research Co-ordinator

- 3 JUN 2011

Scotland A Research Ethics Committee

Secretariat
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
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www.nres.nhs.uk

NHS SCOTLAND

Professor Sally-Ann Cooper
Head of Centre for Population and Health Sciences/Professor of Learning Disabilities
The University of Glasgow
Academic Unit of Mental Health and Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Date: 1 June 2011
Your Ref.:
Our Ref.: 11/AI/0178

Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Professor Cooper

Study title: **Prospective study of the mental health of adults with intellectual disabilities: underlying mechanisms and outcomes**

REC reference: **11/AL/0178**

I refer to Amanda Muir's letter of 16 May 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the Scotland A REC. A list of the Sub-Committee members is attached.

Confirmation of ethical opinion

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

Ethical review of research sites

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

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Conditions of the favourable opinion

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

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

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

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

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

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

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

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

Approved documents

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

Document	Version	Date
REC application: IRAS Form	3.1	06 April 2011
Protocol	1	14 February 2011
Investigator CV: Professor Cooper		21 March 2011
Investigator CV: Miss Muir		21 March 2011
Letter of invitation to participant	1	08 March 2011
Participant Information Sheet: Participant	2	09 May 2011

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Participant Consent Form: Participant: Main Study	1	04 March 2011
Participant Consent Form: Participant 2: Inter-rater reliability study	1	04 March 2011
Participant Information Sheet: Relative	2	09 May 2011
Participant Consent Form: Relative: Main Study	1	04 March 2011
Participant Consent Form: Relative 2: Inter-rater reliability study	1	04 March 2011
Participant Information Sheet: Welfare Guardian	2	09 May 2011
Participant Consent Form: Welfare Guardian: Main Study	1	04 March 2011
Participant Consent Form: Welfare Guardian 2: Inter-rater reliability study	1	04 March 2011
Interview Schedules/Topic Guides	2	09 May 2011
Response to request for further information		16 May 2011

Statement of compliance

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

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

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

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

Notifying substantial amendments
Adding new sites and investigators
Progress and safety reports
Notifying the end of the study

NHS SCOTLAND

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

REC reference number: 11/AL/0178-Please quote this number on all correspondence

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

Yours sincerely

Dr Ian Zealley
Committee Chairman
cc: Dr Erica Packard
NHS Greater Glasgow and Clyde
1st Floor, Central R&D Office
Tennent Institute
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Miss Amanda Muir
PhD Student
Academic Unit of Mental Health and Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

NHS SCOTLAND

Scotland A REC

Attendance at Sub-Committee of the REC meeting on 31 May 2011

Committee Members:

Name	Profession	Present	Notes
Professor Richard Anderson	Professor of Clinical Reproductive Science	Yes	
Mrs Margaret Thomson	Retired	No	
Dr Ian Zealley	Consultant	Yes	

Written comments received from:

Name	Position
Professor Richard Anderson	Professor of Clinical Reproductive Science
Dr Ian Zealley	Consultant

Also in attendance:

Name	Position (or reason for attending)
Mr Walter Hunter	Committee Coordinator

NHS
National Patient Safety Agency

National Research Ethics Service

RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

After ethical review – guidance for sponsors and investigators

This document sets out important guidance for sponsors and investigators on the conduct and management of research with a favourable opinion from a NHS Research Ethics Committee. Please read the guidance carefully. A failure to follow the guidance could lead to the committee reviewing its opinion on the research.

1. Further communications with the Research Ethics Committee

1.1 Further communications during the research with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as "the Committee") are the personal responsibility of the Chief Investigator.

2. Commencement of the research

2.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

2.2 The research must not commence at any site until the local Principal Investigator (PI) or research collaborator has obtained management permission or approval from the organisation with responsibility for the research participants at the site.

2.3 Should the research not commence within 12 months, the Chief Investigator should give a written explanation for the delay

2.4 Should the research not commence within 24 months, the Committee may review its opinion.

3. Duration of ethical approval

3.1 The favourable opinion for the research generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Committee should be notified.

3.2 Where the research involves the use of "relevant material" for the purposes of the Human Tissue Act 2004, authority to hold the material under the terms of the ethical approval applies until the end of the period declared in the application and approved by the Committee.

4. Progress reports

4.1 Research Ethics Committees are expected to keep a favourable opinion under review in the light of progress reports and any developments in the study. The Chief Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2 Progress reports should be in the format prescribed by NRES and published on the website (see www.nres.npsa.nhs.uk/applicants/after-ethical-review/).

4.3 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

5. Amendments

5.1 If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.

5.2 A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee, that is likely to affect to a significant degree:

(a) the safety or physical or mental integrity of the trial participants
(b) the scientific value of the trial
(c) the conduct or management of the trial.

5.3 Notices of amendment should be in the format prescribed by NRES and published on the website, and should be personally signed by the Chief Investigator. The agreement of the sponsor should be sought before submitting the notice of amendment.

5.4 A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the research are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.

5.5 Amendments that are not substantial amendments ("minor amendments") may be made at any time and do not need to be notified to the Committee.

6. Changes to sites

Management permission (all studies)

6.1 For all studies, management permission should be obtained from the host organisation where it is proposed to:

- include a new site in the research, not included in the list of proposed research sites in the original REC application
- appoint a new PI or Local Collaborator at a research site
- make any other significant change to the conduct or management of a research site.

In the case of any new NHS site, the Site-Specific Information (SSI) Form should be submitted to the R&D office for review as part of the R&D application.

Site-specific assessment (where required)

6.2 The following guidance applies only to studies requiring site-specific assessment (SSA) as part of ethical review.

6.3 In the case of *NHS/HSC sites*, SSA responsibilities are undertaken on behalf of the REC by the relevant R&D office as part of the research governance review. The Committee's favourable opinion for the study will apply to any new sites and other changes at sites provided that management permission is obtained. There is no need to notify the Committee (or any other REC) about new sites or other changes, or to provide a copy of the SSI Form.

6.4 Changes at *non-NHS sites* require review by the local REC responsible for site-specific assessment (SSA REC). Please submit the SSI Form (or revised SSI Form as appropriate) to the SSA REC together with relevant supporting documentation. The SSA REC will advise the main REC whether it has any objection to the new site/PI or other change. The main REC will notify the Chief Investigator and sponsor of its opinion within a maximum of 35 days from the date on which a valid SSA application has been received by the SSA REC.

Studies not requiring SSA

6.5 For studies designated by the Committee as not requiring SSA, there is no requirement to notify the Committee of the inclusion of new sites or other changes at sites, either for NHS or non-NHS sites. However, management permission should still be obtained from the responsible host organisation (see 6.1 above).

7. Urgent safety measures

7.1 The sponsor or the Chief Investigator, or the local Principal Investigator at a trial site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

7.2 The Committee must be notified within three days that such measures have been taken, the reasons why and the plan for further action.

8. Serious Adverse Events

8.1 A Serious Adverse Event (SAE) is an untoward occurrence that:

(a) results in death
(b) is life-threatening
(c) requires hospitalisation or prolongation of existing hospitalisation
(d) results in persistent or significant disability or incapacity
(e) consists of a congenital anomaly or birth defect
(f) is otherwise considered medically significant by the investigator.

8.2 A SAE occurring to a research participant should be reported to the Committee where in the opinion of the Chief Investigator the event was related to administration of any of the research procedures, and was an unexpected occurrence.

8.3 Reports of SAEs should be provided to the Committee within 15 days of th Chief Investigator becoming aware of the event, in the format prescribed b NRES and published on the website.

8.4 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss any concerns about the health o safety of research subjects.

8.5 Reports should not be sent to other RECs in the case of multi-site studies

9. Conclusion or early termination of the research

9.1 The Chief Investigator should notify the Committee in writing that the rese has ended within 90 days of its conclusion. The conclusion of the researc defined as the final date or event specified in the protocol, not the complet of data analysis or publication of the results.

9.2 If the research is terminated early, the Chief Investigator should notify the Committee within 15 days of the date of termination. An explanation of th reasons for early termination should be given.

9.3 Reports of conclusion or early termination should be submitted in the form prescribed by NRES and published on the website.

10. Final report

10.1 A summary of the final report on the research should be provided to the Committee within 12 months of the conclusion of the study. This should include information on whether the study achieved its objectives, the main findings, and arrangements for publication or dissemination of the researc including any feedback to participants.

11. Review of ethical opinion

11.1 The Committee may review its opinion at any time in the light of any releva information it receives.

11.2 The Chief Investigator may at any time request that the Committee reviews its opinion, or seek advice from the Committee on any ethical issue relating to the research.

Assessment tools used in the time 3 interview

The Modified PAS-ADD Checklist

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 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 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 problems	[ ]
Some other event (please describe)	[ ]

……

None of these events has been experienced in the last year [ ]

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.		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	1	2
2	**Loss of** interests, enjoyment or motivation, such as spending less time doing things that the person usually likes to do	0	1	2
3	Sad or "down" (noticed for at least 3 days in the past 4 weeks)	0	1	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	1	2
5	Fearful, anxious or panicky (**not** triggered by situations or things)	0	1	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	1	2
7	**Too** happy or "high" (noticed for at least 3 days in the past 4 weeks)	0	1	2
8	**Increased** lability of mood; mood rapidly alternating between misery and elation	0	1	2
9	Excessive talking, singing or laughing, **more** so than usual for the person	0	1	2
10	**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	0	1	2
11	**Increased** interest in sex, or sexual indiscretions which are out of keeping with usual behaviour	0	1	2
12	Attempts suicide or talks about suicide	0	1	2
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	2
14	**Increased** appetite, over-eating	0	1	2
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	1	2
16	Startled by sudden sounds or movements	0	1	2
17	**Loss** of confidence, or repeatedly seeking reassurance	0	1	2
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	2

19	Avoids social contacts **more than usual** for the person (socially withdrawn), or **reduced** speech / communication	0	1	2
20	**Loss** of self-esteem, feeling worthless	0	1	2
21	**More** tearful than usual	0	1	2
22	Delay in falling asleep – at least one hour later than the person's usual time	0	1	2
23	Waking too early (at least one hour later than the person's usual time) and **unable to sleep again**	0	1	2
24	**Broken** sleep, waking up for an hour or more, before falling back to sleep	0	1	2
25	**Less able** to concentrate on or pay attention to chosen activities such as watching television, reading, or other hobbies	0	1	2
26	Restless or pacing, unable to sit still; or **increased** over-activity	0	1	2
27	**More** irritable or bad tempered than usual; or **reduced** level of tolerance	0	1	2
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	1	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	1	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	1	2
31	Strange or new beliefs for which other people can see no reason, such as the person believing someone or something id controlling her/his mind or that she/he has special powers	0	1	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)	0	1	2
33	Odd gestures or mannerisms, which are unusual for the person	0	1	2
34	Odd or repetitive use of language, which is unusual for the person	0	1	2
35	Any other **change** from the person's usual behaviour. Please give details…… …….. ……..	0	1	2

Scores: possible organic [ ] Affective or neurotic disorder [ ][ ] Psychotic disorder [ ] Total [ ][ ]

Glossary of Symptoms for the Modified PAS-ADD Checklist

Glossary of Symptoms for the Modified PAS-ADD checklist

Instructions for use.

