PREVALENCE OF PSYCHOPATHOLOGY AND PATHWAYS TO CARE IN ADOLESCENTS WITH INTELLECTUAL DISABILITIES: A POPULATION STUDY

Thesis submitted to the University of London for the degree of Doctor of Philosophy in the Faculty of Medicine

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ABSTRACT

Background: Adolescents with intellectual disability (ID) and mental health problems are a distinct group with particular difficulties, which need to be addressed. Despite the many studies available on the prevalence of mental health problems in children with intellectual disabilities, very few studies have investigated the prevalence of such disorders in adolescents with ID. Furthermore, there is little information about service provision for this specific age group.

Aim: To investigate the prevalence and presentation of mental health problems in adolescents with intellectual disability in a geographically defined catchment area (West Essex) and to explore the pathways to care available to these adolescents and to their parents.

Method: A cross sectional survey of adolescents aged 12-19 years old was undertaken. The participants were recruited from a wide range of specialist and community services. Structured interviews were conducted with adolescents and their carers and where possible their teachers. A social and health care proforma was also completed.

Results: 75 adolescents were seen in total. The majority (42) had severe/profound intellectual disability. 24% had a history of epilepsy/seizures and 10% cerebral palsy. 50.7% (38/75) had a mental health problem as reported by parents but that increased to 66.7% (50/75) following a clinical assessment. The commonest ICD 10 diagnoses were conduct disorder (21.4%), atypical autism (16%) and hyperkinetic disorder (14.7%). There was moderate agreement between parental reports and clinical diagnoses (kappa=0.51). Caseness was predicted by low levels of adaptive functioning, diagnosis of autism and family history of mental illness. Significant negative correlations were found between subdomain scores of the Vineland Adaptive Behaviour Scale and the Developmental Behaviour Checklist.

In terms of service utilisation, the majority of the participants (94.7% of total sample) were in receipt of health and social care. Almost half of all visits to General Practitioners in the past year were due to the parent seeking help for the young person's behavioural problem. 15% of the adolescents seen were receiving psychiatric medication.

Conclusion: Prevalence rates for mental health problems in adolescents with intellectual disability are high. Adolescents with a diagnosis of autism and low level of adaptive skills appear to be more vulnerable in developing such disorders. Parents and primary health care providers will need targeted mental health promotion and education to recognise problems early and to seek specialist help. Services should co-ordinate their referral and assessment processes in order to meet current and future needs, particularly at the time of transition.

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DEDICATED TO MY FATHER

PART I REVIEW OF LITERATURE

Chapter 1 Introduction

1.1 Definition, aetiology and prevalence of intellectual disability

Intellectual disability (ID) is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence i.e. cognitive, language, motor and social (ICD10) (WHO, 1992). The terminology has changed several times over the years and currently the preferred term in the UK is "learning disabilities". "Mental retardation" is still in use in the United States. To avoid confusion, the term intellectual disability (ID) will be used throughout the text.

The causes of ID are diverse and can be divided in the following categories (Turk, 1996):

Prenatal

- Chromosomal/genetic (e.g. Down's, fragile X, tuberous sclerosis, familial polygenic)
- Metabolic (e.g. PKU, congenital hypothyroidism)
- Maternal malnutrition
- Infections (e.g. Maternal rubella, toxoplasmosis)
- Other maternal physical illness
- Maternal drug and alcohol use

Perinatal

- Oxygen deprivation
- Physical birth trauma

- Complications of prematurity
- Blood-group incompatibility

Postnatal

- Infection
- Head injury
- Intracranial space-occupying lesions
- Uncontrolled epilepsy
- Hormonal and metabolic disorders
- psychological trauma (neglect/deprivation, Rutter et al, 1999)

(For full review of the scientific basis of biological ID see Volkman & Dykens, 2002).

The prevalence of intellectual disability may vary with genetic, cultural, economic, environmental and service factors (Fryers, 1997, p23). Criteria comprise an IQ of less than seventy on individual psychometric assessment, presence of impairments since birth or during the developmental period (<eighteen years of age) and deficits in at least two areas of current adaptive behaviour. Mild Intellectual Disability (ID) (IQ 50-69) is the larger group, its prevalence estimated at approximately three per 100. The prevalence of moderate to profound ID (IQ less than 49 with often additional physical impairments) is estimated at approximately three per 1000 (Feinstein & Reiss, 1996; Bernal & Hollins, 1995; McLaren & Bryson, 1987). A causative factor is evident in the majority of cases with severe ID. Both mild and severe types of ID occur more often in boys (male to female ratio: 2-5:1 and 1.5:1 respectively). ID of unknown aetiology (idiopathic) is

estimated at 45-65% of all cases (Schaeffer & Bodensteiner, 1992). Epidemiological data also suggest that while severe ID is not associated with ethnic or socio-economic factors, mild ID occurs more frequently in socially disadvantaged groups (Flint & Wilkie, 1996).

Increased rates of mental health problems in people with intellectual disabilities across the lifespan have been frequently reported. Prevalence rates are particularly raised for psychotic disorders and schizophrenia (Deb et al, 2001) but are also elevated for personality disorders and problem behaviours (Flynn et al, 2002).
For the purpose of this project the literature review included all epidemiological studies on children and adolescents with ID which had been published from 1960 to 2002. The following electronic databases were searched: MEDLINE, EMBASE, PSYCHINFO. The papers that were obtained were hand-searched in order to identify references to additional relevant studies. I will first report on the findings of the studies and then summarise methodological shortcomings in the published literature in a separate chapter at the end of this section (chapter 2).

1.2 Mental health and intellectual disability-early epidemiological studies

Rutter et al (1970), in the widely reported Isle of Wight (IoW) study of 10 and 11 year old children with neuro-epileptic conditions, established the strong association between psychiatric problems and brain abnormalities and the inverse relationship between IQ and psychiatric disorder. The study, based on parent and teacher reports, showed that the rate of psychiatric disorder increases as intellectual level decreasesThe study included also children with what was then called mental subnormality, i.e. children who were not in the educational system because of their low intellectual ability (IQ<50). Those children were investigated in a separate sub-group. It was hypothesised that the rates of psychopathology in that group would be greater than the rates for children with and without neuroepileptic conditions, as children with severe ID were almost certain to have a serious degree of brain abnormality.

The results of the IoW study showed that in the general population of 10 and 11 year olds, the prevalence of psychiatric disorders was approximately 6.6%. This rate increased to 11.6%, in those with additional disorders such as sensory deficits and further increased to 34.3% in the group with the neuro-epileptic conditions. The commonest diagnoses in the latter group of children were neurotic disorders and antisocial or conduct disorder followed by mixed disorder, hyperkinetic syndrome and psychosis.
However, when the children with severe ID were examined (n=38), 50% were found to suffer with a psychiatric problem, although it was difficult to make such a diagnosis in some of the more severely affected children. The commonest diagnoses found were hyperkinetic syndrome and "psychosis". Neurotic or conduct disorders were less frequently seen. The authors acknowledge that psychiatric disorders are "*much more frequent in children with severe intellectual retardation*" but the comparison of rates of such disorders has not been tested statistically.
The IoW study revealed that apart from the level of intellectual ability, other factors also played an important role in the onset of childhood psychiatric problems. For example, the degree of disability, use of drugs with psychological side-effects, frequent

hospitalizations, social and family circumstances and possibly stigmatization are now well known risk factors associated with the onset of mental disorders. These factors have been investigated to a limited extent in subsequent studies.

The interactions that create the increase in likelihood for a young person with ID to develop mental health problems are complex and occasionally controversial. More recent studies have shown associations between psychological factors such as distorted self-image, "failure experiences" and personality types and the development of psychological difficulties (Dykens, 2000; Feinstein and Reiss, 1996). Similarly, Eaton et al (2001) argued that familial factors, probably related to the child's type of psychopathology, social factors such as stigma, exploitation and exclusion from peer related activities and networks and likely biological factors can create specific vulnerabilities which are in turn associated with the onset of psychopathology in this age group.

Corbett (1977) carried out one of the first epidemiological studies of children with ID in the UK using a service register. He investigated 140 children up to fifteen years of age with severe ID in Camberwell, South London, UK. Nearly half of the children in that sample presented with a psychiatric disorder such as childhood psychosis or autism, severe stereotypies, adjustment reaction, conduct disorder, neurotic disorder and hyperkinetic disorder classified according to the ninth edition of the World Health Organisation International Classification of Diseases (ICD9).

Many of the children with those diagnoses had a history of a co-existing organic disorder, for example neurodegenerative disorders, perinatal infections or intractable epilepsy.

The definition of psychosis for diagnostic purposes is rather unclear. Rutter et al suggest that there is an association with profound intellectual disability and/or brain pathology (p 190). It has also been postulated that the old usage of the term childhood psychosis would include children who would now receive a diagnosis of autism, not just those with extremely early onset schizophrenia and severe mood disorders. This is borne out by Corbett in his description of the symptoms most commonly occurring in children with severe ID. The diagnosis of psychosis includes delayed speech, echolalia, loss of skills or regression in behaviour in early childhood, stereotyped patterns and ritual, lack of imaginative play and social interaction. Other terms used for this condition are disintegrative psychosis, Heller's disease or dementia infantilis which are also associated with degenerative process and other organic pathology such as viral encephalopathies or intrauterine infections of the fetus.

In summary, these two early UK studies establish that children with severe ID (IQ<50) show high rates of psychopathology. However only the IoW study compared the small number of children with severe ID both with peers of normal intelligence and those with mild ID. Therefore, the finding of higher rates of psychopathology in this group of children is based on comparative data from one epidemiological study. Diagnoses of hyperkinesis, autism and childhood psychosis are over-represented in this group. Details of the studies are shown in table 1.

Table 1: Intellectual disability and mental health-early epidemiological studies

Author (country, year)	Study design and sample details	Definition of psychiatric disorder	Prevalence
Rutter et al (Isle of White, UK, 1970)	Community survey. 237 children with physical and neuroepileptic disorders aged 10-11 year with IQ >50 and 38 children with IQ<50 Control group from the general population	In mild and moderate IQ: Neurotic, antisocial/conduct, mixed conduct and neurotic disorder were the commonest diagnoses. However in those with severe ID, hyperkinetic syndrome, child psychosis (infantile, regressive, schizophrenia, manic-depressive) were more prevalent	34.3% (28.6-58.3%) for children with neuroepileptic conditions increasing to 50% in the children with severe ID. Concluded that rates of psychopathology are higher in the children with neuroepileptic conditions and the subgroup of children with IQ<50
Corbett (UK, 1977)	Sample drawn from ID register. No controls. 140 children 15 years old or younger with IQ<50 (descriptive)	Used definitions from ICD 9 multiaxial scheme. Adjustment reaction, conduct disorder, neurotic disorder, isolated habit disorder, severe stereotypies and pica, hyperkinetic behaviour disorder, childhood psychosis	47% (95% CI 38.8,55.2) had a psychiatric disorder

1.3 Prevalence of psychopathology in children with Intellectual Disabilities

Several other studies in the last thirty years have examined the prevalence of mental disorders including behavioural problems, in children with ID.
More recent community based surveys have used larger epidemiological samples and diagnoses of psychiatric problems are commonly made by checklists or behavioural scales. The most important of those studies are discussed below:

Quine (1986) studied the problem behaviours of 399 children aged 0 to 16 years with severe ID from two health districts in South England. The children were assessed with the Disability Assessment Schedule, a carer completed instrument designed to elicit information on impairments, skills and behaviour problems in children with ID. The findings showed that approximately 45% of the sample had behaviour problems such as overactivity, temper tantrums, aggression, destructiveness and self-injury. However, there was no comparison group.

Einfeld and Tonge (1996) investigated 527 children with all levels of ID aged 4 to 16 years who were identified from an epidemiological sample across several Australian regions. The authors used the Developmental Behaviour Checklist (DBCL) which was specifically developed for this population in order to determine caseness, that is, whether a child or adolescent was in further need of psychiatric or specialist assessment and treatment. The authors reported a prevalence of 40.7% of psychiatric problems in their sample. Again, no comparison group was used.

Linna et al (1999) examined a birth cohort of 6000 children aged 8 years, 1.5% of whom attended special needs schools (for the "*educationally subnormal*" and training schools for children with ID). There was no specific ascertainment of level of ID. Psychopathology was measured by the Rutter Parent and Teacher Questionnaire and the Children's Depression Inventory. Rates of all childhood psychiatric disorders were significantly increased in the sample of children with ID than in those without (32.2% versus 10.8% respectively, p<0.001). The rate of psychiatric disorders was raised in both groups of children though it remained significantly higher in the group of children with ID (50% versus 24%, p<0.001). Rates of depressive, behavioural and mixed disorders were significantly higher in the group with ID.

Strømme and Diseth (2000) examined 178 children with both mild and severe ID in Norway aged eight to thirteen years. All children had received psychometric assessments to ascertain level of ID. Thirty-seven per cent (95% CI 29,44) of them were diagnosed with a psychiatric disorder according to ICD 10. Children with a biomedical condition (defined as genetic, bio-familial, other abnormality) were at significant risk of developing a psychiatric disorder compared to those with unspecified ID (OR=4.3, p=0.003). Also male children were at higher risk of developing a psychiatric disorder compared to their female counterparts (OR=2.1, p=0.04).

Children with severe ID had higher rates of psychopathology compared to children with mild ID (42% versus 33% respectively, non significant). The commonest disorders were hyperkinesis and pervasive developmental disorder.

Emerson (2003) carried out a secondary analysis on a national sample of children with and without ID in the UK. The sub-group of children with ID was part of the sample who participated in a wider survey of emotional disorders in children and adolescents in the United Kingdom (Meltzer et al, 2000).

The decision whether a child or young person had ID was taken if it was known that the parents were concerned about the child's language development in early childhood and that the child was reported to have learning "difficulties" or that the child had attended a school for children with learning difficulties. However, children were then excluded from this group if there was information on school performance that suggested they had average ability or if they had not received a statement of educational needs. It is likely that most of these children and young persons had at least a mild (or a more severe) level of ID.