The Modified PAS-ADD is a psychiatric symptom checklist. It asks about problems which 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 and the degree of that symptom should be based on the past four weeks. 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 symptoms 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 then 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, 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. 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.

9. Loss of usual social inhibitions.
This includes behaviour that is out of character for the individual and inappropriate to the circumstances.

10. Increased sexual energy.
The persons sexual interest is heightened and they may show increased sexual activity. Rate only if there is a change from their usual sexual behaviour.

11. Attempts at suicide or talks about suicide.
Any serious attempt at suicide should be rated as severe.

12. Loss of appetite.
There is a definite loss of interest in food and pleasure in eating. In some case it will take much longer to eat food.

13. Increased appetite, over eating.

14. Change of weight.

15. Startled by sudden sounds or movements.

16. 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.

17. 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.

18. Avoids social contact more then usual or reduced speech.
A noticeable reduction in a persons sociability compared to their usual or a reduction in the quantity of speech.

19. 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.

20. 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 then one hour. Do not rate this symptom as present if it is due to physical illness or pain.
21. Waking too early.
If the individual eventually falls back to sleep again rate as broken sleep.
22. More tearful then usual.
23. 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.
24. 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.
25. 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 unable to sit down for very long.
26. ***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.
27. 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.
28. 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.
29. Strange experiences.
If rating voices it is important to establish that they really are hallucinations (a false perception) i.e. exclude such events as hearing the neighbours TV or radio through the wall.
30. 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.
31. Concern that people or the television are referring to him.
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.

32. Odd gestures, mannerisms.

33. Odd or repetitive use of language.

34. Any other behavioural problem, which is a change from the persons usual.

The Problem Behaviour Checklist

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ] All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ] Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

Self-injury

Does the person have any problems with self-injury? E.g. scratching or pinching self, skin-picking, picking at wounds, puling 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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

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? [ ]

Daily=1; weekly=2; monthly=3; every 3 months=4; every 6 months=5;

Yearly=6; less than once a year=7

A. If **YES**, how long does it/ did it last for? [ ]

All day=1; half a day=2; two or three hours; an hour or less=4

A. If **YES**, how severe is it/was it? [ ]

Severe=1; not severe=2; don't know=3

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. restrictions 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 and/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

Demographics questionnaire

Demographics

Age: [ ]

Type of accommodation/support: [ ]
Paid support=1; family carer=2; other=3

Employment/day opportunities: [ ]
Paid employment=1; paid employment with support=2; voluntary work=3;
College course=4; day centre=5; other=6, specify……

Smoking status: [ ]
Yes=1; No=2

Epilepsy: [ ]
Yes=1; No=2

Urinary incontinence: [ ]
Yes=1; No=2

Impaired mobility: [ ]
Yes=1; No=2

Visual impairment: [ ]

Yes=1; No=2

Hearing impairment: [ ]

Yes=1; No=2

Other Professionals

	Yes/No
Dietician	
S&LT	
Physiotherapist	
Occupational Therapist	
Psychologist	
Psychiatrist	
Other doctors & specify type	
Community LD Nurse	
Epilepsy Nurse	
Practice Nurse	
Social Worker	
Care Manager	
Other, specify	

Medications

Drug Name	Dose and frequency

The Modified Interview Measure of Social Relationships (IMSR)

Social networks

For the last 7 days

How many people has the participant been in contacts with:

At home? [ ] [ ] [ ]
(Other tenants, flat-mates, residents, live-in partner, relatives at the same address, support workers)

Relatives whom she/he does not live with? [ ] [ ] [ ]

At work (day centre, college)? [ ] [ ] [ ]

Other friends? [ ] [ ] [ ]
(Personal friends, family friends, people attending same club, leisure event, evening course)

At a faith gathering such as a church? [ ] [ ] [ ]

Other acquaintances? [ ] [ ] [ ]
(Neighbours, shopkeepers, more casual contacts, other non-professional workers who call into the home address)

Professionals? [ ] [ ] [ ]
(Social workers, doctors, nurses, other health care professionals)

How many people has the person had a confrontation or argument with, or an angry exchange? (Include any description of bullying, harassment, abuse or aggression) [ ] [ ]

How many people has the participant had a minor disagreement or problem with? [ ] [ ]

How many people has the participant has an enjoyable social interaction with? [ ] [ ]

In general

Does the participant have someone whom she/he is particularly close to: a special relationship with a relative, partner or a best friend? Would that person regard the relationship as very close? (This excludes the expected level of interest and concern that a responsible support worker would have for a client)

Yes=1; Yes, several=2; No=3 [ ] [ ]

How many people would the participant trust or tell a secret to? [ ] [ ]
One=1; Two-five=2; six or more=3; anyone (too trusting)=4; No one=5

The BILD Life Experiences Checklist (LEC)

How often does the person visit friends or relatives for a meal?
Never=1; At least once a year=2; At least monthly=3; At least weekly=4 [ ] [ ]

How often does the person go out to meet friends or relatives e.g. at the pub or someone's home?
Never=1; At least once a year=2; At least monthly=3; At least weekly=4 [ ] [ ]

How often does the person have friends or relatives to stay overnight at her/his home?
Never=1; At least once a year=2; At least monthly=3; At least weekly=4 [ ] [ ]

How often does the person stay overnight at a friend's or relative's home?
Never=1; At least once a year=2; At least monthly=3; At least weekly=4 [ ] [ ]

Is the person on first name terms with any of her/his neighbours?
Never=1; At least once a year=2; At least monthly=3; At least weekly=4 [ ] [ ]

Who does the person spend most of his/her social or leisure time with?
Other people who have learning disabilities [ ] [ ]
People who do not have learning disabilities [ ] [ ]
Other people who have learning disabilities, and people who do not [ ] [ ]

The Modified Index of Perceived Social Support

My friends and family:

Make me happy
Always=1; Sometimes=2; Never=3 [ ]

Love me
Always=1; Sometimes=2; Never=3 [ ]

I can depend on them
Always=1; Sometimes=2; Never=3 [ ]

Take care of me when I need them
Always=1; Sometimes=2; Never=3 [ ]

Accept me
Always=1; Sometimes=2; Never=3 [ ]

I am important to them
Always=1; Sometimes=2; Never=3 [ ]

Support and encourage me
Always=1; Sometimes=2; Never=3 [ ]

The Index of Community Involvement (ICI)

In the past month, has the individual participated in any of the following?

(Tick each answer)

Activity in the past month	No (Score = 0)	Yes (Score = 1)
Had guests to stay (no. of nights)		
Had family or friends in for a meal		
Been to a social club		
Been on an overnight stay to family or friends (no. of nights)		
Had trips out with family or friends		
Been to a café		
Been to a pub		
Been to a hairdresser		
Been shopping		
Been to a church		
Been to a sports event		
Been to a cinema		
Been to a concert		
Been on a bus		
Been to their bank		
Been on holiday in the past 12 months		

Number of items rated 'yes' ☐

The Index of Participation in Domestic Living

For the past month rate the individual's participation in the listed activities by putting a cross in the relevant box. Total score calculated by adding together the 13 individual scores (Range 0-26).

Activity	**Has not participated in this activity** (Score= 0)	**Participated with support from staff** (Score= 1)	**Participated in the activity alone, without support** (Score= 2)
1. Shopping for food			
2. Preparing meals			
3. Setting table			
4. Serving meals			
5. Washing up			
6. Cleaning kitchen			
7. Cleaning living and dining room			
8. Cleaning own bedroom			
9. Cleaning bathroom and toilet			
10. Shopping for toiletries, clothes etc			
11. Doing own washing			
12. Doing own ironing			
13. Looking after the garden			

The Guernsey Community Participation and Leisure Assessment (GCPLA)

Overleaf is a list of potential activities or contacts clients may have access to.
For each activity, please look at the separate list of definitions.
Please indicate by a number in the column labelled **FREQUENCY** how often they do this:

NUMBER	DEFINITION
0	Never
1	Very occasionally
2	3 monthly or more frequently
3	Monthly "
4	Weekly "
5	Daily "

Activities that have occurred perhaps only once would be rated as very occasionally, i.e. more than never, but less than quarterly or more per year.

Please indicate by a number in the column labelled **SUPPORT** whether they usually are:

NUMBER	DEFINITION	NOTES
1	Supervised	Supervised = **Either** The onus of choice and control lies with carer, **Or** A major part of the carer's attention is concerned with vigilance for the individual, **Or** A combination of the two
2	With carers, but not supervised	Carer = relative or paid member of staff
3	Unaccompanied	-
4	With a peer group	Peer Group = includes all those who do not fulfil criteria of carer. If carer present rate as 1 or 2.

Where the activity has never been done, it is not necessary to complete a hypothetical rating of support and can rated as N/A
For those activities that are seasonal, e.g. beach, try to reflect how often the person would do this at the appropriate time of year.

A C T I V I T Y	FREQUENCY	SUPPORT

A. SERVICES

Doctor (GP)		
Dentist		
Hospital		
Police		

B. PUBLIC TRANSPORT

Bus		
Train		
Taxi		
Boat		
Aeroplane		

C. INDOOR LEISURE

Craft		
Games		
T.V.		
Videos		
Music (Listen)		
Music (Play)		
Pets		

D. LEISURE, SPORT & RECREATION

Fair/Fete/Festival		
Museum/Art Gallery		
Sport (Participation)		
Sport (Spectator)		
Exercise/Aerobic Class		
Cycling		
Cinema		
Theatre		
Concert		

0 = Never, 1 = Very occasionally, 2 = Quarterly or more frequently, 3 = Monthly, 4 = Weekly, 5 = Daily
1 = Supervised, 2 = Accompanied, 3 = Alone, 4 = Peer group. **Activities that have occurred perhaps only once would be rated as very occasionally, i.e. more than never, but less than quarterly or more per year.**

A C T I V I T Y	FREQUENCY	SUPPORT
Park		
Beach		
Walking		
Holiday		
Swimming		
Sailing		
DIY		
Gardening		

E. SOCIAL

Disco		
Pub		
Party		
Restaurant/Cafe		
Friend's House		
Neighbour's Home		
Social Club (Integrated)		
Social Club (Segregated)		

F. FACILITIES/AMENITIES

Local Shop		
High Street Store		
Post Office		
Hairdresser		
Supermarket		
Chemist		
Bank/Building Society		
Place of Worship		
Large Retail Outlet		
Jumble/Car Boot Sale		
Library		
Adult Education		

0 = Never, 1 = Very occasionally, 2 = Quarterly or more frequently, 3 = Monthly, 4 = Weekly, 5 = Daily
1 = Supervised, 2 = Accompanied, 3 = Alone, 4 = Peer group

S C O R I N G

1	Range		Add up the number of regular activities (a score of 2 or more in the Frequency column).
2	'Busy'		Add up the number of very frequent activities (a score of 4 or 5 in the Frequency column).
3	Independence		
	Supervised		Add the number of activities scoring 1 in the Support column
	Accompanied		Add the number of 2s in the Support column
	Solitary activity		Add the number of 3s in the Support column
	Peer		Add the number of 4s in the Support column

S C O R E A N A L Y S I S

	Category	Range	Busy	Supervised	Accompanied	Solitary	Peer
A	Services						
B	Public transport						
C	Indoor leisure						
D	Leisure, sport & recreation						
E	Social						
F	Facilities / amenities						

TOTAL						

'Community' (= Total minus C)						
'Leisure' (=C+D+E)						

GCPLA Item Definitions/Criteria

A. Services	
Doctor (General Practitioner)	A medical doctor working in the community as distinct from a consultant or specialist based in a hospital
Dentist	A dentist or hygienist in the community.
Hospital	Visiting a hospital either as a patient or visitor.
Police	Voluntary interaction with members of the police force in the general community or at a police station or its equivalent.
B. Public Transport	
Bus	To travel as a passenger in a bus serving the public on a fixed route. Does not include coach or buses for private use.
Train	To travel as a passenger on a railway.
Taxi	To travel as a passenger in a taxi.
Boat	To travel as a passenger in a boat. Does not include recreation/enjoyment.
Aeroplane	To travel as a passenger by plane.
C. Indoor Leisure	
Craft	To participate in the practical arts for purposes of education or recreation (e.g. pottery).
Games	To participate in a form or spell of play with formalised rules within the home (e.g. board games). Does not include indoor sports at a leisure centre.
TV	To actively watch by choice live transmitted television programmes. To watch actively requires evidence of attending for at least ten minutes (e.g. continued gaze, emotional response to the programme, protest if switched off or programme changed). Exclude situations where the TV is on in the individual environment with no evidence of attending.
Videos	To actively watch by choice (as in TV) visual images transmitted via a video cassette and video recorder to the television. Exclude situations where the video is on in the individuals environment with no evidence of attending.
Music (Listen)	To actively listen by choice to music (e.g. via radio, cd, cassettes, etc). To actively listen requires evidence of attention (e.g. singing/humming along, tapping feet, dancing, protest when music finishes). Exclude situations where the music is played in the individuals environment with no evidence of attending.
Music (Play)	To actively play by choice any musical instrument to whatever standard for educational or recreational purpose.
Pets	To take the major responsibility for the day to day care of a domestic or tamed animal kept for pleasure or companionship.
D. Leisure, Sport & Recreation	
Fair/Fete/Festival	To visit a gathering of stalls/amusements for public entertainment as a member of the public.
Museum/Art Gallery	To visit for recreational or educational purposes a building used for exhibiting objects of historical, scientific, cultural or artistic interest.
Sport (Participation)	To actively participate by choice with others in a game or competitive activity with formalised rules in the community (e.g. leisure centre, park etc.) Include indoor (e.g. table tennis, squash) and outdoor (e.g. football, cricket) sports. Note, do not include swimming.
Sport (Spectator)	To actively watch by choice for recreational purposes a game or competitive activity with formalised rules in the community. Do not include watching sport on the TV.
Exercise/Aerobic Class	To actively participate by choice in an organised exercise session involving physical effort to sustain or improve health (do not include swimming or cycling).
Cycling	To actively ride by choice a bicycle for recreation purposes.
Cinema	To visit a theatre where motion pictures are shown and to actively watch a motion picture for recreational purposes.
Theatre	To visit by choice a building or outdoor arena to actively watch dramatic performances.
Concert	To visit a building or outdoor site to actively watch an organised public musical performance.
Park	To visit a large area of land in town or in the countryside that is kept mostly undeveloped for public recreational use.
Beach	To visit a shore/coastline for recreational purposes.
Walking	To move on foot (or wheelchair) for its own sake (recreation) i.e. include going for a walk

	not functional walking i.e. getting from A to B.
Holiday	To experience an extended period of recreation away from home.
Swimming	To swim in a pool or the sea for recreational purposes.
Sailing	To spend time on water for recreational purposes (i.e. not to get from A to B); (e.g. dingy, sailing, windsurfing).
DIY	To manually create, build, repair, maintain, utilities/furnishings/fittings within the home environment.
Gardening	To prepare and use a piece of land for growing/maintaining grass, trees, flowers, fruit or vegetables
E. Social	
Disco	A site used by the general public for dancing to recorded popular music (not covered under other categories e.g. party, concert).
Pub	An establishment open to the general public providing alcoholic drinks for consumption on the premises. Include hotel bars, exclude establishments specifically for people with disabilities.
Party	An organised social gathering of invited guests.
Restaurant/Cafe	Public premises where meals or refreshments may be had. Excluding public houses, hotel bars.
Friends House	A home of a person liked by the individual who is not a relative or present paid staff.
Neighbours Home	Visit to the house(s)/flat(s) immediately next door (also above-below) to their own for purposes other than vocational.
Social Club (Integrated)	A club which is not especially for disabled people.
Social Club (Segregated)	A club which is especially for disabled people or for disabled people to meet non disabled people (eg PHAB).
F. Facilities/Amenities	
Local Shop	Small shops outside of town centres, serving a specific community.
High Street Store	Departmental stores and all other shops in a town centre or shopping complex.
Post Office	An establishment where postal business is carried out. Include franchises.
Hairdresser	An establishment where hair is cut or styled. Does not include a visiting hairdresser to the home.
Supermarket	Large self service store selling household goods and groceries.
Chemist	An establishment selling medical goods and toiletries.
Bank/Building Society	A financial establishment used for the purposes of investment and loans.
Place of Worship	Attendance at a building for the purpose of worship. Does not include social activities.
Large Retail Outlet	A retail outlet not included in High Street Store or Local Shop (e.g. large out of town furniture stores, DIY stores and garden centres.
Jumble Sale/Boot Fair	An organised event for selling to the general public, consisting of a number of stalls, etc.
Library	An establishment containing a collection of books for reading or reference rather than for sale.
Adult Education	A local education authority establishment (e.g. evening classes)

Past and Personal History Questionnaire

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?.....
.....
.....
.....

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?).....

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?.....
.....
.....

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.....
.....
.....
.....

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 C

Adjusted change in total PAS-ADD Checklist scores between T1 and T3

Table C.1 Association between personal factors and adjusted change in total PAS-ADD Checklist score between T1 and T3

Group 1: Personal Factors	**Participants n = 100 (%)**	**Adjusted increase in total PAS-ADD Checklist scores Range 0-26, n=100 (%)**	**F value**	***p*-value**
T1 age				
16-35	38 (38.0)	*M*=12.06	2.72	.071*
36-55	45 (45.0)	*M*=14.00		
56+	17 (17.0)	*M*=11.58		
Gender				
Male	50 (50.0)	*M*=12.43	-.799	.373
Female	50 (50.0)	*M*=13.27		
Level of ID				
Mild	39 (39.0)	*M*=12.54	.635	.594
Moderate	29 (29.0)	*M*=12.32		
Severe	19 (19.0)	*M*=14.10		
Profound	13 (13.0)	*M*=13.13		
Down's syndrome				
No	77 (77.0)	*M*=12.96	.185	.668
Yes	23 (23.0)	*M*=12.48		

*$p \leq .1$

1Table C.2 Association between lifestyle & support factors and adjusted change in total PAS-ADD Checklist score between T1 and T3

Group 2: Lifestyle & support	**Participants n = 100 (%)**	**Adjusted increase in total PAS-ADD Checklist scores Range 0-26, n=100 (%)**	**F value**	***p*-value**
T1 accommodation type				
Paid carer	46 (46.0)	*M*=13.90	2.24	.112
Family carer	40 (40.0)	*M*=11.91		
Other	14 (14.0)	*M*=12.11		
T1 smoker				
No	92 (92.0)	*M*=12.78	.258	.612
Yes	8 (8.0)	*M*=13.64		

*$p \leq .1$

Table C.3 Association between past experiences and adjusted change total in PAS-ADD Checklist score between T1 and T3

Group 4: Past experiences	**Participants n = 100 (%)**	**Adjusted increase in total PAS-ADD Checklist scores Range 0-26, n=100 (%)**	**F value**	***p*-value**
T1 life events				
No	51 (51.0)	*M*=13.38	1.23	.269
Yes	49 (49.0)	*M*=12.30		
Parental divorce in childhood				
No	92 (92.0)	*M*=12.92	.300	.585
Yes	8 (8.0)	*M*=11.99		
Abuse or adversity in adulthood				
No	86 (86.0)	*M*=12.92	.097	.757
Yes	14 (14.0)	*M*=13.21		

Former long-stay hospital resident				
No	82 (82.0)	*M*=12.98	.379	.540
Yes	18 (18.0)	*M*=12.25		

*$p \leq .1$

Table C.4 Association between health & disabilities factors and adjusted change in total PAS-ADD Checklist score between T1 and T3