Psychiatric diagnoses were identified with the Development and Well Being Assessment Questionnaire (Goodman et al, 2000) which generates ICD 10 diagnoses of childhood disorders.

Any type of mental illness was identified in 39% of the children with ID compared to 8.1% in the children without ID (OR=7.3, 95% CI 5.6-9.4). It was also shown that conduct disorder, anxiety disorder, ADHD/hyperkinesis and pervasive developmental disorders were significantly more common in children with ID. Significant associations were reported between psychopathology in the child and factors such as age, gender, family characteristics, carer's mental health and child management practices.

In summary, more recent epidemiological studies have used a combination of behavioural checklists which have been developed specifically for use in the population of children and young persons with ID as well as pre-existing categorical classification systems (ICD 10) to diagnose psychiatric disorders in this population. Only two (Emerson, 2003; Linna et al, 1999) of the five studies reported in this section have used a comparison group of individuals with average or near average IQ.

The rates of psychopathology reported vary from 32.2% (Linna et al, 1999) to 45% (Quine, 1986) . Rates appear to be elevated in those with ID but only two studies have shown this to be significantly statistical when compared to their counterparts without ID (Emerson, 2003; Linna, 1999).

The most recent published report, a secondary analysis of a sub-group from the national survey of children in the UK, showed that affective disorders, hyperkinetic syndrome and PDD are the commonest specific conditions. However, the results of this study should be treated with caution because the definition of ID was made arbitrarily and may not reflect the wider population of children with ID.

Details of the studies are presented in table 2.

Table 2: Prevalence of mental disorders in children and adolescents with ID <16 years

Author (country, year)	Study design and sample details	Definition of psychiatric disorder	Prevalence
Quine (UK, 1986)	Community survey. No controls. 399 children aged 0-16 years with *severe ID* ascertained by psychometric testing	Behavioural problems assessed with the Disability Assessment Schedule. Overactivity, temper tantrums, aggression, destructiveness, self-injury	45% (95% CI 40.11,49.9)
Einfeld &Tonge (Australia, 1996)	Epidemiological study. 527 children aged 4-16 years across the *full ID* range ascertained by psychometric testing	Behavioural problems assessed with Developmental Behaviour Checklist.	40.7% (95% CI 37,45)
Linna et al (Finland, 1999)	Epidemiological sample. Normal controls. 90 children 8 years old attending special schools. No psychometric testing	Used the Rutter Parent & Teacher Questionnaire and the Children's Depression Inventory.	32.2% . Including results from all three assessments increased the rates of disorders to 50% but the increase also occurred in the children without ID.
Strømme & Diseth* (Norway, 2000)	Epidemiological sample. 178 children aged 8-13 years across the *full ID range*. Ascertainment of ID with psychometric testing.	Neurodevelopmental examination, ICD10 diagnoses.	37% overall. Ranged from 33% in children with mild ID to 44% in children with severe ID.
Emerson *(UK, 2003)	Secondary analysis of the 1999 survey of mental health of children and adolescents No formal ascertainment of ID N=264	Psychopathology assessed with the Development and Well Being Assessment, DSM IV and ICD 10 diagnoses. Additional family functioning measures	39% had any diagnosable mental illness, higher than in their peers without ID (8.1%)

*: rates of psychiatric disorders were significantly greater than rates of such disorders in children without ID

1.4 Prevalence of psychopathology in clinic and service register populations of children and adolescents with ID

The studies included in this section can be broadly divided in two categories:

Clinic-based studies

The earliest study is by Menolascino (1969) who reported his findings on a clinic sample of 256 children with ID aged from 1.6 to 14.2 years. 177 (69%) children were diagnosed with chronic brain syndromes with behavioural and or psychotic reactions. Other disorders included functional psychosis, personality disorders, adjustment reaction and unspecified psychiatric disorder. The authors further described the symptoms of the group with psychosis thus:

"...Between age two and one half and four years the quality of their personality adjustment underwent an insidious change toward withdrawal, bizarre motor posturing (or ritualistic mannerisms), marked preoccupation with certain inanimate objects, echolalic speech and global regression of previously acquired social adaptive skills....Thus we felt that they represented instances of a schizophrenic adaptation with associated regressive phenomena occurring against the backdrop of delayed early developmental milestones".

Phillips and Williams (1975) studied 100 children with ID who were consecutive referrals to a specialist psychiatric clinic in California. Children with severe ID tended to be referred earlier in their lives for service input. A total of 87 children were found to suffer with an identifiable mental disorder (38 with psychotic conditions including autism and 49 with neurotic disorders including depressive and anxiety symptoms, behavioural and personality problems).

Studies based on service register populations

Service registers provide an administrative prevalence of ID in the area population but are also liable to inclusion bias.

Jacobsen (1982) found high levels of hyperkinesis, self-injury, affective problems and aggression among children with moderate and severe ID (48% and 66% respectively) in a service register survey of 8,784 individuals with ID, in New York State. Cases were identified with the Behaviour Problem Checklist.

Koller et al (1983) in a retrospective study of case notes of young adults with all levels of ID found an association between higher level of ID and behaviour disturbance. However, approximately a fifth of the study sample had borderline intelligence; it was this group that presented with the highest psychiatric morbidity. In addition, 61% of the sample was reported to have had a behaviour disturbance in childhood, which appeared to continue after leaving school (59%).

Hoare et al (1998) carried out a cross sectional survey of psychosocial adjustment in children and their families with severe and profound ID drawn form the Lothian Special Needs Register. Presence of psychopathology was measured by the Developmental Behaviour Checklist (DBCL-parent version). 143 carers (of 145 children) were interviewed. 38% of children met the DBCL criteria for caseness. Behavioural disturbance was shown to increase with increasing ID and disability level.

Cormack et al (2000) interviewed the parents of 123 children and adolescents who attended local special needs schools using the DBCL-parent version. The children and young persons had severe ID. 50.4% were reported to have a psychiatric disorder as reported by the child's parents.

Molteno et al (2001) studied a sample of 355 children and adolescents with a full range of ID in South Africa identified from special school attenders. The authors used the Developmental Behaviour Checklist (teacher version). The authors used a much lower cut-off point to indicate caseness (of 30) than that recommended by Einfeld and Tonge (of 46). They reported rates of psychopathology of 31% in the total sample.

In summary, studies of selected populations of children and young persons with ID show a wide variation in the rates of psychopathology, from as low as 31% (Molteno et al, 2001) to 87% (Phillips & Williams, 1975). Almost all of these studies have used behavioural scales to assess psychopathology.

Details of the studies are shown in table 3.

Table 3: Studies based on clinic samples and service register populations

Author (country, year)	Study design and sample details	Definition of psychiatric disorder	Prevalence
Menolascino (USA, 1969)*	No controls. 256 children 15 years old or younger across *full ID range* ascertained by an interdisciplinary team, might have included psychometric testing	Behavioural disturbance, functional psychosis, personality disorders, adjustment reaction, psychiatric disorder-other	69% (95% CI 63.4,74.7)
Phillips & Williams (USA, 1975)*	No controls. 100 consecutive referrals to specialist clinic across *full ID range* ascertained by psychometric testing	Psychosis (inclusive of autism), neurotic disorders (anxiety, depression, behavioural and personality disorders)	38% were diagnosed with psychosis and 49% with neurotic disorders
Jacobsen (USA, 1982)†	Survey of children and adults on ID register (n=8784 <21 years)	Behaviour Problem Checklist	48-66% found to have a behavioural problem. Rates increased with decreasing IQ.
Koller et al (UK, 1983) †	163 young adults receiving services. *Full range of ID.* Retrospective account of behaviour problems before and after school leaving. A fifth of the participants had borderline intelligence	Behavioural problems were classified into emotional and conduct disorders	Prevalence of 61% pre- and 59% post school. Highest rates were in the subgroup of mild ID or borderline intelligence. Severe ID was associated with hyperactivity and aggression
Hoare et al (UK, 1998) †	Cross sectional survey. 145 children over 3 years of age included. *Severe and profound ID* as defined by the register	Developmental Behaviour Checklist (parent interview)	38% met criteria for caseness
Cormack et al (UK, 2000) †	123 children 4-18 years old attending special schools. *Severe ID* defined by service register	Developmental Behaviour Checklist (parent interview)	50.4% were reported to be cases
Molteno et al (South Africa, 2001) †	355 children and adolescents aged 6-18 years old from special schools with *full ID range* defined by service register	Developmental Behaviour Checklist (teacher interview)	31% were reported to be cases. Antisocial behaviour prominent in mild ID

*: studies based on clinic samples, †: studies based on service register populations

1.5 Prevalence of psychopathology in adolescents with ID

The most rigorously carried out study in a population of young persons with ID is by Gillberg et al (1986). Diagnoses were made either according to DSM-III or through operationalised criteria for problems such as emotional disorder which were devised for the study. In an epidemiological survey of 149 adolescents with all levels of ID aged 13-17, the authors found that 57% of the adolescents with mild ID and 64% of those with severe ID suffered from a handicapping psychiatric condition which also included the notion of social impairment. Severe ID included all young person with an IQ below 50. As with earlier studies, the commonest disorder identified in those with severe ID was "psychotic behaviour" (50%) which incorporated schizophrenia, infantile autism, and language and social impairment. This was also the commonest disorder in those with mild ID (14%) followed by conduct disorder (12%), hyperactive disorder (11%) and emotional disorder (10%).

The study is summarised in table 4.

Table 4: Psychiatric disorders in adolescents with ID

Author (country, year)	Study design and sample details	Definition of psychiatric disorder	Prevalence
Gillberg et al (Sweden, 1986)	Epidemiological sample. 149 adolescents aged 13-17 years across the *full ID range* ascertained by psychometric testing	DSM III as well as operational criteria for emotional disorders	57% in adolescents with mild ID and 64% in adolescents with severe ID (mainly "autism-like psychotic behaviour")

1.6 Rates and correlates of specific mental disorders in children and adolescents with Intellectual Disabilities

These studies are of interest because on the one hand they are novel in their approach of investigating the presentation of common childhood disorders in young persons with ID. On the other, despite the limited data, they contribute to the gradual development of an explanatory psychosocial model for the onset of common childhood disorders in this population.

Depressive disorders

A few studies have examined the prevalence of depression in young persons with ID.

Matson et al (1988) presented the first study of depression in children with ID who had been hospitalised for emotional disturbance. Level of ID was ascertained by psychometric testing. They compared this group with thirty-one children of normal intelligence matched for age and sex but without history of emotional disorder. Psychiatric diagnoses were based on DSM-III but the Child Depression Inventory (CDI) and the Child Behaviour Profile Scores were also used as diagnostic aids. They found that having ID was significantly associated with total CDI score, affective behaviour (CDI factor I) and guilt/irritability (CDI factor IV).

Manikam et al (1995) compared self-reported measures of depression and general psychopathology (measured by the Psychopathology Instrument for Mentally Retarded Adults-PIMRA) in adolescents with and without ID. The participants were aged 13 to 17 years and the IQ ranged from above normal intelligence to moderate ID. They found that as IQ level decreased, the mean scores for depressive and other psychiatric symptoms increased. In particular, the highest mean scores on the depressive measures were reported by those with mild ID whilst those with moderate ID level reported other types of psychopathology. The authors comment on the impact of intellectual ability on the psychological adjustment of young individuals.

Attention Deficit Hyperactivity Disorder

Epstein et al (1986) in a case control study of children with different types of learning difficulties and ID showed that 19.7% of boys and 15.7% of girls with ID scored above the cut-off point on the Conners' Abbreviated Symptom Questionnaire. However, there was no formal diagnosis of ADHD.

Fee et al (1994) compared four groups (25 children in each group) of boys aged six to eight years with and without ID and attention deficit hyperactivity disorder (ADHD). Level of ID was assessed by psychometric testing. They reported that the boys with ID and ADHD showed significantly higher rates on the conduct problem factor, the hyperactivity factor and the hyperactivity index when compared to the groups of non

ADHD children with and without ID. This was similar to the findings in the group of children with ADHD but without AD. The authors argue that established ADHD diagnostic symptoms may also be used to diagnose the disorder in children with ID.

In summary, these studies show patterns of symptoms and correlates of mental disorders in young persons with ID. In particular, depressive symptoms as well as symptoms of ADHD may be seen in children and young persons with ID and that current diagnostic instruments can be used to aid such diagnoses either in clinical practice or research in this population.

The studies are summarised in table 5.

Table 5: Prevalence of specific mental disorders in children and adolescents with ID

Author (country, year)	**Study design and sample details**	**Definition of psychiatric disorder**	**Prevalence**
Matson et al (USA, 1988)*	Matched case control study of children with and without ID (n=62). Inpatient sample aged 3-16 years	Child Depression Inventory and Child Behaviour Profile. Also measured total psychopathology including schizophrenia and hyperactivity	Depression was more prevalent in the children with ID. Depressed children and adolescents had significantly higher rates of problem behaviours
Manikam et al (USA, 1995)*	Study of 100 adolescents aged 13 to 17 years of adolescents with *(mild to moderate)* and without ID aged 13-17	Children's Depression Inventory, Reynolds Adolescent Depression Scale, Bellvue Index of Depression, Psychopathology Instrument for Mentally Retarded Adults (PIMRA) as well as assessment of skills and adaptive behaviour	Adolescents with mild ID reported higher rates of depression. Higher rates of general psychopathology were found in the moderate ID group. Depression correlated positively with lack of adaptive skills and lower intellectual functioning
Epstein et al (USA, 1986)†	Case control study of children with ID only, behavioural disorders only, learning difficulties and non ID children	Conner's Abbreviated Symptom Questionnaire	14.3-21.4% of children with ID met criteria for caseness
Fee et al (USA, 1994) †	Case control study of 4 groups of boys with and without ID and ADHD (n=100). Level of ID ascertained by psychometric testing	Conner's Teacher Rating Scale DSM III-R	Boys with ID and ADHD show similar symptom profile to boys with ADHD but without ID

*: studies of depressive disorder, †: studies of hyperactivity disorder

1.7 Rates of psychopathology and patterns of symptoms in children and young persons with ID with genetic conditions, pervasive developmental disorders, motor disorders and epilepsy

1.7.1 Behavioural phenotypes

A new line of inquiry has emerged in the study of mental disorders in individuals with ID in the last ten years or so. Research has focussed on the association between specific syndromes and their behavioural or psychiatric correlates. Such studies therefore, investigate the behavioural phenotype of a syndrome, that is, the possible presence of distinctive behaviours that occur in almost every case of the condition and rarely in other conditions. It is postulated that the behaviours have a direct and specific relationship to the genetic anomaly causing the physical manifestations of the condition (Flint & Yule, 1994).