Group 5: Health & disabilities	**Participants n = 100**	**Adjusted increase in total PAS-ADD Checklist scores Range 0-26, n=100**	**F value**	***p*-value**
Urinary incontinence				
No	68 (68.0)	*M*=12.41	1.98	.163
Yes	32 (32.0)	*M*=13.79		
Impaired mobility				
No	78 (78.0)	*M*=12.79	.065	.799
Yes	22 (22.0)	*M*=13.07		
Visual impairment				
No	53 (53.0)	*M*=12.93	.038	.847
Yes	47 (47.0)	*M*=12.76		
Hearing impairment				
No	70 (70.0)	*M*=12.69	.267	.607
Yes	30 (30.0)	*M*=13.21		
Autistic spectrum disorder				
No	92 (92.0)	*M*=12.73	.783	.379
Yes	8 (8.0)	*M*=14.23		
Epilepsy				
No	60 (60.0)	*M*=12.84	.017	.897
Yes	39 (39.0)	*M*=12.71		

*$p \leq .1$

Adjusted change in total PAS-ADD Checklist scores between T2 and T3

Table C.5 Association between personal factors and adjusted change in total PAS-ADD Checklist score between T2 and T3

Group 1: Personal Factors	**Participants n = 100 (%)**	**Adjusted increase in total PAS-ADD Checklist scores Range 0-27, n=100 (%)**	**F value**	***p*-value**
T1 age				
16-35	38 (38.0)	*M*=8.55	2.80	.066*
36-55	45 (45.0)	*M*=10.50		
56+	17 (17.0)	*M*=7.71		
Gender				
Male	50 (50.0)	*M*=8.54	2.29	.134
Female	50 (50.0)	*M*=10.02		
Level of ID				
Mild	39 (39.0)	*M*=9.14	2.10	.105
Moderate	29 (29.0)	*M*=7.89		
Severe	19 (19.0)	*M*=11.43		
Profound	13 (13.0)	*M*=9.67		
Down's syndrome				
No	77 (77.0)	*M*=9.44	.353	.554
Yes	23 (23.0)	*M*=8.74		

*$p \leq .1$

Table C.6 Association between lifestyle & support factors and adjusted change in total PAS-ADD Checklist score between T2 and T3

Group 2: Lifestyle & support	**Participants n = 100 (%)**	**Adjusted increase in total PAS-ADD Checklist scores Range 0-27, n=100 (%)**	**F value**	***p*-value**
T1 accommodation type				
Paid carer	46 (46.0)	*M*=10.47	2.16	.079*
Family carer	40 (40.0)	*M*=8.13		
Other	14 (14.0)	*M*=8.69		

T2 accommodation type				
Paid carer	47 (47.0)	*M*=10.23		
Family carer	39 (39.0)	*M*= 8.22	1.79	.172
Other	14 (14.0)	*M*=9.05		
T2 deprivation Index				
1- most deprived	37 (37.0)	*M*=9.07	.400	.811
2	32 (32.0)	*M*=9.75		
3	11 (11.0)	*M*=9.50		
4	11 (11.0)	*M*=9.80		
5- least deprived	9 (9.0)	*M*=7.56		
T1 smoker				
No	92 (92.0)	*M*=9.30	.019	.889
Yes	8 (8.0)	*M*=9.04		
T2 smoker				
No	90 (90.0)	*M*=9.23	.003	.955
Yes	10 (10.0)	*M*=9.20		

*$p \leq .1$

Table C.7 Association between T2 social networks & activities and adjusted change in total PAS-ADD Checklist score between T2 and T3

Group 3: Social networks & activities at T2	**Participants n = 100 (%)**	**Adjusted increase in total PAS-ADD Checklist scores Range 0-27, n=100 (%)**	**F value**	***p*-value**
Contacts past week				
0-20	27 (27.0)	*M*=9.81	.887	.451
21-50	41 (41.0)	*M*=9.81		
51-100	23 (23.0)	*M*=8.62		
>100	7 (7.0)	*M*=6.96		
Angry interaction in past week				
No	83 (83.0)	*M*=8.72	7.37	.008*
Yes	15 (15.0)	*M*=12.36		

Minor disagreement in past week				
No	77 (77.0)	*M*=8.95	1.60	.210
Yes	21 (21.0)	*M*=10.48		
Enjoyable interaction in past week				
None	9 (9.0)	*M*=11.00	.713	.493
1-10	53 (53.0)	*M*=9.25		
>10	35 (35.0)	*M*=8.76		
Having a close relationship				
No	14 (14.0)	*M*=12.15	2.84	.064*
Yes, 1	22 (22.0)	*M*= 9.10		
Yes, several	64 (64.0)	*M*=8.71		
People trusted with a secret				
None	11 (11.0)	*M*=11.17	3.48	.011*
1	9 (9.0)	*M*=11.79		
2-5	46 (46.0)	*M*=7.98		
>5	22 (22.0)	*M*=8.37		
Anyone	10 (10.0)	*M*=12.20		
Frequency of meeting family/ friends for a meal				
Never	13 (13.0)	*M*=11.42	1.26	.294
Yearly	25 (25.0)	*M*= 9.12		
Monthly	31 (31.0)	*M*=8.31		
Weekly	30 (30.0)	*M*=9.57		
Frequency of meeting family/ friends at their home or pub				
Never	11 (11.0)	*M*=9.59	1.33	.268
Yearly	19 (19.0)	*M*=10.89		
Monthly	22 (22.0)	*M*=7.85		
Weekly	48 (48.0)	*M*=9.23		

Frequency of having family/friends stay overnight at own home				
Never	75 (75.0)	*M*=9.21	.501	.608
Yearly	17 (17.0)	*M*= 10.15		
Monthly	8 (8.0)	*M*=8.09		
Weekly	0 (0.0)	n/a		
Frequency of overnight stays at family/friends home				
Never	65 (65.0)	*M*=9.42	.137	.937
Yearly	26 (26.0)	*M*= 8.77		
Monthly	6 (6.0)	*M*=9.64		
Weekly	3 (3.0)	*M*=9.91		
Group most social time spent with				
People with ID	19 (19.0)	*M*= 8.00	.360	.699
People without ID	14 (14.0)	*M*=9.28		
Mix of both	45 (45.0)	*M*=8.96		

*$p \leq .1$

Table C.8 Association between past experiences and adjusted change in total PAS-ADD Checklist score between T2 and T3

Group 4: Past experiences	**Participants n = 100 (%)**	**Adjusted increase in total PAS-ADD Checklist scores Range 0-27, n=100 (%)**	**F value**	***p*-value**
T1 life events				
No	51 (51.0)	*M*=9.18	.045	..832
Yes	49 (49.0)	*M*=9.39		
T2 life events				
No	31 (31.0)	*M*=8.26	1.98	.162
Yes	69 (69.0)	*M*=9.74		

T3 life events No Yes	14 (14.0) 86 (86.0)	*M*=7.57 *M*=9.56	2.00	.160
Parental divorce in childhood No Yes	92 (92.0) 8 (8.0)	*M*=9.36 *M*=8.35	.311	.579
Abuse or adversity in adulthood No Yes	86 (86.0) 14 (14.0)	*M*=9.16 *M*=10.02	.354	.553
Former long-stay hospital resident No Yes	82 (82.0) 18 (18.0)	*M*=9.48 *M*=8.36	.760	.386

*$p \leq .1$

Table C.9 Association between health & disabilities factors and adjusted change in total PAS-ADD Checklist score between T2 and T3

Group 5: Health & disabilities	**Participants n = 100 (%)**	**Adjusted increase in total PAS-ADD Checklist scores Range 0-27, n=100 (%)**	**F value**	***p*-value**
Urinary incontinence No Yes	68 (68.0) 32 (32.0)	*M*=8.75 *M*=10.41	2.49	.118
Impaired mobility No Yes	78 (78.0) 22 (22.0)	*M*=9.22 *M*=9.49	.052	.821
Visual impairment No Yes	53 (53.0) 47 (47.0)	*M*=9.52 *M*=9.01	.258	.612
Hearing impairment No Yes	70 (70.0) 30 (30.0)	*M*=9.00 *M*=9.93	.741	.392

Autistic spectrum disorder				
No	92 (92.0)	*M*=9.10	1.63	.204
Yes	8 (8.0)	*M*=11.40		
Epilepsy				
No	60 (60.0)	*M*=9.25	.000	.986
Yes	39 (39.0)	*M*=9.26		

*$p \leq .1$

Mental ill-health relapse at T3

Table C.10 Association between personal factors and relapse of mental ill-health at T3

Group 1: Personal Factors	**Participants experiencing resilience or relapse n = 47**	**Mental ill-health relapse at T3**		***x²* value**	***p*-value**
		No n=21	**Yes n=26**		
T1 age (%)					
16-35	18	10 (47.6)	8 (30.8)	1.46	1.00
36-55	23	9 (42.9)	14 (53.8)		
56+	6	2 (9.5)	4 (15.4)		
Gender (%)					
Male	21	13 (61.9)	8 (30.8)	4.56	.043*
Female	26	8 (38.1)	18 (69.2)		
Level of ID (%)					
Mild	21	9 (42.9)	12 (46.2)	8.59	1.00
Moderate	12	9 (42.9)	3 (11.5)		
Severe	10	3 (14.3)	7 (26.9)		
Profound	4	0 (0.0)	4 (15.4)		
Down's syndrome (%)					
No	35	16 (76.2)	19 (73.1)	.059	1.00
Yes	12	5 (23.8)	7 (26.9)		

*$p \leq .1$

Table C.11 Association between lifestyle & support factors and relapse of mental ill-health at T3

Group 2: Lifestyle & support	**Participants experiencing resilience or relapse n = 47**	**Mental ill-health relapse at T3**		***x²* value**	***p*-value**
		No n=21	**Yes n=26**		
T1 accommodation (%)					
Paid carer	23	6 (28.6)	17 (65.4)	7.06	1.00
Family carer	16	11 (52.4)	5 (19.2)		
Other	8	4 (19.0)	4 (15.4)		
T2 accommodation (%)					
Paid carer	22	6 (28.6)	16 (61.5)	6.45	1.00
Family carer	16	11 (52.4)	5 (19.2)		
Other	9	4 (19.0)	5 (19.2)		
T2 deprivation Index					
1- most deprived	15	6 (28.6)	9 (34.6)	2.10	1.00
2	18	9 (42.9)	9 (34.6)		
3	5	1 (4.8)	4 (15.4)		
4	4	2 (9.5)	2 (7.7)		
5- least deprived	5	3 (14.3)	2 (7.7)		
T1 smoker (%)					
No	44	20 (95.2)	24 (92.3)	.167	1.00
Yes	3	1 (4.8)	2 (7.7)		
T2 smoker (%)					
No	44	20 (95.2)	24 (92.3)	.167	1.00
Yes	3	1 (4.8)	2 (7.7)		

*$p \leq .1$

Table C.12 Association between T2 social network & activity factors and relapse of mental ill-health at T3

Group 3: Social networks & activities at T2	**Participants experiencing resilience or relapse n = 47**	**Mental ill-health relapse at T3**		***x²* value**	***p*-value**
		No n=21	**Yes n=26**		
Contacts past week (%)					
0-20	12	3 (14.3)	9 (34.6)	4.35	1.00
21-50	21	9 (42.9)	12 (46.2)		
51-100	10	6 (28.6)	4 (15.4)		
>100	4	3 (14.3)	1 (3.8)		
Angry interaction in past week (%)					
No	38	19 (90.5)	19 (73.1)	1.67	.260
Yes	8	2 (9.5)	6 (23.1)		
Minor disagreement in past week (%)					
No	38	18 (85.7)	20 (76.9)	.259	.710
Yes	8	3 (14.3)	5 (19.2)		
Enjoyable interaction in past week (%)					
None	3	0 (0.0)	3 (11.5)	3.83	1.00
1-10	26	11 (52.4)	15 (57.7)		
>10	17	10 (47.6)	7 (26.9)		
Having a close relationship (%)					
No	6	0 (0.0)	6 (23.1)	7.05	1.00
Yes, 1	9	3 (14.3)	6 (23.1)		
Yes, several	32	18 (85.7)	14 (53.8)		

People trusted with a secret (%)					
None	5	0 (0.0)	5 (19.2)	10.50	1.00
1	5	1 (4.8)	4 (15.4)		
2-5	26	15 (71.4)	11 (42.3)		
>5	8	5 (23.8)	3 (11.5)		
Anyone	3	0 (0.0)	3 (11.5)		
Meets family/ friends for a meal (%)					
Never	3	1 (4.8)	2 (7.7)	.473	1.00
Yearly	15	7 (33.3)	8 (30.8)		
Monthly	15	6 (28.6)	9 (34.6)		
Weekly	14	7 (33.3)	7 (26.9)		
Meets family/ friends at their home or pub (%)					
Never	6	2 (9.5)	4 (15.4)	5.03	1.00
Yearly	8	1 (4.8)	7 (26.9)		
Monthly	14	8 (38.1)	6 (23.1)		
Weekly	19	10 (47.6)	9 (34.6)		
Has family/friends stay overnight at own home (%)					
Never	34	13 (61.9)	21 (80.8)	2.49	1.00
Yearly	9	5 (23.8)	4 (15.4)		
Monthly	4	3 (14.3)	1 (3.8)		
Weekly	0	0 (0.0)	0 (0.0)		
Stays overnight at family/friends home (%)					
Never	30	12 (57.1)	18 (69.2)	.754	1.00
Yearly	13	7 (33.3)	6 (23.1)		
Monthly	2	1 (4.8)	1 (3.8)		
Weekly	2	1 (4.8)	1 (3.8)		

Most social time spent with (%)					
People with ID	5	2 (9.5)	3 (11.5)	.358	1.00
People without ID	7	4 (19.0)	3 (11.5)		
Mix of both	23	11 (52.4)	12 (46.2)		

*$p \leq .1$

Table C.13 Association between past experience factors and relapse of mental ill-health at T3

Group 4: Past experiences	**Participants experiencing resilience or relapse n = 47**	**Mental ill-health relapse at T3**		***x²* value**	***p*-value**
		No n=21	**Yes n=26**		
T1 life events (%)					
No	21	14 (66.7)	7 (26.9)	7.42	.009*
Yes	26	7 (33.3)	19 (73.1)		
T2 life events (%)					
No	14	8 (38.1)	6 (23.1)	1.25	.342
Yes	33	13 (61.9)	20 (76.9)		
T3 life events (%)					
No	7	6 (28.6)	1 (3.8)	5.60	.035*
Yes	40	15 (71.4)	25 (96.2)		
Parental divorce in childhood (%)					
No	42	18 (85.7)	24 (92.3)	.531	.644
Yes	5	3 (14.3)	2 (7.7)		
Abuse or adversity in adulthood (%)					
No	43	20 (95.2)	23 (88.5)	.685	.617
Yes	4	1 (4.8)	3 (11.5)		
Former long-stay hospital resident (%)					
No	40	19 (90.5)	21 (80.8)	.864	.436
Yes	7	2 (9.5)	5 (19.2)		

*$p \leq .1$

Table C.14 Association between health & disabilities factors and relapse of mental ill-health at T3

Group 5: Health & disabilities	**Participants experiencing resilience or relapse n = 47**	**Mental ill-health relapse at T3**		***x²* value**	***p*-value**
		No n=21	**Yes n=26**		
Urinary incontinence (%)					
No	34	18 (85.7)	16 (61.5)	3.39	.102
Yes	13	3 (14.3)	10 (38.5)		
Impaired mobility (%)					
No	38	19 (90.5)	19 (73.1)	2.27	.160
Yes	9	2 (9.5)	7 (26.9)		
Visual impairment (%)					
No	25	11 (52.4)	14 (53.8)	.010	1.00
Yes	22	10 (47.6)	12 (46.2)		
Hearing impairment (%)					
No	32	14 (66.7)	18 (69.2)	.035	1.00
Yes	15	7 (33.3)	8 (30.8)		
ASD (%)					
No	42	20 (95.2)	22 (84.6)	1.38	.362
Yes	5	1 (4.8)	4 (15.4)		
Epilepsy (%)					
No	30	13 (61.9)	17 (65.4)	.061	1.00
Yes	17	8 (38.1)	9 (34.6)		

*$p<.1$

Onset of new mental ill-health at T3

Table C.15 Association between personal factors and onset of new mental ill-health at T3

Group 1: Personal Factors	**Participants healthy at T1 and T2 n = 53**	**Onset of mental ill-health at T3**		***x²* value**	***p*-value**
		No n=21	**Yes n=32**		
T1 age (%)					
16-35	20	10 (47.6)	10 (31.3)	3.03	1.00
36-55	22	9 (42.9)	13 (40.6)		
56+	11	2 (9.5)	9 (28.1)		
Gender (%)					
Male	31	13 (61.9)	18 (56.3)	.167	.779
Female	22	8 (38.1)	14 (43.8)		
Level of ID (%)					
Mild	21	9 (42.9)	12 (37.5)	4.86	1.00
Moderate	18	9 (42.9)	9 (28.1)		
Severe	8	3 (14.3)	5 (15.6)		
Profound	6	0 (0.0)	6 (18.8)		
Down's syndrome (%)					
No	39	16 (76.2)	23 (71.9)	.121	.763
Yes	14	5 (23.8)	9 (28.1)		

*$p \leq .1$

Table C.16 Association between lifestyle & support factors and onset of new mental ill-health at T3

Group 2: Lifestyle & support	**Participants healthy at T1 and T2 n = 53**	**Onset of mental ill-health at T3**		***x²* value**	***p*-value**
		No n=21	**Yes n=32**		
T1 accommodation (%)					
Paid carer	19	6 (28.6)	13 (40.6)	2.35	1.00
Family carer	28	11 (52.4)	17 (53.1)		
Other	6	4 (19.0)	2 (6.3)		
T2 accommodation (%)					
Paid carer	18	6 (28.6)	12 (37.5)	1.18	1.00
Family carer	28	11 (52.4)	17 (53.1)		
Other	7	4 (19.0)	3 (9.4)		
T2 deprivation Index					
1- most deprived	16	6 (28.6)	10 (31.3)	3.65	1.00
2	18	9 (42.9)	9 (28.1)		
3	5	1 (4.8)	4 (12.5)		
4	9	2 (9.5)	7 (21.9)		
5- least deprived	5	3 (14.3)	2 (6.3)		
T1 smoker (%)					
No	50	20 (95.2)	30 (96.8)	.053	1.00
Yes	3	1 (4.8)	2 (6.3)		
T2 smoker (%)					
No	48	20 (95.2)	28 (87.5)	.889	.637
Yes	5	1 (4.8)	4 (12.5)		

*$p \leq .1$

Table C.17 Association between T2 social network & activity factors and onset of new mental ill-health at T3

Group 3: Social networks & activities at T2	**Participants healthy at T1 and T2 n = 53**	**Onset of mental ill-health at T3**		***x²* value**	***p*-value**
		No n=21	**Yes n=32**		
Contacts past week (%)					
0-20	9	3 (14.3)	6 (18.8)	2.38	1.00
21-50	23	9 (42.9)	14 (43.8)		
51-100	17	6 (28.6)	11 (34.4)		
>100	4	3 (14.3)	1 (3.1)		
Angry interaction in past week (%)					
No	49	19 (90.5)	30 (93.8)	.195	1.00
Yes	4	2 (9.5)	2 (6.3)		
Minor disagreement in past week (%)					
No	44	18 (85.7)	26 (81.3)	.179	1.00
Yes	9	3 (14.3)	6 (18.8)		
Enjoyable interaction in past week (%)					
None	1	0 (0.0)	1 (3.1)	.695	1.00
1-10	27	11 (52.4)	16 (50.0)		
>10	24	10 (47.6)	14 (43.8)		
Having a close relationship (%)					
No	2	0 (0.0)	2 (6.3)	3.75	1.00
Yes, 1	13	3 (14.3)	10 (31.3)		
Yes, several	38	18 (85.7)	20 (65.6)		