The most researched syndromes are Fragile X (Turk, 1998; Einfeld et al, 1999a, 1994) in terms of inattention, anxiety and association with autism; Down Syndrome (Dykens et al, 2002; Gath & Gumley, 1986) regarding oppositional disorders, inattention, stubborness and withdrawal; Williams syndrome (Einfeld et al, 2001; Davies et al, 1998) regarding communication disorders, social disinhibition and anxiety and Prader-Willi syndrome (Clarke et al, 2002; Einfeld et al, 1999b) regarding self-injury and psychiatric symptoms such as obsessions and compulsive acts.

These studies were mainly set out as case control studies comparing the behavioural profile of young persons with the syndrome of interest with matched controls of young persons with Down syndrome and idiopathic ID (Einfeld et al, 1999b; Turk, 1998;

Dykens et al, 2002; Gath & Gumley, 1986). Longitudinal follow-up studies have also been used to investigate the persistence of behaviours over time (Clarke et al, 2002; Einfeld et al, 2001; Einfeld et al, 1999a, 1994).

1.7.2 Motor disorders and cerebral palsy

Goodman (1998) carried out a longitudinal study of 328 children aged 16 years and under who were recruited from the London Hemiplegia Register. He found that psychiatric problems identified at baseline had persisted four years later and furthermore, about a third of the children who were free of psychiatric problems initially were classified as cases at follow up. The author concluded that psychiatric complications are a common and persistent difficulty in children with this neurological condition and are likely to require early intervention strategies.

1.7.3 Pervasive developmental disorders

Tonge et al (1999) explored the behavioural profile of children and adolescents with high functioning autism (n=75) and Asperger syndrome (n=52). The authors found that controlling for age and level of ID, the young persons with Asperger syndrome were more disruptive, antisocial and anxious as reported by parents (DBCL-primary carer version) compared to their counterparts with a diagnosis of autism.

1.7.4 Epilepsy and ID

Steffenburg et al (1996) examined the rate and type of psychiatric disorders in a sample of 98 children with ID and active epilepsy in Sweden. The authors used several diagnostic instruments to detect psychiatric and pervasive developmental disorders. 59% of the children had at least one psychiatric diagnosis. Autism and autistic-type conditions were prevalent in 38% of the sample (27 % and 11% respectively). However, a more recent epidemiological study of 115 children and young persons with ID with and without epilepsy (Lewis et al, 2000), found no differences in psychopathology between participants with and without epilepsy. Furthermore, participants who were receiving treatment for epilepsy did not differ on measures of psychopathology from those not receiving medication.

In summary, there is limited information on the psychiatric profile of genetic syndromes and other disorders associated with ID. From the available evidence, the following conclusions can be drawn:

young persons with Down syndrome may be relatively free from extreme behaviours compared with children with other types of ID but who have higher rates of psychopathology compared to children without ID; children with fragile X and Prader-Willi syndrome show behaviours that correspond with the proposed behavioural phenotype, i.e. children with fragile X are more inattentive and hyperactive whereas those with Prader-Willi appear to have high prevalence of compulsive acts, hoarding and antisocial behaviours.

Williams syndrome appears to be associated with increased levels of anxiety and inattention.

High functioning autism appears to differ from Asperger syndrome in terms of the latter being associated with disruption, antisocial and anxious behaviour.

Children with epilepsy and ID appear to have high rates of psychiatric problems including pervasive developmental disorder though this was not replicated in subsequent studies. Children with cerebral palsy show increased problem behaviours and pervasive developmental disorders, which may carry on as they grow older.

The most important of these studies are shown in table 6.

Table 6: Prevalence of psychopathology in genetic conditions

Author (country, year)	Study design and sample details	Definition of psychiatric disorder	Prevalence
Gath & Gumley (UK, 1986)	A matched case control study of 193 children aged 6 to 17 years with Down syndrome compared with 154 children with other types of ID and with 101 children without ID	Rutter parent and teacher scales Adaptive Behaviour Scale Clinical interview (ICD 9)	Children with ID had the highest rates compared with the group with Down syndrome and without ID (36% vs. 30% vs. 12%)
Einfeld et al (Australia, 1994)	Matched case control study of 48 children and young adults with Fragile X compared with 454 young people with ID.	Developmental Behaviour Checklist	The Fragile X group were significantly more shy avoided eye contact but less antisocial behaviours
Steffenburg et al (Sweden, 1996)	Population based survey. 98 children aged 8 to 16 years with ID and active epilepsy across *full ID range*	Handicap, Behaviour and Skills Schedule plus clinical interview Swedish Autism Rating Scale and Autism Behaviour Checklist Asperger Syndrome Diagnostic Checklist Global Assessment of Functioning Scale Occupational Functioning Assessment Scale	59% had at least one psychiatric diagnosis, 38% had either true autism or autistic like symptoms. In 33% with profound ID no diagnosis could be made.
Goodman (UK, 1998)	Longitudinal survey of 328 children of school and preschool age recruited for the London Hemiplegia Register Data on at least one questionnaire were available at 4 year follow up	Behaviour Checklist Preschool Behaviour Checklist Rutter Behaviour Screening Questionnaire Conners Teacher Rating Scale	Continuity of psychiatric disorders in 70% of children 30% new cases diagnosed at follow up
Turk (UK, 1998)	Case control study of 49 boys with Fragile X compared with 45 boys with Down	Childhood Behaviour Checklist (parent & teacher) Parental Account of Childhood Symptoms	Boys with Fragile X were found to have significantly higher scores on

	syndrome and 42 boys with ID of unknown aetiology	MRC Schedule of Handicaps, Behaviour and Skills	restlessness, hyperactivity and inattention
Einfeld et al (Australia, 1999a)	Matched case control study of 46 cases with Prader-Willi syndrome compared with 454 cases with ID of other aetiology	Developmental Behaviour Checklist	Persons with Prader-Willi syndrome had significantly increased antisocial behaviour than controls
Clarke et al (UK, 2002)	Epidemiological survey of compulsive and ritualistic behaviours in children and adults with Prader-Willi syndrome. 33 out of 65 persons identified, were aged 16 or younger. Full range of ID	Prader-Willi Structured Interview Questionnaire Developmental Behaviour Checklist Aberrant Behaviour Checklist Vineland Adaptive Behaviour Scale Weschsler intelligence scales	Significantly more people with Prader-Willi syndrome had ritualistic and compulsive behaviours such as need to ask or tell (49.1% vs. 13,8%); routines (29.8% vs. 12.1%), hoarding (21.1% vs. 3%)

1.8 Prevalence of psychiatric disorders in children and adolescents without Intellectual Disabilities - UK

The most recent survey in the UK to examine the mental health of children and adolescents in Great Britain (Meltzer et al, 1999) showed that 10% of all children aged 5 to 15 years have a mental disorder. The study generated ICD 10 and DSM IV diagnoses of mental disorders using the Development and Well Being Assessment (Goodman et al, 2000). The commonest disorder identified was conduct disorder (5%), followed by emotional disorders (4%) and hyperactivity (1%). Male gender and living in a low-income household with single parents appear to predispose or to precipitate the onset of mental disorder.

A further follow up study of that sample (Goodman et al, 2002) showed that conduct disorder and hyperkinesis persisted in 73% of the children at 18 months follow up. Emotional disorders may also persist but to a lesser degree (only 36% of children had symptoms).

Chapter 2 Critical appraisal of previous studies

2.1 Methodological considerations of previous studies

2.1.1. Current findings from the literature

The investigation of emotional and behavioural problems in children and adolescents with an ID reflects the heterogeneity of the population under study. Children and adolescents with ID suffer from a variety of conditions, which are occasionally of a clear neuro-biological nature but most often are thought to be the result of complex interactions between contributing biological and social factors.

The prevalence studies that have been mentioned cover all published reports to the best of the researcher's knowledge. Data on prevalence include the whole range of ID levels, children as well as adolescents and in older studies adults.

It is evident that there is substantial variability in the rates of psychopathology, which are reported in the literature. Firstly, the prevalence of emotional and behavioural problems reported appears to be consistently high, and in studies where there have been comparisons with a control group of children of normal intelligence generally higher. Rutter et al's (1970) original conclusion that organic brain disorders increase the young person's vulnerability to develop psychiatric disorders has also been borne out by the published studies.

In summary, the prevalence figures range from 30% to 87%. Elevated rates reflect studies of hospital or clinic based populations and lower rates mostly community based samples.

In terms of the nature of the psychiatric disorders, children and adolescents with additional organic brain conditions and severe intellectual disability appear to suffer with higher rates of psychopathology. Disorders that have been commonly described in this group include infantile or childhood psychosis, autism-type psychosis or autistic relating, stereotypies, overactivity, self-injury, communication deviance and being self-absorbed.

Children and adolescents with mild ID show a different profile which resembles the psychiatric problems found in their peers of normal intelligence. They are reported to be more disruptive and antisocial and to suffer with anxiety, depression and other common childhood psychiatric disorders.

Within syndromes comparisons show that constellations of behaviours are more prominent in some syndromes (see section 1.7, p 35) and that psychiatric disorders are likely to run a longitudinal course (Einfeld et al, 1999; Goodman, 1998).

2.1.2. Appraisal of published studies

The wide range of prevalence rates can be explained by several factors:

1. Identification and levels of ID: several studies restrict the ascertainment of participants to those who fulfil psychometric assessment of intellectual disability while others may use service driven criteria to identify the participants with ID. The former approach may be overinclusive, in that individuals' level of overall functioning maybe

underestimated if only IQ test scores are considered whereas the latter may be biased as only those in receipt of services are included. Also, severe ID level appears to be associated with higher rates of psychiatric morbidity than mild ID level (Stromme & Diseth, 2000; Einfeld & Tonge, 1996; Gillberg et al, 1986; Rutter et al, 1970).

2. The setting and sample type (clinic vs. epidemiological vs. service register): studies have reported on 1) prevalence rates for psychiatric disorders, 2) specific symptoms and samples have been drawn from both the community (more recent studies) and specialist clinics (older studies). Studies of individuals drawn from specialist service registers tend to show higher rates of psychiatric disorders than those found in epidemiological samples.

3. Diagnostic instruments for detection of psychiatric disorder (checklist versus clinical diagnosis; parent/teacher/clinician made diagnoses): Earlier studies (Gillberg et al, 1986; Corbett, 1977; Rutter et al, 1970) included diagnostic categories such as childhood psychosis and organic brain disorders. The former would currently be diagnosed as suffering with autism or other pervasive developmental disorders. The latter is a term that has serious implications especially when applied to children and young persons with ID whose development may exceed the timeframe norms that have been described in their peers of normal intelligence. It is also likely to have been over-diagnosed in the absence of a readily identifiable mental illness when problem behaviours may be present. Organic brain syndrome may also be diagnosed inaccurately in those who may have behavioural disturbance as a result of an associated genetic syndrome or epilepsy (DC-

LD, 2001, p74). Further doubts about the appropriateness of an organic brain syndrome are raised by its application to samples of individuals with severe level of ID (Menolascino, 1966; Corbett, 1977). The lack of screening and diagnostic instruments specifically developed for people with ID has been long-standing. However, there has been a proliferation of improved instruments in the last ten years or so which is a measure of the concern that clinicians and researchers in the field share about the true nature and prevalence of psychiatric disorders in this population (e.g. Einfeld & Tonge, 1996). Such progress notwithstanding, there continues to be significant variability in the constructs that such instruments rate that further research in their psychometric properties is of paramount importance.

4. The age of the participants (children <12 years of age; children and adolescents; lifespan) (Molteno et al, 2001; Cormack et al, 2000; Hoare et al, 1998; Koller et al, 1983; Jacobsen et al, 1982; Eaton & Menolascino, 1982; Phillips & Williams, 1975; Menolascino, 1969): It may be that prevalence rates for childhood psychiatric disorders are likely to be different from those present in older children or adolescents. Current classification systems suggest that certain diagnoses cannot be applied to children over a specific age. This is an appreciable problem in young persons with ID who are beyond the conventional cut-offs but may present with constellations of symptoms more usually seen in younger individuals because of the gap between their chronological and developmental ages (Borthwick-Duffy, 1994).

5. Informants: studies with lower prevalence tend to use only one source of information, i.e. parent or teacher, whereas, increased rates are shown in studies utilising more than one data source.

2.2 Excluded studies

Other studies which also provide information on the presentation of and contributing factors in the development of psychiatric disorders in children and young persons with ID were considered. They were excluded from the review (chapter 1) because of their methodological shortcomings.

Chess and Hassibi (1970) examined a small sample of 52 children aged from 5 to 11 years with mild to moderate ID level, living at home. They reported that 20 out of the 52 children (38%) had a psychiatric problem, i.e. "reactive behaviour disorder", "psychosis" and "neurotic behaviour disorder". Another 11 children had "cerebral dysfunction".

The study by Reid (1980) is an interesting but descriptive report of clinical practice in an unrepresentative sample. He reported the diagnoses in 60 children who attended a clinic for children with psychiatric disturbance and ID in the UK. The commonest diagnosis was conduct disorder and neurotic disorders (depressive, anxiety and phobic states). In 20 children a second or third diagnosis was necessary.

Eaton & Menolascino (1982) evaluated a small group of children and adolescents drawn from 114 individuals with ID aged 6 to 76 years in the state of Nebraska, USA, in a generic study of psychopathology. 49% (n=56) of the study group were 20 years of age or younger. Organic brain syndromes appeared to be frequently diagnosed as were personality disorders, adjustment reactions and schizophrenia.

The study by Saxby & Morgan (1993) is excluded because the researchers did not use a recognised instrument to elicit behavioural symptoms and they do not report the properties of the modified questionnaire.