People trusted with a secret (%)					
None	2	0 (0.0)	2 (6.3)	10.61	1.00
1	4	1 (4.8)	3 (9.4)		
2-5	25	15 (71.4)	10 (31.3)		
>5	14	5 (23.8)	9 (28.1)		
Anyone	7	0 (0.0)	7 (21.9)		
Meets family/ friends for a meal (%)					
Never	9	1 (4.8)	8 (25.0)	4.76	1.00
Yearly	13	7 (33.3)	6 (18.8)		
Monthly	12	6 (28.6)	6 (18.8)		
Weekly	19	7 (36.8)	12 (37.5)		
Meets family/ friends at their home or pub (%)					
Never	4	2 (9.5)	2 (6.3)	6.63	1.00
Yearly	8	1 (4.8)	7 (21.9)		
Monthly	12	8 (38.1)	4 (12.5)		
Weekly	29	10 (47.6)	19 (59.4)		
Has family/friends stay overnight at own home (%)					
Never	34	13 (61.9)	21 (65.6)	.305	1.00
Yearly	13	5 (23.8)	8 (25.0)		
Monthly	6	3 (14.3)	3 (9.4)		
Weekly	0	0 (0.0)	0 (0.0)		
Stays overnight at family/friends home (%)					
Never	33	12 (57.1)	21 (65.6)	2.34	1.00
Yearly	15	7 (33.3)	4 (12.5)		
Monthly	4	1 (4.8)	3 (9.4)		
Weekly	1	1 (4.8)	0 (0.0)		

Most social time spent with (%)					
People with ID	9	2 (9.5)	7 (21.9)	1.20	1.00
People without ID	9	4 (19.0)	5 (15.6)		
Mix of both	27	11 (52.4)	16 (50.0)		

*$p \leq .1$

Table C.18 Association between past experience factors and onset of new mental ill-health at T3

Group 4: Past experiences	**Participants healthy at T1 and T2 n = 53**	**Onset of mental ill-health at T3**		**x^2 value**	***p*-value**
		No n=21	**Yes n=32**		
T1 life events (%)					
No	36	14 (66.7)	22 (68.8)	.025	1.00
Yes	17	7 (33.3)	10 (31.3)		
T2 life events (%)					
No	18	8 (38.1)	10 (31.3)	.265	.768
Yes	35	13 (61.9)	22 (68.8)		
T3 life events (%)					
No	8	6 (28.6)	2 (6.3)	4.93	.047*
Yes	45	15 (71.4)	30 (93.8)		
Parental divorce in childhood (%)					
No	49	18 (85.7)	31 (96.9)	2.26	.289
Yes	4	3 (14.3)	1 (3.1)		
Abuse or adversity in adulthood (%)					
No	47	20 (95.2)	27 (65.6)	1.49	.384
Yes	6	1 (4.8)	5 (15.6)		

Former long-stay hospital resident (%)					
No	44	19 (90.5)	25 (78.1)	1.37	.291
Yes	9	2 (9.5)	7 (21.9)		

*$p \leq .1$

Table C.19 Association between health & disabilities factors and onset of new mental ill-health at T3

Group 5: Health & disabilities	**Participants healthy at T1 and T2 n = 53**	**Onset of mental ill-health at T3**		***x²* value**	***p*-value**
		No n=21	**Yes n=32**		
Urinary incontinence (%)					
No	41	18 (85.7)	23 (71.9)	1.39	.323
Yes	12	3 (14.3)	9 (28.1)		
Impaired mobility (%)					
No	43	19 (90.5)	24 (75.0)	1.98	.282
Yes	10	2 (9.5)	8 (25.0)		
Visual impairment (%)					
No	32	11 (52.4)	21 (65.6)	.930	.397
Yes	21	10 (47.6)	11 (34.4)		
Hearing impairment (%)					
No	39	14 (66.7)	25 (78.1)	.856	.525
Yes	14	7 (33.3)	7 (21.9)		
ASD (%)					
No	51	20 (95.2)	31 (96.9)	.094	1.00
Yes	2	1 (4.8)	1 (3.1)		
Epilepsy (%)					
No	33	13 (61.9)	20 (62.5)	.002	1.00
Yes	20	8 (38.1)	12 (37.5)		

*$p \leq .1$

Resilience to mental ill-health at all 3 time points

Table C.20 Association between personal factors and resilience to mental ill-health between T2 and T3 for the adults who had been free from mental ill-health at T1, compared with the rest of the cohort

Group 1: Personal Factors	**Participants n = 100**	**Resilience to mental ill-health**		***x²* value**	***p*-value**
		No n=79	**Yes n=21**		
T1 age (%)					
16-35	38	28 (35.4)	10 (47.6)	1.55	1.00
36-55	45	36 (45.6)	9 (42.9)		
56+	17	15 (19.0)	2 (9.5)		
Gender (%)					
Male	50	37 (46.8)	13 (61.9)	1.51	.326
Female	50	42 (53.2)	8 (38.1)		
Level of ID (%)					
Mild	38	30 (38.0)	9 (42.9)	5.63	1.00
Moderate	30	20 (25.3)	9 (42.9)		
Severe	19	16 (20.3)	3 (14.3)		
Profound	13	13 (16.5)	0 (0.0)		
Down's syndrome (%)					
No	77	61 (77.2)	16 (76.2)	.010	1.00
Yes	23	18 (22.8)	5 (23.8)		

*$p \leq .1$

Table C.21 Association between lifestyle & support factors and resilience to mental ill-health between T2 and T3 for the adults who had been free from mental ill-health at T1, compared with the rest of the cohort

Group 2: Lifestyle &support	**Participants n = 100**	**Resilience to mental ill-health**		***x²* value**	***p*-value**
		No n=79	**Yes n=21**		
T1 accommodation (%)					
Paid carer	46	40 (50.6)	6 (28.6)	3.26	1.00
Family carer	40	29 (36.7)	11 (52.4)		
Other	14	10 (12.7)	4 (19.0)		
T2 accommodation (%)					
Paid carer	47	41 (51.9)	6 (28.6)	3.63	1.00
Family carer	39	28 (35.4)	11 (52.4)		
Other	14	10 (12.7)	4 (19.0)		
T2 deprivation Index					
1- most deprived	37	31 (39.2)	6 (28.6)	3.31	1.00
2	32	23 (29.1)	9 (42.9)		
3	11	10 (12.7)	1 (4.8)		
4	11	9 (11.4)	2 (18.2)		
5- least deprived	9	6 (7.6)	3 (14.3)		
T1 smoker (%)					
No	92	72 (91.1)	20 (95.2)	.379	1.00
Yes	8	7 (8.9)	1 (4.8)		
T2 smoker (%)					
No	90	70 (88.6)	20 (95.2)	.810	.684
Yes	10	9 (11.4)	1 (4.8)		

*$p \leq .1$

Table C.22 Association between social network & activity factors and resilience to mental ill-health between T2 and T3 for the adults who had been free from mental ill-health at T1, compared with the rest of the cohort

Group 3: Social networks & activities at T2	**Participants n = 100**	**Resilience to mental ill-health**		***x²* value**	***p*-value**
		No n=79	**Yes n=21**		
Contacts past week (%)					
0-20	27	24 (30.4)	3 (14.3)	3.92	1.00
21-50	41	32 (40.5)	9 (42.9)		
51-100	23	17 (21.5)	6 (28.6)		
>100	7	4 (5.1)	3 (14.3)		
Angry interaction in past week (%)					
No	83	64 (81.0)	19 (90.5)	.689	.514
Yes	15	13 (16.5)	2 (9.5)		
Minor disagreement in past week (%)					
No	77	59 (74.7)	18 (85.7)	.810	.550
Yes	21	18 (22.8)	3 (14.3)		
Enjoyable interaction in past week (%)					
None	9	9 (11.4)	0 (0.0)	3.50	1.00
1-10	53	42 (53.2)	11 (52.4)		
>10	35	25 (31.6)	10 (47.6)		
Having a close relationship (%)					
No	14	14 (17.7)	0 (0.0)	6.40	1.00
Yes, 1	22	19 (24.1)	3 (14.3)		
Yes, several	64	46 (58.2)	18 (85.7)		

People trusted with a secret (%)					
None	11	11 (13.9)	0 (0.0)	9.73	1.00
1	9	8 (10.1)	1 (4.8)		
2-5	46	31 (39.2)	15 (71.4)		
>5	22	17 (21.5)	5 (23.8)		
Anyone	10	10 (12.7)	0 (0.0)		
Meets family/ friends for a meal (%)					
Never	13	12 (15.2)	1 (4.8)	2.26	1.00
Yearly	25	18 (22.8)	7 (33.3)		
Monthly	31	25 (26.6)	6 (28.6)		
Weekly	30	23 (29.1)	7 (33.3)		
Meets family/ friends at their home or pub (%)					
Never	11	9 (11.4)	2 (9.5)	6.02	1.00
Yearly	19	18 (2.8)	1 (4.8)		
Monthly	22	14 (17.7)	8 (38.1)		
Weekly	48	38 (48.1)	10 (47.6)		
Has family/friends stay overnight at own home (%)					
Never	75	62 (78.5)	13 (61.9)	2.65	1.00
Yearly	17	12 (15.2)	5 (23.9)		
Monthly	8	5 (6.3)	3 (14.3)		
Weekly	0	0 (0.0)	0 (0.0)		
Stays overnight at family/friends home (%)					
Never	65	53 (67.1)	12 (57.1)	1.15	1.00
Yearly	26	19 (24.1)	7 (33.3)		
Monthly	6	5 (6.3)	1 (4.8)		
Weekly	3	2 (2.53)	1 (4.8)		

Most social time spent with (%)					
People with ID	19	17 (21.5)	2 (9.5)	1.98	1.00
People without ID	14	10 (12.7)	4 (19.0)		
Mix of both	45	34 (43.0)	11 (52.4)		

*$p \leq .1$

Table C.23 Association between past experience factors and resilience to mental ill-health between T2 and T3 for the adults who had been free from mental ill-health at T1, compared with the rest of the cohort

Group 4: Past experiences	**Participants n = 100**	**Resilience to mental ill-health**		***x²* value**	***p*-value**
		No n=79	**Yes n=21**		
T1 life events (%)					
No	51	37 (46.8)	14 (66.7)	2.61	.142
Yes	49	42 (53.2)	7 (33.3)		
T2 life events (%)					
No	31	23 (29.1)	8 (38.1)	.626	.596
Yes	69	56 (70.9)	13 (61.9)		
T3 life events (%)					
No	14	8 (10.1)	6 (28.6)	4.69	.069*
Yes	86	71 (89.9)	15 (71.4)		
Parental divorce in childhood (%)					
No	92	74 (93.7)	18 (85.7)	1.43	.359
Yes	8	5 (6.3)	3 (14.3)		
Abuse or adversity in adulthood (%)					
No	86	66 (83.5)	20 (95.2)	1.88	.289
Yes	14	13 (16.5)	1 (4.8)		

Former long-stay hospital resident (%)					
No	82	63 (79.7)	19 (90.5)	1.29	.348
Yes	18	16 (20.3)	2 (9.5)		

*$p \leq .1$

Table C.24 Association between health & disabilities factors and resilience to mental ill-health between T2 and T3 for the adults who had been free from mental ill-health at T1, compared with the rest of the cohort

Group 5: Health & disabilities	**Participants n = 100**	**Resilience to mental ill-health**		**x^2 value**	***p*-value**
		No n=79	**Yes n=21**		
Urinary incontinence (%)					
No	68	50 (63.3)	18 (85.7)	3.83	.066*
Yes	32	29 (36.7)	3 (14.3)		
Impaired mobility (%)					
No	78	59 (74.7)	19 (90.5)	2.41	.148
Yes	22	20 (25.3)	2 (9.5)		
Visual impairment (%)					
No	53	42 (53.2)	11 (52.4)	.004	1.00
Yes	47	37 (46.9)	10 (47.6)		
Hearing impairment (%)					
No	70	56 (70.9)	14 (66.7)	.141	.790
Yes	30	23 (29.1)	7 (33.3)		
ASD (%)					
No	92	72 (91.1)	20 (95.2)	.379	1.00
Yes	8	7 (8.9)	1 (4.8)		
Epilepsy (%)					
No	60	47 (59.4)	13 (61.9)	.019	1.00
Yes	39	31 (39.2)	8 (38.1)		

*$p \leq .1$

Onset of new problem behaviour at T3

Table C.25 Association between personal factors and onset of new problem behaviour at T3

Group 1: Personal Factors	**Participants healthy at T1 and T2 n = 81**	**Onset of problem behaviour at T3**		***x²* value**	***p*-value**
		No n= 61	**Yes n=20**		
T1 age (%)					
16-35	32	27 (44.3)	5 (25.0)	4.55	1.00
36-55	36	23 (37.7)	13 (65.0)		
56+	13	11 (18.0)	2 (10.0)		
Gender (%)					
Male	39	31 (50.8)	8 (40.0)	.706	.448
Female	42	30 (49.2)	12 (60.0)		
Level of ID (%)					
Mild	37	30 (49.2)	7 (35.0)	2.58	1.00
Moderate	20	15 (24.6)	5 (25.0)		
Severe	15	11 (18.0)	4 (20.0)		
Profound	9	5 (8.2)	4 (20.0)		
Down's syndrome (%)					
No	59	45 (73.8)	14 (70.0)	.108	.776
Yes	22	16 (26.2)	6 (30.0)		

*$p \leq .1$

Table C.26 Association between lifestyle & support factors and onset of new problem behaviour at T3

Group 2: Lifestyle & support	Participants healthy at T1 and T2 n = 81	Onset of problem behaviour at T3		x^2 value	*p*-value
		No n= 61	Yes n=20		
T1 accommodation (%)					
Paid carer	33	20 (32.8)	13 (65.0)	7.17	1.00
Family carer	35	31 (50.8)	4 (20.0)		
Other	15	10 (16.4)	3 (15.0)		
T2 accommodation (%)					
Paid carer	33	20 (32.8)	13 (65.0)	7.17	1.00
Family carer	35	31 (50.8)	4 (20.0)		
Other	13	10 (16.4)	3 (15.0)		
T2 deprivation Index					
1- most deprived					
2	33	24 (39.3)	9 (44.0)	5.27	1.00
3	28	19 (31.1)	9 (45.0)		
4	8	8 (13.1)	0 (0.0)		
5- least deprived	7	5 (8.2)	2 (10.0)		
	5	5 (8.2)	0 (0)		
T1 smoker (%)					
No	74	55 (90.2)	19 (95.0)	.446	.675
Yes	7	6 (9.8)	1 (5.0)		
T2 smoker (%)					
No	73	54 (88.5)	19 (95.0)	.710	.672
Yes	8	7 (11.5)	1 (5.0)		

*$p \leq .1$

Table C.27 Association between T2 social network & activity factors and onset of new problem behaviour at T3

Group 3: Social networks & activities at T2	**Participants healthy at T1 and T2 n = 81**	**Onset of problem behaviour at T3**		***x²* value**	***p*-value**
		No n= 61	**Yes n=20**		
Contacts past week (%)					
0-20	22	16 (26.2)	6 (30.0)	.814	1.00
21-50	32	23 (37.7)	9 (45.0)		
51-100	19	15 (24.6)	4 (20.0)		
>100	7	6 (9.8)	1 (5.0)		
Angry interaction in past week (%)					
No	70	54 (88.5)	16 (80.0)	1.97	.220
Yes	9	5 (8.2)	4 (20.0)		
Minor disagreement in past week (%)					
No	66	51 (83.6)	15 (75.0)	1.42	.296
Yes	13	8 (13.1)	5 (25.0)		
Enjoyable interaction in past week (%)					
None	8	5 (8.2)	3 (15.0)	.670	1.00
1-10	42	32 (52.5)	10 (50.0)		
>10	28	21 (34.4)	7 (35.0)		
Having a close relationship (%)					
No	11	4 (6.6)	7 (35.0)	10.38	1.00
Yes, 1	16	13 (21.3)	3 (15.0)		
Yes, several	54	44 (72.1)	10 (50.0)		

People trusted with a secret (%)					
None	8	2 (3.3)	6 (30.0)	14.50	1.00
1	8	5 (8.2)	3 (15.0)		
2-5	36	30 (49.2)	6 (30.0)		
>5	20	17 (27.9)	3 (15.0)		
Anyone	7	6 (9.8)	1 (50.0)		
Meets family/ friends for a meal (%)					
Never	12	8 (13.1)	4 (20.0)	1.58	1.00
Yearly	22	17 (27.9)	5 (25.0)		
Monthly	23	19 (31.1)	4 (20.0)		
Weekly	23	16 (26.2)	7 (35.0)		
Meets family/ friends at their home or pub (%)					
Never	10	7 (11.5)	3 (15.0)	.432	1.00
Yearly	16	12 (19.7)	4 (20.0)		
Monthly	18	13 (21.3)	5 (25.0)		
Weekly	37	29 (47.5)	8 (40.0)		
Has family/friends stay overnight at own home (%)					
Never	57	45 (73.8)	12 (60.0)	1.48	1.00
Yearly	16	11 (18.0)	5 (25.0)		
Monthly	8	5 (8.2)	3 (15.0)		
Weekly	0	0 (0.0)	0 (0.0)		
Stays overnight at family/friends home (%)					
Never	52	40 (65.6)	12 (60.0)	.832	1.00
Yearly	21	16 (26.2)	5 (25.0)		
Monthly	5	3 (4.9)	2 (10.0)		
Weekly	3	2 (3.3)	1 (5.0)		

Most social time spent with (%)					
People with ID	15	13 (21.3)	2 (10.0)	.614	1.00
People without ID	12	9 (14.8)	3 (15.0)		
Mix of both	39	31 (50.8)	8 (40.0)		

*$p \leq .1$

Table C.28 Association between past experience factors and onset of new problem behaviour at T3

Group 4: Past experiences	**Participants healthy at T1 and T2 n = 81**	**Onset of problem behaviour at T3**		**x^2 value**	***p*-value**
		No n= 61	**Yes n=20**		
T1 life events (%)					
No	43	28 (45.9)	15 (75.0)	5.12	.038*
Yes	38	33 (54.1)	5 (25.0)		
T2 life events (%)					
No	27	21 (34.4)	6 (30.0)	.133	.790
Yes	54	40 (65.6)	14 (70.0)		
T3 life events (%)					
No	10	8 (13.1)	2 (10.0)	.135	1.00
Yes	71	53 (86.9)	18 (90.0)		
Parental divorce in childhood (%)					
No	75	56 (91.8)	19 (95.0)	.224	1.00
Yes	6	5 (8.2)	1 (5.0)		
Abuse or adversity in adulthood (%)					
No	69	50 (83.6)	19 (95.0)	2.03	.276
Yes	12	11 (18.0)	1 (5.0)		

Former long-stay hospital resident (%)					
No	70	53 (86.9)	17 (85.0)	.046	1.00
Yes	11	8 (13.1)	3 (15.0)		

*$p<.1$

Table C.29 Association between health & disabilities factors and onset of new problem behaviour at T3

Group 5: Health & disabilities	**Participants healthy at T1 and T2 n = 81**	**Onset of problem behaviour at T3**		***x²* value**	***p*-value**
		No n= 61	**Yes n=20**		
Urinary incontinence (%)					
No	59	47 (77.0)	12 (60.0)	2.21	.156
Yes	22	14 (23.0)	8 (40.0)		
Impaired mobility (%)					
No	64	50 (83.6)	14 (70.0)	1.30	.342
Yes	17	11 (18.0)	6 (30.0)		
Visual impairment (%)					
No	44	34 (55.7)	10 (50.0)	.200	.797
Yes	37	27 (44.3)	10 (50.0)		
Hearing impairment (%)					
No	57	44 (72.1)	13 (65.0)	.367	.580
Yes	24	17 (27.9)	7 (35.0)		
ASD (%)					
No	75	57 (93.4)	18 (90.0)	.260	.633
Yes	6	4 (6.6)	2 (10.0)		
Epilepsy (%)					
No	52	39 (63.9)	13 (65.0)	.128	.789
Yes	28	22 (36.1)	6 (21.4)		

*$p\leq.1$

Resilience to problem behaviour at all 3 time points

Table C.30 Association between personal factors and resilience to problem behaviour between T2 and T3 for the adults who had been free from problem behaviour at T1, compared with the rest of the cohort

Group 1: Personal Factors	**Participants n = 100**	**Resilience to problem behaviour**		***x²* value**	***p*-value**
		No n= 39	**Yes n=61**		
T1 age (%)					
16-35	38	11 (28.2)	27 (44.3)	3.56	.065*
36-55	45	22 (56.4)	23 (37.7)		
56+	17	6 (15.4)	11 (18.0)		
Gender (%)					
Male	50	19 (48.7)	31 (50.8)	.042	1.00
Female	50	20 (51.3)	30 (49.2)		
Level of ID (%)					
Mild	38	9 (23.1)	30 (49.2)	8.06	.005*
Moderate	30	14 (35.9)	15 (24.6)		
Severe	19	8 (20.5)	11 (18.0)		
Profound	13	8 (20.5)	5 (8.2)		
Down's syndrome (%)					
No	77	32 (82.1)	45 (73.8)	.921	.466
Yes	23	7 (17.9)	16 (26.2)		