One other study has been published on adolescents with severe ID (Brooks & Bouras, 1994). The emphasis of the study, however, was on maternal stress and coping during the transition of adolescents with severe ID to adult services. The authors identified 57 adolescents 13-19 years old who attended special schools in a South London area. "Behavioural problems" were found in 59% of the sample; older adolescents with greater degree of disability being the most affected. Unfortunately, the authors do not report on how they assessed the behavioural problems, though it would appear that a checklist of behavioural problems was used.

Hardan and Sahl (1997) conducted a retrospective case notes analysis of 233 children and adolescents with developmental disorders who attended a specialised programme in the USA. They found that the commonest diagnoses were oppositional defiant disorder and attention deficit hyperactivity disorder. Children with severe ID showed higher rates for disorders such as pica and autistic disorder whilst those with mild ID showed increased rates of depression, posttraumatic stress disorder and speech and language disorders. Additional findings showed increased numbers of single parent families and high rates of family history of mental illness. Hardan & Sahl, (1999) in the same retrospective case notes review showed that suicidality is over-represented in those with mild ID but less so in those with other developmental disorders. The children in this study frequently contemplated suicide, often by hanging. These studies were subject to record keeping standards as well as including unrepresentative samples.

The presence of dysthymic disorder was investigated in a small case control study of adolescents with and without ID (Masi et al, 1999). The patients were consecutive referrals to a Child Psychiatric Clinic. The researchers used the Kiddie-Schedule for Affective Disorder and Schizophrenia (K-SADS) which generates DSM-IV diagnoses. Although the authors found that 10 times more children in the study group were suffering with dysthymia than the control group (20% vs. 2%), the small numbers involved make the clinical significance of this finding uncertain.

Chadwick et al (2000) examined a community-based group of 114 children with severe ID aged from 4 to 11 years. The authors used the Aberrant Behaviour Checklist to ascertain parental and teacher reports of problem behaviours. They found that ambulant children were reported as presenting with more behaviour problems but overall, sleeping difficulties, screaming and self-injury were common among all children. The problem behaviours were significantly associated with lower levels of ability. Although this is an interesting and well-executed study, the authors do not report on the prevalence of problem behaviours.

A pilot study by Hepper & Garralda (2001) explored the impact of transition on the mental health of 10 adolescents with ID 6 months after leaving school. The authors found no change in the mental health of the adolescents after leaving school. However, the study was too small to be able to identify transition unequivocally as one of several potential factors which might influence the course or onset of psychiatric problems in this group. A sample size/power calculation was not undertaken.

Chapter 3 Service issues

3.1 Setting the scene

According to the Royal College of Psychiatrists' Council Report (1998), it is expected that in every health district of 300,000 people, 150 children and adolescents with a learning disability will present with significant psychiatric disorders at any one time. By extrapolation from the work of Kiernan & Kiernan (1994), it is estimated that approximately 2,000 pupils in England and Wales show severe challenging behaviour (CB) whereas another 3,400 present a less significant problem. Furthermore, a catchment area of 250,000 population would have approximately 25 children with ID who have at least one type of CB which is a serious management problem and which requires specialist interventions. In half of those children, the behaviour is considered to be particularly serious.

A child with chronic problems and disabilities is likely to be seen by several professionals from an early age. Paediatrics, hospital and community nursing, occupational therapy, health visitors, GPs, speech and language therapy, social services, child psychiatry, psychology, education and physiotherapy are some of the professional disciplines involved. The points of access to services may vary locally and nationally and it is not always clear to parents and carers which provider is responsible for those who develop mental health problems. The speed of service response is dependent on several factors. Delays or miscommunication can be a frequent occurrence, particularly in semi-rural and isolated communities (Gater et al, 1991).

These difficulties are echoed in the report by the Audit Commission (1994) which found that

"children with disabilities are most noticeably absent in services available to all children in those authorities where responsibility for them resided in the adult disability service. They have a legitimate place in all services but are central to none and their needs and those of their families are easily marginalised. Mainstream services do not always recognise them and information on need and outcome is difficult to collect, categorise and use".

Gradual emphasis on improving the social and educational inclusion of this group led to the recognition of children and young persons with ID as being "in need" by the Children Act 1989.

Change is often a stressful time in the life of persons with ID and their families. Usually, for children with ID, school provides a wide range of support, not only in educational terms but also for health checks and social activities. At the point of leaving school, therefore, the young person moves out of a supportive framework which comprised health and social care arrangements and teachers and classrooms assistants who have known him/her over the years.

There is currently increasing interest in young persons with intellectual disability in transition defined as the time from the 16th to 18th year leading to transfer to adult specialist services. Anecdotal accounts indicate that the experience of young persons and their families at that stage in their lives is one of lack of coordination of services, different care ideologies and dissatisfaction despite the guidance available to Social Services on how to plan for this phase.

The Education Act and the Code of Practice on the Identification and Assessment of Special Needs recommend that a statement of special educational need should lead into the transition arrangements after the adolescent's 14th birthday. Ideally, joint planning between services with involvement of the young person and his/her family at every stage is considered the best way in which to ensure that the process is a shared one with agreed outcomes and expectations.

3.2 Adolescents with ID, mental health problems and their families: Social networks and service delivery

One of the first experiments aimed at the social rehabilitation of adolescents with ID was carried out by the *Slough Project* of the National Society for Mentally Handicapped Children, UK (Baranyay, 1971). The project was set up for adolescents with ID in the moderate range (IQ 30-50). It was developed as a consequence of the considerable changes in the philosophies and social attitudes underpinning the treatment and community care of people with ID and followed a similar endeavour by Tizard (Brooklands Experiment). Tizard had shown that young children with ID could achieve "*remarkable advances in language ability, verbal intelligence and emotional and social development ....living under family conditions and in a stimulating environment...*". The project opened in 1961 and included both residential "family-like living" and day centre facilities with a sheltered workshop. Although not formally evaluated, it added further support for the care of adolescents with ID in the community and the benefits of social inclusion and meaningful occupation. In particular, it was suggested that a limited and scheduled period away from home could provide adolescents with the skills necessary to lead a more independent and fulfilling life. At the same time it was acknowledged that a small group of individuals (6 out of 67 during the project life) failed to complete their training because of behavioural difficulties which could not be contained within that environment.

Brooks and Bouras (1994) in their study of maternal coping during the transition of adolescents with ID highlighted the problems faced by parents of older and more disabled individuals. The mothers appeared to be more negative in their appraisals of the future and their expectations of the adolescent and showed more evidence of stress and difficulty in coping. Mothers also held a negative perception of received social care. Worryingly, the authors commented that

"none of the adolescents with behaviour problems in this study had been seen previously by the child psychiatric services".

Parental comments such as "extra time demands", "life centring around their offspring", "need to constantly supervise and watch" captured the carers' experience of looking after a severely disabled child.

Einfeld and Tonge (1996) found that 47% of primary caregivers had not sought any professional help for the mental health problems of their child. Only about 10% of the participants in the epidemiological study had been seen by specialists in child mental health. This is surprising in the light of research evidence suggesting that "felt need" for assistance by parents is mostly predicted by the presence of behavioural problems. It would appear that parents either do not perceive a need for services or do not trust professional input even though it may be beneficial to their child (Evans and Brown, 1993). Anecdotal evidence from clinical experience with children with ID and their families also suggests that parents may be unaware that such services are available at all.

Diagnostic overshadowing (Reiss et al, 1982) has been blamed repeatedly for the underestimate of mental health problems in people with ID across the life span. The term suggests that when children or adults with ID present with mental health problems those tend to be attributed to the presence of ID rather than recognised as a separate co-existing disorder.

General Practitioners have frequent contact with children and therefore would be well placed to detect those at risk of developing or having symptoms of a mental disorder. The actual health support that carers and individuals will finally receive will be influenced by awareness and recognition of the mental health problem, accessibility of the different agencies and by service user expectations and complexity of the referral process. Studies of referral pathways for people with ID are lacking but the available published evidence suggests that adolescents with ID consult their GPs less than their counterparts of normal intelligence (Howells, 1986). This may be due to problems, which range from communication difficulties in the young person causing diagnostic difficulties (knowing when and in what way they are sick) as well as difficulties in the GP's recognition of the symptoms and consequent lack of access to services. Primary Care is set to become the gatekeeper to service input to people with ID. As GPs are asked to hold copies of the individual health action plans of all the people with ID in their practices, increased awareness of the mental health needs in this population will be paramount.

There is no shortage of reports on service provision for children and adolescents with ID. The Royal College of Paediatrics and Child Health (then known as the British Paediatric Association) developed a working party to investigate the needs of children and young persons with ID and published its findings in 1994. The report emphasises the need for multi-agency collaboration between specialists with different expertise, for example, Child Psychiatrists, Learning Disability Psychiatrists, Primary Care and Community

Child Development Teams. It recommends strategic planning for the transition between services and the development of individual care plans. It expresses a clear preference for specialist teams for children with ID to be based within the framework of children's services.

The Mental Health Foundation (Foundation for People with Learning Disabilities) is an organisation that has shown growing concerns over the situation of children with severe challenging behaviour. A Committee was set up in 1993 to explore the facilities, service provision and interventions available to those children and their families. The final report *Don't Forget Us* (1997) recommends the development of community services, improvement of residential provision and commissioning of new appropriate services which are integrated within the local community and able to provide specialist input for children with complex needs. It also promotes an inclusive framework of "children first" and emphasises the need for joint working between agencies which traditionally tend to keep rigid service boundaries.

A further report by the Department of Health (Lindsey, 1998) discussed in detail the requirements of developing services for children and adolescents with mental health problems. The author recommends that early identification and intervention in well-coordinated services is most likely to be successful in treating severe and recurrent problems. However, needs in areas such as housing, education, respite and parent support opportunities should also be considered when service specifications are drawn up (p 55).

The new *National Strategy for People with ID "Valuing People*" (DoH, 2001) openly addresses the long standing problems of providing for children and young people with ID and sets a new vision in the objective of:

"...ensuring that disabled children gain maximum life chance benefits from educational opportunities, health and social care while living with their families or in other appropriate settings".

More recently, The Foundation for People with Learning Disabilities has completed an inquiry (2002) into meeting the mental health needs of young persons aged 14-25 with ID and those of their parents. The inquiry collected oral and written evidence, carried out focus groups and heard from representatives of the young persons, their families and professionals across the UK. *Count us in,* the published report, confirms that services often fail a substantial number of those young persons, there is lack of clarity about service responsibility (mainstream versus specialist), and the young people may be unable to access interventions or be provided by different agencies as health and social services have varying age cut-off inclusion criteria.

Better support at school and at home, accessibility to mainstream school and continuity of care during the transition to adulthood are seen as key starting points.
Questions of eligibility can take time to resolve; educational opportunities, particularly for older adolescents with complex needs and severe problem behaviours, are difficult to identify; there is limited capacity in existing services for appropriate community and

occupational activities. As a result, the emotional well being of the adolescent is compromised and service delivery can be woefully inadequate. Local data from an inner London Learning Disability Service (Camden Learning Disability Service) indicate that approximately twelve 16 year olds are referred to the adult intellectual disability service annually and there are approximately fifty young persons about to reach their eighteenth birthday already waiting for psychometric and social care assessments by that service. It is hoped that agencies such as Connexions, the new youth support service, will ensure that young persons with ID are included in the community support programmes, information is disseminated to service users and that their opinions filter through to the decision-making process.

Table 7 summarises key points in the policy development and service provision for children and adolescents with ID.

Table 7: Selected aspects of policy development and service provision for children and adolescents with ID

Title (year)	Main Objectives	Outcome
Children Education Act (1971)	All children have a legal right to education regardless of their ability level Statement of special educational need	Children with IQ level below 50 started education Increased educational resources
Children Act (1989)	"Children in need"	Improved integration of services
Psychiatric services for children & adolescents with a learning disability, RCPsych (1998)	Provided a template for service provision	Improvement of local service provision and delivery
Signposts for Success in commissioning and providing health services for people with learning disabilities, NHS Executive (1998)	Guidelines for good practice: • recognition of needs of parents and children • co-ordination of services • community participation • provision for those who need home care • increase respite options • nursing input	Improve service delivery sensitive to the needs of the child and his/her family including those with mental health problems Increase opportunities for social inclusion
"Valuing People: a new strategy for people with Learning Disabilities for the 21st Century", DoH (2001), England	• Quality Protects programme • DEE Special Needs Programme of Action • Connexions Service • Schools Access Initiative • Continuity of care in transition • Implementation of the carers and Disabled Children Act 2000	£60m over three years to improve support Improve accessibility to mainstream schools. Standards Fund to improve education for children with special needs
Count us in, Mental Health Foundation for People With	• Inquiry into meeting the mental health needs of	Promotion of : psychological well-

Learning Disabilities, 2002, UK	adolescents with ID	being Multi-disciplinary support & partnership with families Focus on outreach and ethnic minority groups Joint work between mainstream and specialist services

3.3 Service models for children and adolescents with Intellectual Disabilities and Mental Health Problems

Lack of specialist services for children and adolescents has been highlighted already. A survey by the Royal College of Psychiatrists showed that 25% of existing services for people with intellectual disabilities were also treating younger persons as part of a "lifespan" service (RCPsych, 1989). However, several years on, most of the service provision in England is restricted to adults with ID with only a few services specifically designated to treat children and young people with ID. In particular in-patient facilities for the latter group are almost non existent. These are commissioned both for local and tertiary provision and offer expertise and support both in inpatient and community settings (Prudhoe Hospital, Northumberland; St Andrews Hospital, Northampton; National Assessment Service, South East London; Harper House, Hertfordshire; Birmingham, Oxford, South West London). All these services vary in the type of treatment options offered, the criteria for patient admission, staffing skill mix and setting. Several well-established charities or parent support groups have developed residential specialist homes for young persons with ID. However, admissions to those units are mainly dependent on assessment and treatment provision from NHS services as described above.

There is widespread agreement between specialist agencies and organisations associated with people with ID that young persons with comorbid ID and mental health problems are poorly served by existing resources. It is recognised that young persons with emotional or problem behaviours will have disrupted education and in a minority of cases may require specialist treatment in out-of-area units. In the absence of national data, there is a clinical impression, dependent on local factors, that demand for inpatient admissions units for those aged between sixteen to eighteen years is significant. These will usually be young persons with severe mental health problems of early onset for whom admission to adult psychiatric wards is inappropriate. It is encouraging that the new strategy for people with ID has created an impetus for change in service delivery, which also considers the needs of young people in transition.

Chapter 4 Justification of the study

4.1 Need for a new epidemiological study

Several studies of psychopathology in adolescents of normal intelligence have been carried out in the past decade (Romano et al, 2001). This research has emphasised the need to consider age factors separately in the estimates of prevalence and nature of psychiatric disorders as they present in different population groups.

This type of enquiry has not filtered through epidemiological research in ID where different age groups are studied together. In particular, adolescents with mental health problems are a distinct group with diverse needs who are likely to suffer with on-going mental health problems and occasionally require specialist provision. Little is known about the nature and severity of disorders that are prevalent in this group. In addition, life changes that are normal for the majority of adolescents such as the development of peer relationships, carrying on in higher education or obtaining employment and finally leaving home, occur only in a small minority of adolescents with ID. Their progress is further hindered by the presence of an emotional problem, which is poorly articulated and understood. Attitudes of the parents and the service system towards the changing needs of the adolescent as well as deficits in adaptive competencies in the young persons with ID contribute to making adolescence a difficult and stressful time for all concerned.

For example, a study of two birth cohorts of adolescents with Down syndrome in Wales showed that over half of the older sample was dependent for all aspects of their self-care and 15% were not left alone at all. However, those who were born a decade later were learning more independence skills earlier and were able to go out unaccompanied. The study also showed that very few participants had mastered self-care skills during the conventional adolescent years but had done so by early adulthood (Shepperdson, 2001, pp 58-61). It can be argued that adolescence is not only a protracted but also an extremely challenging time for a person with ID and his or her family.

Several reasons make the study of psychopathology in adolescents with ID essential:

1. Mental health problems such as schizophrenia may arise de novo during adolescence especially in young persons with likely neuro-developmental deficits.

2. Although there are documented continuities in illness manifestation with the earlier part of childhood, there could also be discontinuities, further deterioration, improvement or even change in symptoms. Some of the features of childhood autism may improve as the child grows older and the hyperkinetic syndrome is not seen in adolescents as often as in the younger child (Goodman et al, 2002). Despite common statements by parents that their child "will get over it as he or she grows older", there is sufficient evidence which indicates that emotional problems in this population are often life-long. A recent 5 year follow up study of children with hemiplegia drawn from the London Hemiplegia Register (Goodman, 1998) showed that, once psychiatric problems arise, they tend to continue in the future. Thus, the children who were diagnosed as "cases" initially, were all still "cases" 5 years on. Furthermore around a third who had been symptom free, developed psychiatric problems at follow up. Clearly, the research evidence raises implications about service provision and effective treatment interventions

3. As children grow up, they are less likely to receive the same level of services they were receiving when younger. There should usually be a graded transition into adult services after a thorough evaluation of the person's needs. However, existing service barriers may lead to a significant minority of adolescents becoming isolated and excluded as well as not being offered input at all ("falling through the net"). The latter are not unique problems to the Psychiatry of Learning Disability but can afflict other services which have established age cut-off points in terms of the population they serve, for instance in cases where psychiatric disorders such as presenile dementia occur.

4. Parents may not know what type of services they should ask for. They may find the complex negotiations for eligibility of specialist service provision time-consuming and complicated.

5. A further argument for the study of adolescents with ID is the suggestion from the few available studies of adolescents with ID and specific mental disorders which demonstrates that if the disorders are recognised early, they can be amenable to existing treatments with obvious benefits to the young person's quality of life.

On a personal note, I became interested in studying the prevalence of mental health problems in adolescents with ID because in the course of my clinical practice, running a mainly adult learning disability service, I had direct exposure to the ongoing problems in diagnosing and treating this age group. My experience was one of fragmented service delivery, poor communication between agencies with inflexible working patterns and lack of adequate resources for evaluation and treatment especially of the older age group, that is the sixteen to eighteen years olds. Although, my own experience may not be representative of all service provision nationally, it is nevertheless illustrative of the experience of other colleagues working in the specialism.

This study will add to the literature by investigating the prevalence, nature and severity of mental health problems in adolescents with ID, the associations with the degree and cause, where possible, of ID and will chart the pathways of the adolescents and their carers to health and social care.

PART II THE STUDY

Chapter 5 Method

5.1 Aims

- To describe a population of adolescents with intellectual disabilities in one catchment area
- To identify the nature including aetiology, comorbidity and prevalence of mental health problems in adolescents with ID
- To explore the association between sociodemographic and clinical variables with the presence of psychopathology
- To chart the pathways to healthcare and service use of this population
- To make recommendations about service provision and future research

5.2 Hypotheses

Main:

1. Adolescents with ID as a group have high rates of mental health problems
2. Rates of mental health problems in the sample of adolescents will be significantly associated with sociodemographic factors (level of ID, gender, level of adaptive behaviour, paternal employment status) and clinical factors (psychiatric problems in the carer, diagnosis of autism, epilepsy)

Secondary:

1. Adolescents with ID and mental health problems will require increased service input as a result of high rates of mental health problems

5.3 Design and case ascertainment

The study is a cross-sectional survey of adolescents with ID in a defined geographical area. West Essex (WE) is a county of 256,000 and includes 3 districts: Epping, Harlow and Uttlesford. It is a combination of rural and urban centres of variable degrees of socio-economic prosperity. The most deprived area is the district of Harlow (Jarman index of 10.2). Approximately 13% of the population are children between 5-15 years of age and 13.5% are aged between 16-24 (OPCS, 1991). The area average of minority ethnic groups is 1.9% of the total population (Chinese, Indian, Pakistani). The local register for people with ID suggested that 0.33% (approximately 850) of the total West Essex population were eligible to receive specialist services. This rate is likely to be an administrative prevalence as several individuals with mild ID may not be known to services and others refuse to be registered (approximately 2% in the whole of Essex county). Cross reference of register data from the Local Education Authority and the newly developed West Essex register indicated that 154 young persons aged 12 to 19 years may require services but suitability to receive such services had not been established in 50 cases. Adolescents with ID aged 12-19 (birth range: 1980-1987) were identified through contact with the following agencies:

- The Social Services Department for Children with Special Needs
- The local schools for children with special needs and mainstream schools,
- The TABBS information service for people with ID (Essex wide register started in 1999)
- The Local Education Authority
- The three Community Child Development Teams,
- The two Child and Family Consultation Services,

- Primary Care,
- Association for Fragile X syndrome.

The majority of the participant sources were not biased towards those with coexisting psychiatric disorders as they were obligated to provide social support irrespective of additional psychiatric problems.

Each source was asked to nominate individuals and, where appropriate, the individuals' case records where available were also examined. Obstetrics records per se were not sought due to limited resources.

The threshold for referral to the study was deliberately low in order to include as many participants as possible and to ensure that the sample was representative of the population who might require services.

5.4 Power calculation

Power calculation for this study was hindered by the existing configuration of Child and Adolescent and Learning Disabilities Mental Health Services. It is not possible to know from the outset what numbers of referrals are received annually and what proportion are due to mental health problems. Therefore, this project is exploratory. However, using known estimates of prevalence rates of psychiatric problems in children and adolescents with ID, I calculated the sample size needed using the formula based on calculations allowing for 95% confidence that the study result will differ from the true population prevalence by no more than e $[n \geq 4p\% \ (100-p\%)/e^2]$.

Assuming a prevalence of 40% and a maximum accepted sampling error of plus/minus 10 (=e) I would need to recruit 96 individuals. If the prevalence rate was increased to 50% with a margin of 15 (=e), the required number of participants would be 45.

5.5 Data handling and Consent

When the study was approved by the Local Research Ethics Committee, an information sheet about the study and a request to refer eligible individuals was sent to all departments and professional groups listed above. The Head teachers of the area mainstream and special needs schools, the Head of the Education Psychology Service and the Manager of the local Social Services Department for Children with Special Needs asked that parents should be approached first to consent to their name and contact details being passed on to the researcher. A letter was sent to inform parents that their details might be used for research and ask whether they agreed to being contacted by the researcher (opt in).

Those who agreed were sent a letter containing an information sheet about the research and a consent form (appendices) which they were required to sign and return in the enclosed self-addressed envelope. Non-responders were sent a second letter within a month and a final reminder a month after that.

Where potential participants were sixteen years of age or older they were also asked to consent to the study. However, those adolescents who lacked capacity to consent were also likely to be those with most disability and need. It was important to include them in order to explore the level of access to services and perceived need for service input. No physical risk or inconvenience to any incapacitated individual was anticipated as a result of the project, since in such cases all the data would be collected from an informant. In addition, any information gathered might be potentially beneficial to the incapacitated person and their family, as services to them could be improved in response to the results (Strydom, 2002). In cases where it became evident during the interview that the young person was getting distressed or showed signs of change in behaviour and mood, the interview was interrupted and was either carried out after a break or at a later date. Participants were offered the choice of being seen either at their home or at the researcher's consulting room, at Spencer Close within the grounds of St Margaret's Hospital, Epping. Appointment dates were confirmed by letter. The interview duration was approximately two and a half hours. There were no payments made to individuals for their participation.

The researcher is a specialist psychiatrist in Learning Disabilities experienced in communicating with people who have a learning disability.

All the interviews and statistical analyses were undertaken by the researcher.

5.6 Assessments and instruments

- Sociodemographic data, developmental and medical history

A questionnaire was devised for the study and administered to parents. Social class classification was based on occupation of the household head. The categories used were: Professional (I); managerial & technical (II); skilled-non manual (III-N); skilled-manual (III-M); partly skilled (IV) and unskilled (V) (Office of Population Censuses and Surveys, 1991). Obstetric information was derived from current medical records and the following questionnaire items: 1) duration of pregnancy (prematurity <37 weeks gestation), 2) complications at birth (time in intensive care, abnormal movements, breathing difficulties, feeding difficulties), 3) use of substances by mother during pregnancy (i.e. smoking, use of illicit drugs, alcohol intake > 14 units per week).

- Assessment of psychopathology

Developmental Behaviour Checklist (*DBCL–Primary carer and teacher version*) (Einfeld & Tonge, 1994). The DBCL is an informant rated screening tool for psychiatric symptoms and problem behaviours in children and adolescents with ID. It has been used widely in many prevalence studies of psychopathology including those investigating the psychiatric profile of genetic disorders in children and young persons with ID (please refer to section 1.7). It has acceptable validity (Einfeld & Tonge, 1994, p14-29) and reliability (Einfeld & Tonge, 1994, p 11-13). It comprises a 96 item checklist which scores problem behaviours across 6 domains: disruptive (measures disruption in purposeful activities such as learning), self-absorbed (usually seen in severe levels of ID), communication deviance (mainly seen in those with autism and good verbal skills), anxiety, autistic relating (shows cluster of behaviours commonly seen in this disorder) and antisocial (disruptive behaviours mainly seen in those with mild ID). A total score is derived which defines a "case" if above a certain number (>46). The scale is sufficiently sensitive and specific in distinguishing true positive cases (area under the ROC curve is 92%). The instrument was given to the parent/primary carer or teacher to complete but assistance was available and any questions about statements that were unclear were discussed.

Clinical diagnoses: The clinical assessment of the young person was based on a semi-structured interview with the parents and the young person, if able to do so, which followed the diagnostic criteria set out in the International Classification of Diseases 10th Edition (ICD10) (World Heath Organisation, 1992). The interview schedule included a checklist which covered questions on symptoms identifying axis 1 mental disorders and emotional and behavioural problems. If it became evident during the interview that the participant had not experienced particular symptoms of a disorder, the interview proceeded to questions on the next disorder on the list. The interview took up to three hours to complete with several carried on on two separate occasions. The interview with the young person took place where appropriate, i.e. the participant did not show distress and was able to agree to be seen on his or her own. Accessible language was used to describe symptoms and diagnosis was aided by observation of behaviour, interaction with the interviewer (AH) and direct communication.

Previous notes of medical, including psychiatric, consultations were obtained where possible to confirm contact with services, previous diagnosis and treatment and to confirm what, if any, investigations had been carried out. In particular, diagnosis of atypical autism was made to account for the level of intellectual disability and lack of history of childhood development. The final ICD 10 diagnosis was derived using information from the parent and young person interview and other medical/psychiatric information as described above.

Atypical autism was diagnosed in cases where it was not possible to ascertain either age of onset, the criteria for childhood autism were not met or the individual had severe or profound ID.

- Adaptive Behaviour

Vineland Adaptive Behaviour Scale (*VABS-survey form*) (Sparrow et al, 1984). The VABS is designed specifically to test adaptive behaviours across the range of ID. It contains 297 items clustered in the following domains: communication, activities of daily living, socialisation and motor development for those up to 6 years of age or older if they have serious motor deficits. It is informant rated and is standardised for an American sample but used widely in international studies and clinical practice as it has proven validity and reliability. The VABS allows derivation of an adaptive behaviour composite score and individual domain standard scores. These are a measure of the person's adaptive competence. There is also another category, that of *maladaptive behaviour*, which indicates the frequency of such behaviours. The severity of disturbance is categorised as non-significant, intermediate and significant. As with IQ scores, the overall and domain composite scores are standardised to have a mean of 100 and a standard deviation of approximately 15. Therefore, a composite score below 70 can be regarded as a significant impairment of adaptive competence. Specifically, the adaptive levels which correspond to standard scores are as follows: mild deficit (55-70), moderate deficit (40-50), severe deficit (25-35), profound deficit (below 20) (VABS-survey edition manual, p 232).

Provided that this has occurred during the developmental period, it indicates that those individuals are likely to meet diagnostic criteria for "Mental Retardation" according to ICD 10. The Vineland Adaptive Behaviour Scale also has a motor scale which was used to measure motor ability in the sample.