*$p \leq .1$

Table C.31 Association between lifestyle and support factors and resilience to problem behaviour between T2 and T3 for the adults who had been free from problem behaviour at T1, compared with the rest of the cohort

Group 2: Lifestyle & support	**Participants n = 100**	**Resilience to problem behaviour**		***x²* value**	***p*-value**
		No n= 39	**Yes n=61**		
T1 accommodation (%)					
Paid carer	46	26 (66.7)	20 (32.8)	11.15	.000*
Family carer	40	9 (23.1)	31 (50.8)		
Other	14	4 (10.3)	10 (16.4)		
T2 accommodation (%)					
Paid carer	47	27 (69.2)	20 (32.8)	12.97	.000*
Family carer	39	8 (20.5)	31 (50.8)		
Other	14	4 (10.3)	10 (16.4)		
T2 deprivation Index					
1- most deprived	37	13 (33.3)	24 (39.3)	2.13	1.00
2	13	13 (33.3)	19 (31.1)		
3	3	3 (7.7)	8 (13.1)		
4	6	6 (15.4)	5 (8.2)		
5- least deprived	4	4 (10.3)	5 (8.2)		
T1 smoker (%)					
No	92	37 (94.9)	55 (90.2)	.716	.477
Yes	8	2 (5.1)	6 (9.8)		
T2 smoker (%)					
No	90	36 (92.3)	54 (88.5)	.378	.736
Yes	10	3 (7.7)	7 (11.5)		

*$p \leq .1$

Table C.32 Association between T2 social network & activity factors and resilience to problem behaviour between T2 and T3 for the adults who had been free from problem behaviour at T1, compared with the rest of the cohort

Group 3: Social networks & activities at T2	**Participants n = 100**	**Resilience to problem behaviour**		***x²* value**	***p*-value**
		No n= 39	**Yes n=61**		
Contacts past week (%)					
0-20	27	11 (28.2)	16 (26.2)	2.42	1.00
21-50	41	18 (46.2)	23 (37.7)		
51-100	23	8 (20.5)	15 (24.6)		
>100	7	1 (2.6)	6 (9.8)		
Angry interaction in past week (%)					
No	83	29 (74.4)	54 (88.5)	5.34	.025*
Yes	15	10 (25.6)	5 (8.2)		
Minor disagreement in past week (%)					
No	77	26 (66.7)	51 (83.6)	5.45	.025*
Yes	21	13 (33.3)	8 (13.1)		
Enjoyable interaction in past week (%)					
None	9	4 (10.3)	5 (8.2)	.075	1.00
1-10	53	21 (53.8)	32 (52.5)		
>10	35	14 (35.9)	21 (34.4)		
Having a close relationship (%)					
No	14	10 (25.6)	4 (6.6)	7.84	.003*
Yes, 1	22	9 (23.1)	13 (21.3)		
Yes, several	64	20 (51.3)	44 (72.1)		

People trusted with a secret (%)					
None	11	9 (23.1)	2 (3.3)	11.41	1.00
1	9	4 (10.3)	5 (8.2)		
2-5	46	16 (41.0)	30 (49.2)		
>5	22	5 (12.8)	17 (27.9)		
Anyone	10	4 (10.3)	6 (9.8)		
Meets family/ friends for a meal (%)					
Never	13	5 (12.8)	8 (13.1)	1.25	.367
Yearly	25	8 (20.5)	17 (27.9)		
Monthly	31	12 (30.8)	19 (31.1)		
Weekly	30	14 (35.9)	16 (26.2)		
Meets family/ friends at their home or pub (%)					
Never	11	4 (10.3)	7 (11.5)	.110	1.00
Yearly	19	7 (17.9)	12 (19.7)		
Monthly	22	9 (23.1)	13 (21.3)		
Weekly	48	19 (48.7)	29 (47.5)		
Has family/friends stay overnight at own home (%)					
Never	75	30 (76.9)	45 (73.8)	.137	1.00
Yearly	17	6 (15.4)	11 (18.0)		
Monthly	8	3 (7.7)	5 (8.2)		
Weekly	0	0 (0.0)	0 (0.0)		
Stays overnight at family/friends home (%)					
Never	65	25 (64.1)	40 (65.6)	.357	1.00
Yearly	26	10 (25.6)	16 (26.2)		
Monthly	6	3 (7.7)	3 (4.9)		
Weekly	3	1 2.6)	2 (3.3)		

Most social time spent with (%)					
People with ID	19	6 (15.4)	13 (21.3)	.106	1.00
People without ID	14	5 (12.8)	9 (14.8)		
Mix of both	45	14 (35.9)	31 (50.8)		

*$p \leq .1$

Table C.33 Association between past experience factors and resilience to problem behaviour between T2 and T3 for the adults who had been free from problem behaviour at T1, compared with the rest of the cohort

Group 4: Past experiences	**Participants n = 100**	**Resilience to problem behaviour**		**x^2 value**	***p*-value**
		No n= 39	**Yes n=61**		
T1 life events (%)					
No	51	23 (59.0)	28 (45.9)	1.63	.224
Yes	49	16 (41.0)	33 (54.1)		
T2 life events (%)					
No	31	10 (25.6)	21 (34.4)	.858	.384
Yes	69	29 (74.4)	40 (65.6)		
T3 life events (%)					
No	14	6 (15.4)	8 (13.1)	.102	.774
Yes	86	33 (84.6)	53 (86.9)		
Parental divorce in childhood (%)					
No	92	36 (92.3)	56 (91.8)	.008	1.00
Yes	8	3 (7.7)	5 (8.2)		
Abuse or adversity in adulthood (%)					
No	86	36 (92.3)	50 (82.0)	2.11	.237
Yes	14	3 (7.7)	11 (18.0)		

Former long-stay hospital resident (%)					
No	82	29 (74.4)	53 (86.9)	2.53	.181
Yes	18	10 (2.6)	8 (13.1)		

*$p \leq .1$

Table C.34 Association between health & disabilities factors and resilience to problem behaviour between T2 and T3 for the adults who had been free from problem behaviour at T1, compared with the rest of the cohort

Group 5: Health & disabilities	**Participants n = 100**	**Resilience to problem behaviour**		**x^2 value**	***p*-value**
		No n= 39	**Yes n=61**		
Urinary incontinence (%)					
No	68	21 (53.8)	47 (77.0)	5.89	.018*
Yes	32	18 (46.2)	14 (23.0)		
Impaired mobility (%)					
No	78	28 (71.8)	50 (82.0)	1.44	.322
Yes	22	11 (28.2)	11 (18.00)		
Visual impairment (%)					
No	53	19 (48.7)	34 (55.7)	.471	.542
Yes	47	20 (51.3)	27 (44.3)		
Hearing impairment (%)					
No	70	26 (66.7)	44 (72.16)	.338	.656
Yes	30	13 (33.3)	17 (27.9)		
ASD (%)					
No	92	35 (89.7)	57 (93.4)	.442	.708
Yes	8	4 (10.3)	4 (6.6)		
Epilepsy (%)					
No	60	21 (53.8)	39 (63.9)	.737	.406
Yes	39	17 (43.6)	22 (36.1)		

*$p \leq .1$

The relationship between total PAS-ADD Checklist scores and participation in activities at T3

Table C.35 The relationship between total PAS-ADD Checklist scores at T3 and participation in activities at T3

Measures and/or subscales	Total PAS-ADD Checklist score	
	Spearman's correlation r_s	*p*
INDEX OF COMMUNITY INVOLVEMENT		
Total score	-.080	.431
INDEX OF PARTICIPATION IN DAILY LIVING	-.164	.104
Total score		
GUERNSEY COMMUNITY PARTICIPATION AND LEISURE ASSESSMENT **ALL CATEGORIES** total number of:		
Activities	-.142	.159
Frequent activities	-.133	.189
Supervised activities	.133	.262
Accompanied activities	-.113	.262
Solitary activities	-.043	.668
Peer activities	-.245	.014*
SERVICES total number of:		
Activities	.145	.150
Frequent activities	.132	.192
Supervised activities	.169	.092
Accompanied activities	-.017	.863
Solitary activities	-.030	.768
Peer activities	.038	.707
PUBLIC TRANSPORT total number of:		
Activities	.096	.340
Frequent activities	-.088	.386
Supervised activities	.166	.099
Accompanied activities	-.092	.363
Solitary activities	-.107	.290

Peer activities	-.173	.086
INDOOR LEISURE total number of:		
Activities	-.069	.493
Frequent activities	-.041	.686
Supervised activities	.088	.382
Accompanied activities	-.194	.052
Solitary activities	-.051	.617
Peer activities	-.131	.194
OUTDOOR LEISURE total number of:		
Activities	-.145	.150
Frequent activities	-.225	.025*
Supervised activities	.101	.316
Accompanied activities	-.148	.142
Solitary activities	-.053	.603
Peer activities	-.145	.150
SOCIAL total number of:		
Activities	-.202	.043*
Frequent activities	-.041	.685
Supervised activities	.108	.286
Accompanied activities	-.071	.484
Solitary activities	-.007	.945
Peer activities	-.219	.029*
FACILITIES total number of:		
Activities	-.106	.293
Frequent activities	-.010	.920
Supervised activities	.122	.225
Accompanied activities	-.123	.222
Solitary activities	-.067	.507
Peer activities	.047	.640
COMMUNITY (all categories – indoor leisure) total number of:		
Activities	-.147	.143
Frequent activities	-.128	.205

Supervised activities	.130	.196
Accompanied activities	-.121	.232
Solitary activities	-.070	.489
Peer activities	-.170	.090
TOTAL LEISURE (indoor + outdoor + social) total number of:		
Activities	-.190	.059
Frequent activities	-.135	.179
Supervised activities	.114	.258
Accompanied activities	-.126	.211
Solitary activities	-.058	.569
Peer activities	-.241	.016*
The modified Index of Perceived Social Support		
Total score	-.202	.178

*$p \leq .05$

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