- Relationship between the VABS and intelligence tests

It is recognised that an Adaptive Behaviour Scale and an intelligence test measure different areas of ability. However, the correlation between the VABS communication domain and Kaufman Assessment Battery for Children appears to be good. This is likely to be due to similarities the two instruments share in the way they examine verbal skills and comprehension (VABS manual). Given that the majority of the participants did not have separate psychometric assessment, because of lack of resources, a decision was taken to use the VABS adaptive behaviour composite score along with information from clinical notes to group the sample into different levels of ID. The association between mental and social age has been examined before and the measures were found to correlate highly (Turk J, Doctoral Thesis, University of London, 1995, p 111).

- Cytogenetic and DNA studies were ordered if there was no record of genetic screening in the notes. Request for testing was for main genetic disorders such as fragile X syndrome, Prader-Willi syndrome and for chromosomal deletions.
- Service utilisation: the structure of the questionnaire consisted of the following direct questions: information on the sources of care used by patients, frequency of visits to the GP in the past year and reason, the disciplines of the professionals involved with each individual, how often the contact took place, the source and reason of referral to different professionals and current treatment. Positive responses to one or more of these were used as a trigger for in depth dialogue between researcher and carer in order to obtain and clarify details.

5.7 Statistical analysis

The Statistical Package for the Social Sciences for windows, SPSS V11, was used to analyse the data.

Descriptive statistics were used to examine basic sociodemographic attributes of the sample. Categorical variables are described in terms of numbers and percentages. For continuous variables, the means and standard deviations are given. Histograms were also drawn for each of the scales used to measure skewness and kurtosis which test for deviation from the normal distribution.

The difference between means of more than one group (continuous data) was tested initially by using the *t-test* but as some of the distributions did not follow normal distribution, the Mann-Whitney U test (non parametric test) was used instead for uniformity of presentation of the results. Associations between categorical variables were tested by using Chi-square test and where appropriate the Fisher's Exact Test for a 2x2 table was applied (i.e. degrees of freedom (df)=1). All tests were two-sided. The analyses were planned in advance.

A 5% level of statistical significance was adopted, that is for each test there is a 1 in 20 chance that the result of interest is due to chance. Bonferroni corrections were applied to significance testing to take into account the effects of multiple testing.

Agreement between parent reports and clinical diagnosis was calculated as Kappa correlation coefficient. Relative risk for psychiatric disorder was estimated as odds ratio (OR) with 95% confidence intervals.

Logistic regression was undertaken (independent variable entry<0.05 and removal <0.1) to explore the proportion of variance of the dependant variable explained by each predictor variable (response variable coded 1 and reference variable 0). Variables were entered into the equation simultaneously (Tabachnick & Fidell 2001, chapters 5 and 12) as there is no clear evidence in the literature about relative importance of each variable.

Correlation statistics were used to examine the relationship between (1) scores on the Developmental Behaviour Checklist and the Vineland Adaptive Behaviour Scale and (2) the Developemtnal Behavioural Checklist scores and age.

For the interpretation of results, there was consideration not only of the statistical significance of the difference but also of the clinical importance of the findings (Bland, 2000).

PART III RESULTS

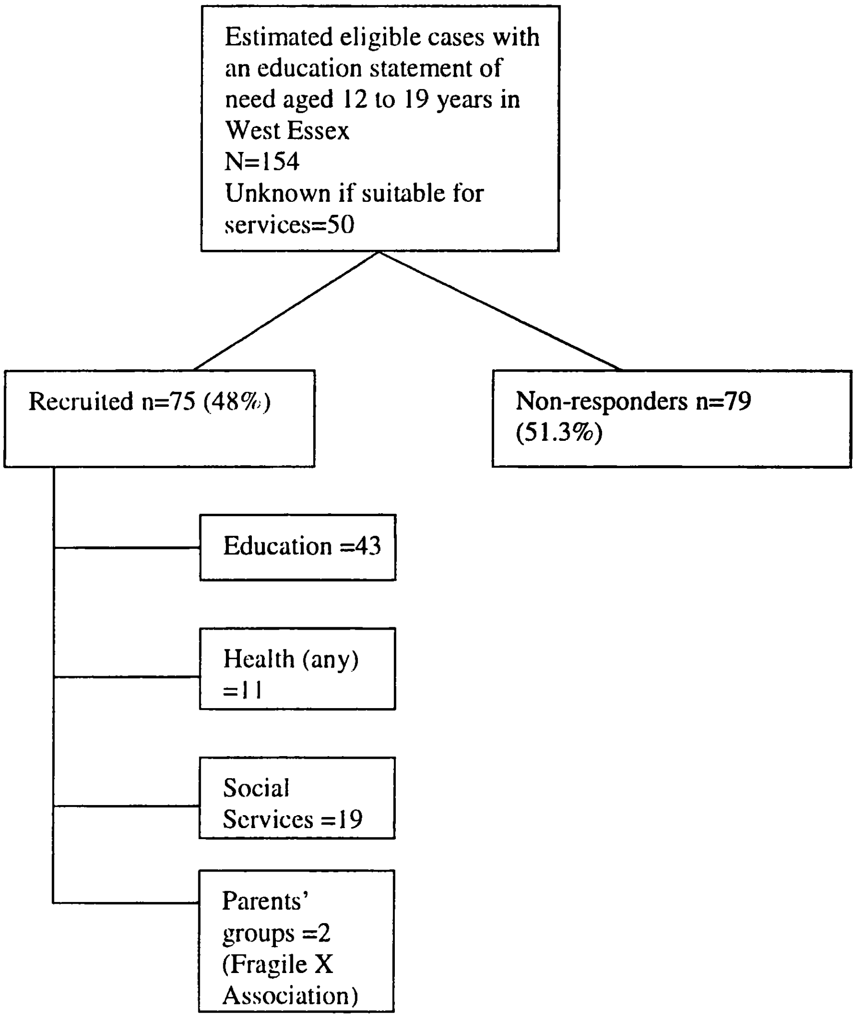
Chapter 6 Description of the group

6.1 Recruitment and non responders

Seventy-five adolescents in total participated in the study out of the eligible 104. Anonymised data were collected on non-responders (79) including those whose suitability assessments were pending. Reasons for non-response were non-contact (64), refusal (10) and drop-out (5). Comparison of responders and non-responders showed that non-responders were significantly younger (mean age 14.5 vs. 15.5, *t-test*= -2.932 p=0.004) but non difference in gender was found (*chi squared=.089, df=1, p>0.05*).

Details of the recruitment are presented in figure 1.

Figure 1: Flowchart of recruitment sources



6.2 Intellectual disability status

According to information obtained from medical and education records (although only a few of the adolescents had had a psychometric assessment on file), they were assigned an ID level by education psychology based on a social systems perspective, i.e. social services described potential service users as having a learning disability (Llewellyn & McConnell, 2003). However, according to the scores obtained on the VABS, the distribution of the level of intellectual disability was as follows:

Mild: ten cases (13.3%), moderate: twenty-three cases (30.7%) and severe/profound: forty-two cases (56%). In addition, the researcher was satisfied that the disability was present during the developmental period and that there were current difficulties in at least two areas of adaptive behaviour as required by the ICD 10 classification system.

For the analyses, the mild and moderate groups have been merged.

6.3 Sociodemographic characteristics

The participants' ages ranged from twelve to nineteen years (mean 15.4, SD 2.1). Forty-eight were male (64%).

The majority of the families resided in Harlow (41.3%), followed by Epping (38.7%) and Uttlesford (20%).

They were mainly from White UK background (90.7%). Minority ethnic groups (Afrocarribbean, Asian) constituted only 6.6% of the sample.

Paternal mean age was forty-seven years (SD 8.1) and maternal mean age forty-three years (S.D. 6.05). In terms of family composition, 67% of parents were married and 29.3% divorced or separated. In 88% of the cases, the adolescents were brought up by one or both of their biological parents, 8% lived with foster or adoptive parents and 4% were looked after by paid carers either within West Essex or in residential placement.

73.4% of fathers were employed full or part-time although only 46.6% of mothers were in employment mostly part-time (33.3%). In terms of social class distribution, 37.3% were social class I and II, 56% social class III and IV and 6.7% in social class V.
There was a median of 2 children in the families (ranged from no siblings at all up to 11 in one family). Only one adolescent was a dizygotic twin (1.3%).
Most of the adolescents were in local schools for students with special needs (67.9%) but 9.3% were at home without any day occupation because the educational placement had broken down. Intermittent private tuition was available to those young people. Other placements such as out-of-area schools, specialist schools (i.e. for the Deaf and for children with emotional and behavioural disorders), mainstream schools as well as colleges for those aged sixteen years and over were also used (14.7%).

The sociodemographic characteristics of the sample are summarised in table 8.

Table 8: sociodemographic characteristics of the participants (N=75)

Sociodemographic characteristics	N (%)
Age range: 12-19 years (mean 15.4, S.D. 2.1)	
Gender	
Male	48 (64)
Female	27 (36)
Residence	
Family home	64 (85.3)
Foster home	2 (2.7)
Out-of-area	6 (8)
Residential facility	3 (3.9)
Ethnicity	
White UK	68 (90.7)
Other	7 (9.3)
Family composition	
Married	50 (66.7)
Divorced/separated	22 (29.3)
Single	3 (4)
Parental employment	
Fathers in f/t or p/t employment	55 (73.4)
Mothers in f/t or p/t employment	35 (46.6)
Education	
Special needs schools (day)	51 (67.9)
Mainstream schools & College	11 (14.7)
Home	7 (9.3)
Other	6 (7.9)

6.4 Health Status

Cause of ID

In the majority of the adolescents seen (forty-five), there was no identifiable cause of the intellectual disability. In fifteen of these instances genetic tests were requested on the basis of dysmorphic features but the results were all negative for chromosomal disorders. Twenty-one individuals had a chromosomal or inherited genetic disorder including fragile X syndrome (6), Down syndrome (5), chromosome 9 monosomy (2), Prader-Willi syndrome (2), chromosome 8 deletion (1), Cornelia De Lange syndrome (1), Williams syndrome (1), neurofibromatosis (1), adrenoleucodystrophy (1) and Kippel-Feil syndrome (1). In nine adolescents, infections and other perinatal problems were reported as having caused ID.

Obstetric history

Regarding obstetric and perinatal history data were collected form 67 cases. 22.7% (seventeen) of the mothers questioned reported that they had suffered ill health during their pregnancy (e.g. rubella). Other conditions mentioned appeared to be pregnancy-related illnesses such as elevated blood pressure or gestational diabetes. Forty-two mothers (62.7%) reported that they smoked during pregnancy and eight (12%) consumed alcohol (up to 14 units per week).

80% of the adolescents were born by vaginal delivery and in twelve cases (16%) the delivery was before 37 weeks gestation. 13.3% had spent some time in an intensive care unit either immediately after birth or in the first year of life. Only 4% of mothers recalled their babies as having had breathing difficulties in the neonatal period; 13.3% were described as "floppy" in the first year of life and unable to reach normal motor milestones. Sixty-six children (75.7%) were reported to have had some form of feeding problem including "sucking or swallowing difficulties", food fads being the commonest (56.8%) and failure to gain weight also reported in two cases.

Epilepsy and other disabilities

Twenty-nine adolescents (38.7%) had additional long-standing medical problems including epilepsy either currently or at some time in the past (eighteen or 24%), metabolic disorders (four or 5.3%) (hypothyroidism (2), growth hormone deficiency (1), diabetes (1)) and cerebral palsy (any type seven or 9.3%)).

Other reported physical or medical problems were: frequent infections in childhood (33%), sleeping problems (10.7%), visual and /or hearing defects (5.4%).

At the time of assessment, 22.7% had enuresis, encopresis or both, and 16.7% showed abnormal gait/impaired muscle tone/ tremor or were non ambulant.

Investigations

All but two of the adolescents had had one or more investigations for their disability, the most frequent being: head CT or MRI scan (41.4%), genetic screening (28%), EEG (21.3%) and other specialised investigations (12%).

Family history of mental illness, intellectual disability or epilepsy

In forty-five cases (60%) there was a positive family history of mental illness or intellectual disability. Ten siblings (13.3%) of participants were also reported to have either intellectual disabilities or epilepsy. The disorders reported included intellectual disability (21.3%), affective disorders (14.4%), schizophrenia (8%), other (minor psychiatric problems, epilepsy and speech delay 12%).

Details of the participants' health status are summarised in table 9.

Table 9: Obstetric and health background of participants (N=75)

Cause of ID	**N (%)**
Idiopathic	45 (60)
Genetic disorder	21 (28)
Fragile X	6
Down Syndrome	5
Chromosome 9 monosomy	2
Prader-Willi Syndrome	2
Chromosome 8 deletion	1
Cornelia de Lange syndrome	1
Williams syndrome	1
Neurofibromatosis	1
Kippel-Fiel syndrome	1
Adrenoleucodystrophy	1
Infections/other	9 (12)
Obstetric and perinatal history	
Ill during pregnancy (↑ BP, bleeding, diabetes)	17 (22.7)
Normal delivery	60 (80)
Delivery <37 wks	12 (16)
Time in intensive care	10 (13.3)
"floppy at birth"	10 (13.3)
Feeding problems	66 (75.7)
Breathing difficulties	3 (4)
Epilepsy and other disabilities	
Epilepsy	18 (24)
Metabolic disorders	4 (5.3)
Hypothyroidism	2
Growth hormone deficiency	1
Diabetes	1
Motor problems/cerebral palsy	
Frequent illness in childhood	7 (9.3)
Sleeping problems	25 (33)
	8 (10.7)
Current	
Visual/hearing problems	
Enuresis/encopresis/both	
Motor difficulties	4 (5.4)
	17 (22.7)
	11 (14.7)

6.5 Adaptive skills profile

Comparisons of the sub-domain (communication, activities of daily living and socialisation) and total composite standard scores of the VABS between male and female participants showed no significant differences between the two groups in the level of adaptive skills (Mann-Whitney non parametric tests for two independent groups). Tables 10 and 11 show a) descriptive details of the VABS scores for the whole group and the subgroups (mean, median, standard deviation-SD) and b) between group comparisons.

Table 10: Adaptive behaviour profile of 75 adolescents with ID

	SDCOMM	SDADL	SDSOCIAL	COMPSCORE
	Mean (median) sd			
MALE	35.54 (35.5)	35.23 (26)	39.20 (41)	34.16 (31)
N=48	17.84	17.21	19.45	16.07
FEMALE	40.07 (37)	36.92 (24)	37.77 (37)	35.51 (30) 16.6
N=27	21.21	22.36	16.07	
TOTAL	37.17 (36)	35.84 (24)	38.69 (40) 18.2	34.65 (30)
	19.11	19.09		16.16

SDCOMM: standard communication score, SDADL: standard activities of daily living score, SDSOCIAL: standard socialisation score, COMPOSCO: composite standard score

Table 11: Comparison of adaptive behaviour profile between male and female participants

	SDCOMM	SDADL	SDSOCIAL	COMPOSCO
Mann-Whitney U	596.000	648.000	614.500	620.500
Wilcoxon W	1772.000	1026.000	992.500	1796.500
Z	-.580	.000	-.372	-.307
Asymp. Sig. (2-tailed)	.562	1.000	.710	.759

Chapter 7 Psychopathology

7.1 General issues

Forty-five (60%) of the respondents gave a positive family history for either mental illness or ID. This included only ID (twelve or 16.4%), affective disorders (eleven or 25.1%), schizophrenia (six or 8.2%), other psychiatric disorders (five or 6.7%) and a combination of psychiatric problems and ID (four or 5.5%).

Other less frequent psychiatric morbidity in the family included speech delay in siblings (1.3%), motor difficulties (1.3%), epilepsy (2.7%).

7.2 Developmental Behaviour Checklist- Parent

The group as a whole scored a mean total on the DBCL of 40.51.
Thirty-eight out of seventy five (50.7% 95% CI 39.9,62.1) adolescents scored above the threshold for caseness (>46) according to parent information. The group as a whole were reported to be disruptive (75th percentile compared to norms) and antisocial (76th percentile compared to norms) where it was about average (50th perecntile) for the anxiety, autistic relating, self-absorbed and communication disturbance subdomains. The mean, median and standard deviation of the DBCL total and sub-domain scores and norm percentiles are shown in table 12.

The following results were found in comparisons of the total and subdomain scores on the DBCL by:

Age

There was no association between age and DBCL total and subdomain scores (r=-.0.010-0.073, p>0.05)

Gender

The male to female ratio in being a case was 2.8:1. The risk, however, of being a case was non significant between male and female young persons (OR=2.38, 95% CI 0.903,6.27) (figure 2).

Comparisons between male and female adolescents on the sub domains of the DBCL did not show any significant differences (Table 13, Mann-Whitney non parametric test).

Level of adaptive behaviour

Comparisons between adolescents in the mild and moderate adaptive behaviour group with those in the severe and profound showed that adolescents in the latter had significantly higher scores in the self-absorbed domain (*Mann-Whitney* $z=-2.221$, $p=0.001$ *after Bonferroni correction for multiple testing*).

The details of all the results are shown in table 14.

However, the relationship between caseness and level of adaptive functioning was non significant (*chi squared with continuity correction* $x^2=1.067$, *with associated significance level .302*).

Table 12: DBCL total and sub-domain scores 1) for male and female adolescents and 2) by level of adaptive behaviour

DBCL domains	Gender	Adaptive level
	Male (N=48)	Mild/Moderate (N=33)
	Female (N=27)	Severe/Profound (N=42)
	mean (median) S.D	
Total Score		
40.51 (34.00) 24.61	49.81 (49) 23.015	41.27 (34) 23.97
	43.44 (35) 31.78	52.43 (49.5) 27.57
Antisocial		
1.34(0.5 (76th))	1.94 (1.5) 2.04	1.76 (1) 2.16
21.887	1.3 (0) 2.21	1.67 (1) 2.10
Anxiety		
5.40 (5.0 (54th)) 3.726	5.98 (5) 4.14	6.12 (5) 3.51
	6.15 (5) 3.9	5.98 (5) 4.43
Autistic relating		
4.18 (4.0 (50-60th))	5.05 (4.5) 3.61	3.67 (4) 3.02
3.294	4.15 (4) 3.43	5.60 (5) 3.74
Disruptive		
13.49 (11.50 (75th))	17.17 (17.50)8.98	15.18 (13) 9.66
9.46	13.93 (11) 11.16	16.64 (16.5) 10.10
Self absorbed		
6.46 (5.0 (50th)) 6.14	8.56 (8) 6.71	5.18 (5) 4.55
	6.89 (5) 6.97	10.14 (9) 7.51
Communication disturbance		
2.71 (2.0 (50th)) 3.20	3 (3) 3.06	2.39 (1) 3.15
	3.67 (2) 4.21	3.90 (3) 3.66

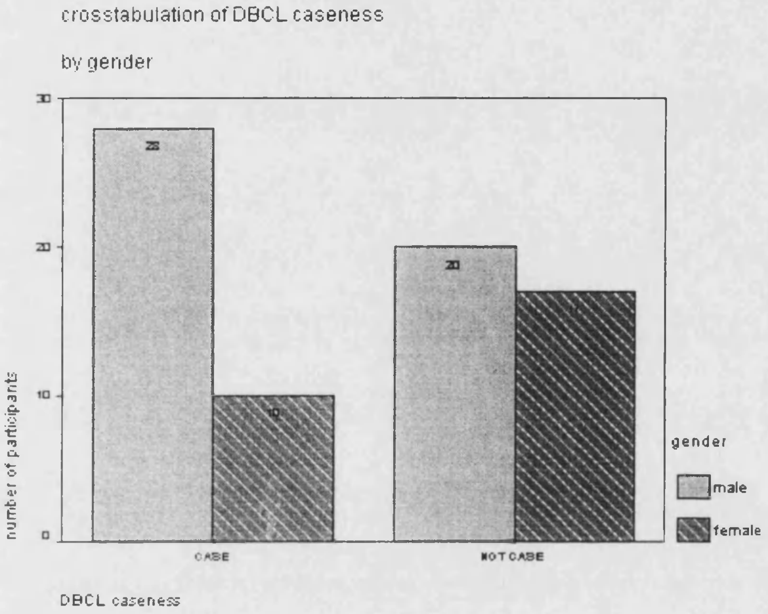
Table 13: Comparison of DBCL total and subdomain scores between male and female participants

	total DBCL score	disruptive	self absorbed	communication disturbance	anxiety	autistic relating	antisocial
Mann-Whitney U	495.000	505.500	528.500	624.500	608.500	542.500	491.500
Wilcoxon W	873.000	883.500	906.500	1800.500	1784.500	920.500	869.500
Z	-1.689	-1.574	-1.322	-.264	-.439	-1.172	-1.807
Asymp. Sig. (2-tailed)	.091	.116	.186	.791	.661	.241	.071

Table 14: Comparison of DBCL total and subdomain scores between levels of adaptive behaviour

	total scores	disruptive	self absorbed*	communication disturbance	anxiety	autistic relating	antisocial
Mann-Whitney U	528.000	637.500	380.000	506.500	619.500	475.500	681.500
Wilcoxon W	1089.000	1198.500	941.000	1067.500	1522.500	1036.500	1584.500
Z	-1.762	-.593	-3.350	-2.030	-.790	-2.336	-.128
Asymp. Sig. (2-tailed)	.078	.553	.001	.042	.430	.020	.898

Figure 2



(OR=2.38, 95% CI 0.903,6.27)

7.3 Developmental Behaviour Checklist-Teacher

Teachers returned twenty-four valid questionnaires (8.7% of potential response). Teacher questionnaires could not be completed for 13 participants who were out of school or were at home for the past year. The adolescents, as a group, scored a mean total of 35.16 (median 26.0, S.D. 33.87, total scores ranged from 0 to120).

Boys were more likely to have a higher total DBCL score compared with girls (*Mann-Whitney* $z=-2.199$, $p=0.026$). Further analyses were not carried out because of the small sample size.

7.4 Clinical Diagnoses (ICD 10)

Fifty out of seventy-five adolescents (66.7% 95% CI 56.2 77.2) were diagnosed with an identifiable mental illness following clinical interview, twelve more than those reported as cases by their parents. Cases were more likely to be male (*chi squared with continuity correction 7.878,* $df=1$, $p<0.01$. $OR=4.75$, *95% CI 1.695 13.309*).

There was no significant relationship between caseness at clinical interview and level of adaptive functioning (*chi squared with continuity correction 1.522,* $df=1$, $p>0.05$).

The commonest diagnoses were conduct disorder (21.4%), followed by Pervasive Developmental Disorders including both childhood and atypical autism (16%), hyperkinetic disorder (14.7%) and emotional disorders (12.1%).

Also, four cases were comorbid for more than one ICD 10 diagnosis and in addition to ID. Those cases were hyperkinetic disorder and Gilles de la Tourette syndrome (1), Personality disorder and substance misuse (1) and substance misuse and depressive disorder (2).

Two new cases of atypical autism were identified at clinical interviews in addition to the participants who had been diagnosed previously.

Comparisons between cases and non cases according to ICD 10 on the total and subdomain scores of the DBCL showed that cases had significantly increased scores on most of the subdomains (after Bonferroni correction for multiple testing): disruptive (*Mann-Whitney* $z=-5.363$, $p>0.0001$), anxiety ($z=-3.038$, $p=0.002$), communication disturbance ($z=-2.842$, $p=0.004$), self-absorbed ($z=-5.386$, $p>0.0001$) and autistic relating ($z=-2.787$, $p=0.005$).

Agreement between parental reports of psychopathology and clinical interviews was moderate (Cohen's kappa=0.518).

Table 15 shows the distribution of ICD 10 diagnoses recorded.

In conclusion,

- The majority of the sample appeared to have psychiatric morbidity in the family.
- There was no association between age and DBCL total and subdomain scores.
- Adolescents in the severe and profound level of adaptive functioning had

significantly higher scores on the self-absorbed subdomain of the DBCL.

- Male adolescents are more likely to be diagnosed as cases at clinical interview.
- Adolescents diagnosed as cases at clinical interview have significantly higher scores on most DBCL subdomains.

Table 15: Clinical (ICD 10) diagnoses -whole group

ICD 10 Diagnoses	ICD 10 code	N (%)
No mental disorder	-	25 (33.3)
Any mental illness		50 (66.7)
Type of mental illness		
Childhood autism	F84	4 (5.3)
Atypical autism	F84.1	8 (10.7)
Hyperkinetic disorder	F90	11 (14.7)
Conduct disorder		16 (21.4)
Confined to family context	F91.0	3 (4)
Socialised	F91.2	3 (4)
Conduct disorder, unspecified	F91.9	8 (10.7)
Other mixed disorders of conduct and emotions	F91.8	2 (2.7)
Emotional disorders		9 (12.1)
Anxiety disorder	F93.80	5 (6.7)
Social anxiety disorder	F93.2	2 (2.7)
Depressive disorder	F32.1	2 (2.7)
Personality Disorder (dissocial)	F60.2	1 (1.3)
Substance misuse	F12 & F18	2 (2.6)
Tourette syndrome	F95.2	1 (1.3)
More than one ICD 10 diagnosis		4 (5.4)

7.5 Participants with autism

Twelve adolescents had a diagnosis of atypical autism (nine male). Their mean age was 15.3 years (SD=2.04). They were significantly more likely to be reported as cases (*chi* *squared test with continuity correction,* $x^2=4.642$, *df=1, p=0.031*). A comparison of this group with the rest of the group of adolescents showed that they had significantly higher scores on the self-absorbed subdomain of the DBCL (Levene's test for equality of variance was non significant, *t-test*=2.882, df=73, p=0.005). There was no significant association between having autism and level of adaptive functioning (*chi squared with continuity correction,* $x^2=0.245$, *df=1, p>0.05*).

Figure 3 shows a diagrammatic comparison of diagnosis of autism between DBCL reported cases and non-cases.

7.6 Adolescents in transition

The sample of participants was divided in to two groups according to their age; a younger group (aged twelve to fourteen) and a subgroup of forty-four adolescents (58.7%) aged fifteen to nineteen years (mean=16.9 years, sd.=1.34).
Comparisons between these groups (aged 12 to 14 years) showed that the adolescents in transition had significantly lower scores on the VABS socialisation domain (*Mann-Whitney non parametric test, z=-3.319, p=0.001 after correction for multiple testing*).
No other differences were found in terms of: being a case either in the DBCL or clinical interview, level of ID, gender, paternal occupation.

7.7 Associations

Finally, a direct logistic regression was performed on caseness by parental reports (dependent binary variable based on the cut-off score of the DBCL) and six demographic and clinical predictors: VABS composite standard score (as a measure of overall social adaptive ability and cognitive level), gender, paternal occupation, family history of mental illness, presence of epilepsy and autism.

Firstly, univariate analyses were performed with each of the variables, then a multiple regression analysis with all the variables (mode enter) and lastly a forward and backward stepwise analysis were also performed. The prediction was good with 71.1% of cases and 67.6% of non cases predicted correctly, for an overall success rate of 69.3% (when all variables are included).

According to the Wald statistic the Vineland composite standard score, the presence of autism and family history of mental illness significantly predict caseness. The variance in case status accounted for is, however, rather small (Nagelkerke R squared=.306).

Table 16 shows regression coefficients, wald statistics, odds ratios and 95% confidence intervals for each of the six predictors for the univariate and multivariate analyses.

The strength and direction of the correlation between the continuous variables of adaptive behaviour scores and the domain and total scores on psychopathology were also examined (Pearson product-moment correlation coefficient r). Significant and negative correlations were found between 1) standard communication scores and self-absorbed (r=-.341, p=0.003); 2) standard activities of daily living scores and self-absorbed (r=-.404, p<0.001), communication disturbance (r=-.310, p=0.007), autistic relating (r=-.257, p=0.026), total DBCL scores (r=-.305, p=0.008); 3) standard socialisation scores and self-absorbed (r=-.438, p<0.001), autistic relating (r=-.303, p=0.008), total DBCL score (r=-.291, p=0.011); 4) composite standard score and communication disturbance (r=-.433, p<0.001), anxiety (-.288, p=0.012), autistic relating (r=-.277, p=0.016) and total DBCL score (r=-.307, p=0.007).

In other words, decreases in the Vineland domains and total score were associated with increases in the domains and total DBCL scores. However, only a few variables explain significant shared variance. That is, self-absorbed explains 12% of the variance on standard communication domain, 17% of the variance on standard activities of daily living domain and 20% of the variance on the standard socialisation domain. Communication disturbance explains approximately 10% of the variance on the standard composite adaptive score.

All correlation results are shown in table 17.

Table 16. Logistic Regression analysis of caseness (DBCL) as a function of demographic and clinical variables

Variables	Odds ratio (95% CI for Odds Ratio)		
	Univariate analysis	Multivariate analysis	Stepwise logistic regression (final model)*
Gender	.420 (1.108-.159)	.445 (1.319-.150)	n/s
Autism	.160 (0.791-.032)	.164 (.957-.028)	.144 (.814-.026) p=.028
Paternal employment	1.267 (3.541-.454)	1.387 (4.656-.413)	n/s
Epilepsy	1.389 (4.030-.479)	1.546 (5.422-.441)	n/s
Family history of mental illness	.487 (1.247-.190)	.323 (1.002-.104)	.326 (.954-.112) p=.041
VABS composite standard score	.957 (.993-.923)	.953 (.993-.916)	.957 (.995-.921) p=.026

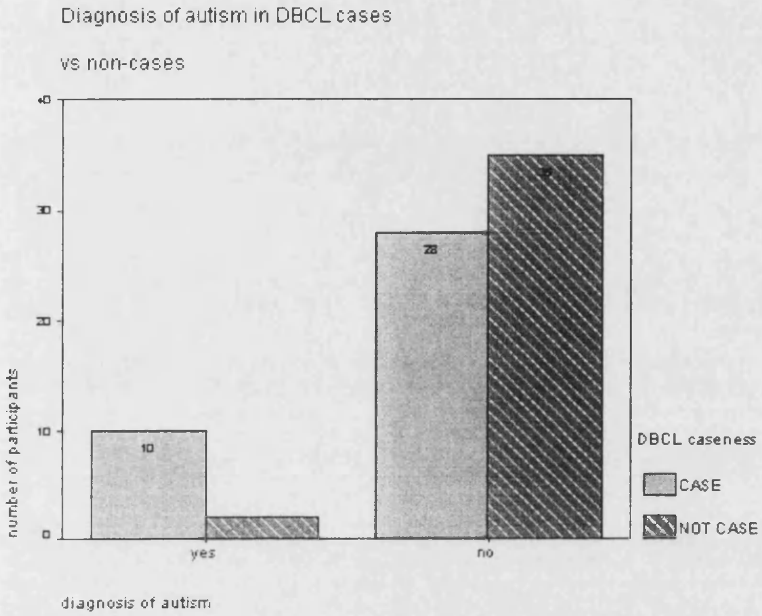
*: significant variables remain

Table 17. Pearson product-moment correlation coefficient between measures of psychopathology (DBCL) and adaptive functioning (VABS)

Measures	composite standard score	composite communication score	composite ADL score	composite socialisation score
1 Total DBCL score	-.307**	n/s	-.305**	-.291*
2 Anxiety	n/s	n/s	n/s	n/s
3 Autistic relating	-.277*	n/s	-.257*	-.303**
4 Communication disturbance	-.288*	n/s	-.310**	n/s
5 Disruptive	n/s	n/s	n/s	n/s
6 Antisocial	n/s	n/s	n/s	n/s
7 Self-absorbed	-.433**	-.341**	-.404**	-.438**

N=75. *: p<0.05 (two-tailed), **: p<0.01 (two-tailed)

Figure 3



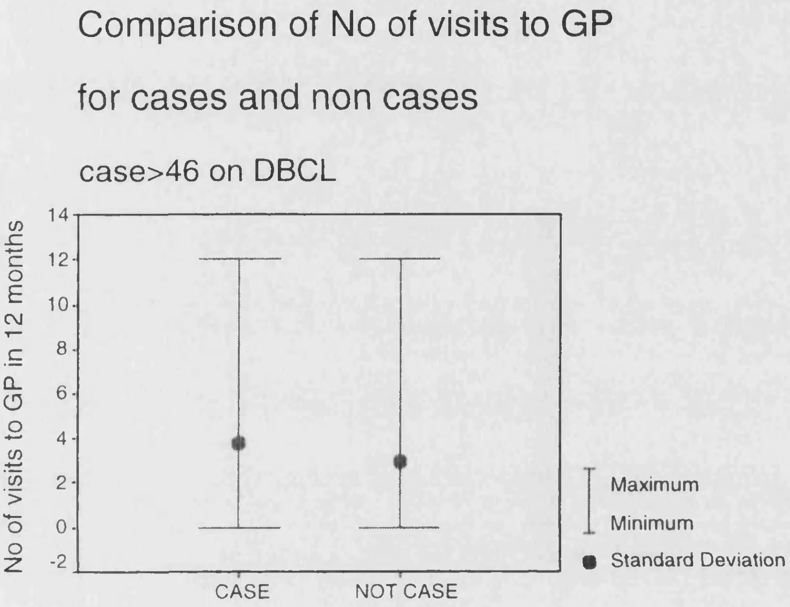
$x^2=4.642$, df=1, $p=0.031$

Chapter 8 Service Utilisation

8.1 Primary Care

All adolescents were registered with their family General Practitioner (GP). 68% of parents interviewed reported that they had visited their GP more than three times in the past year (mean 3.6, median 2.0, S.D. 3.40) and 8% of them as often as once a month. Almost half (46.7%) of the parents interviewed said that the reason for visiting was to seek help for their child's behavioural problems (twenty-one or 55.3% of cases and fourteen or 37.8% of non cases). There was no significant difference in the annual number of visits between cases and non cases identified by both the DBCL and clinical assessment (figure 4)

Figure 4:



t-test (.998, df=73, p=0.322)

8.2 Health and Social Care Provision

Being a case[1] did not distinguish between those having contact with services from non cases as seventy-one (94.7%) adolescents overall were in receipt of health and/or social care input (thirty-six cases and thirty-five of non cases). Twenty-nine (76.3%) cases had involvement from both health and social services, the former offered by
Child and Family Consultation Service (3), Learning Disability Service (2) and the Child Development Teams (24).

The corresponding number for non cases was seventeen (45.9%). One case was monitored only by a paediatrician (versus six non cases) and seven cases only received social services input compared to ten non cases.

Two adolescents were also seen at a tertiary centre. Additional treatments such as occupational therapy or physiotherapy had limited availability. Only two adolescents, one case and one non case had current intervention by occupational therapist and physiotherapist. Two carers reported lack of contact with services because what was on offer was felt to be unhelpful or irrelevant to their problems.
At the time of the interviews, four cases and eight non cases were either discharged including referral to another service or had dropped out of treatment (two participants in each group).

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[1] Caseness defined by parental report (DBCL)

Contact with services, as expected, had been ongoing since childhood for fifty-nine (78.7%) adolescents but with decreasing frequency, for example, non cases were reviewed once or twice a year either at school or at the Child Development Centre.

Reasons for ongoing contact varied from additional physical disabilities or medical conditions (such as incontinence) to various neurological symptoms including epilepsy. At the time of assessment, referrals were pending for psychology assessment (1), a tertiary centre for a second opinion (1), counselling (1) and decisions from the Education Authority about out-of-area placements (2).

Forty families overall (53.4%) reported being satisfied with the input they were receiving (seventeen cases and twenty-three non cases). However, more cases were reported to be dissatisfied (twenty-one or 55.2%) compared to non cases (fourteen or 37.8%).

Table 18 shows a detailed breakdown of service contact.

Table 18: professional involvement, outcome and satisfaction with services

Professional group	N (%)	
All registered with General Practitioners		
	Case	Non case
Social Services only	7 (18.42)	10 (27)
Health & Social Services	29 (76.3)	17 (45.9)
CDT†	24	15
CAMH‡	3	1
Learning Disability Service	2	1
Other	-	1
Health only (CDT)	1 (2.6)	6 (16.2)
OT* & Physiotherapy	-	1 (2.7)
Outcome of contact		
Ongoing	32 (84.2)	27 (72.9)
Discharged/referred	4 (10.5)	8 (21.6)
Dropped out	2 (5.3)	2 (5.4)
Satisfaction with services		
Yes	17 (44.7)	23 (62.1)
No	21 (55.2)	14 (37.8)

†: Child Development Teams, ‡: Child and Adolescent Mental Health Service

*: Occupational Therapy

8.3 Treatment

Medication

Fifty (66.7%) adolescents (thirty cases and twenty non cases) were treated with medication which included: anticonvulsants (eight cases and seven non cases), antipsychotics (eleven cases and six non cases), and hormone replacement therapy (one case and four non cases). One adolescent (case) received antidepressants and two cases amphetamines. Eight cases but only one non case were receiving more than one medication at the time of the study.

Informant and medical reports indicated that antipsychotic medication was being used for behavioural problems. Twenty-five (eight cases and seventeen non cases) (33.3%) adolescents were medication free.

Other therapeutic input

Psychological input was in the main provided by the Child and Family Consultation Service and included a systemic approach to family problems, behavioural techniques in some cases and operant conditioning such as positive reinforcement. One referral had been made to a tertiary London service for Psychotherapy.

Comment: Isn't operant conditioning/positive reinforcement a behavioural technique?

This is a necessarily discursive account, as parents were unable to recall past treatments with accuracy nor were detailed records available of treatment history other than a medical one. The impression given to the researcher was that most social and psychological interventions such as Speech and Language Therapy, Physiotherapy and Occupational Therapy had been available during childhood. Parents viewed some therapies such as Speech and Language therapy and physiotherapy as beneficial in the management of their child and were upset that in several cases such provision was stopped at the time of the young person starting at secondary school. At the time of the interviews, adolescents were reported to be receiving limited (monthly reviews) or no such treatment.

8.4 Social care

Most adolescents (86.7%) lived within the Local Authority responsible for their educational and social care provision.

Respite care was available in one home outside West Essex.
Five families used it regularly. Other parents did not want to make use of it (7 "thought it was inappropriate or not safe") and some of the adolescents were reported not to like it (2 cases). Other opportunities for respite and recreational activities included foster family respite (3 cases); summer camp (1 case); day club during holidays (2 cases); a specialist home out-of-area for children with severe physical disabilities (1 case); community support worker or be-friender to take the adolescent for community outings or arranged activities (3 cases). Four families used relatives, i.e. grandparents or parental siblings to look after the young person.

8.5 Carer comments

Although the study did not include a qualitative component from the outset, during the course of the interviews several parents made comments about their perception of local care. These are summarised below:

"Have tried everything but it had not worked"; "Felt that they were not understood by the services"; Had attended appointments to start with but did not want to carry on", "parent was told by GP that there was not any professional who could see their son".

Other needs identified by parents were lack of funds for holidays, lack of flexible arrangements of care and lack of information on what services were available ("I would not know where to start from").

PART IV DISCUSSION

Chapter 9 Main findings of the study

The study reported in this thesis is a cross sectional survey of adolescents with ID in a specified catchment area. The study aimed to examine firstly the prevalence rates of psychiatric problems in this population and secondly the pathways to care of this group. The results indicate that **a)** adolescents with ID have high rates of psychiatric problems and that these rates far exceed current rates of psychopathology in their counterparts of average intelligence (hypothesis 1), **b)** diagnosis of autism and level of adaptive functioning are significantly associated with the presence of psychopathology (hypothesis 2).

The study has not confirmed whether there is a distinctive pattern of engagement with services in this population since both cases and non cases appear to have long-term engagement with both health and social services (hypothesis 3).

9.1 Sociodemographic characteristics

Seventy-five adolescents aged 12 to 19 years and their primary carer participated in the study, drawn form a wide variety of community settings. Thirty-three (44%) adolescents had mild or moderate levels of adaptive functioning, and fourt-two (56%) severe or profound. The definition of adaptive functioning was based on the composite standard score (see methods section). The distribution of the sample reflected the relative population density of the study area; most adolescents were recruited from Harlow, a smaller proportion from Epping and Uttlesford.

Two thirds of the adolescents lived in a two-parent household. A small minority (4%) were either within borough or out-of-area residential care. The majority attended either school or college (sixty-eight or 90.6%) but seven (9.4%) were at home with family.

As expected, in the majority of cases there was no identifiable cause for the intellectual disability. In line with known prevalence rates, the commonest genetic disorders found in the sample were fragile X and Down syndromes.

The sociodemographic profile of the sample has been already reported in the results section. It is worth noting that ethnic mix and employment details are representative of the West Essex locality.

9.2 Clinical findings

The proportion of cases identified by parental reports (DBCL) was more than half of the total sample (50.7%). Clinical interviews increased this to two-thirds of the sample (66.7%).

Because of the small number of DBCL questionnaires returned by the teachers no comparisons were made between subgroups. However, male adolescents were more likely to be reported as cases.

There was moderate agreement between DBCL and ICD10 diagnoses.

Level of adaptive functioning and a diagnosis of autism were significant predictors of psychopathology.

9.3 Care pathways

Primary care consultation appeared to be used by parents to seek help with the young person's behaviour, but it was not used more often by cases compared to non cases.

Input by health and social services was lifelong in the majority of cases and non cases. Antipsychotic medication was prescribed for a quarter of adolescents for behavioural problems. Parents valued input by other professionals but its availability was limited. There were limited options for social care and community activities were mainly organised by Social Services with lack of more flexible individualised care plans.

Chapter 10 Limitations of the study

10.1 Sample selection

The participant list was drawn from all available local sources. However, due to resource limitations it was not possible to screen mainstream schools for students with intellectual disability. Thus several young persons who might be at the lower end of normal intelligence, or who might have been manageable in mainstream schools because of lack of challenging behaviours, would not have been approached. This includes the sub sample of fifty children whose suitability assessments were pending.

The comparison between respondents and non-respondents showed that the latter group tended to be younger. Parents may have felt that they were sufficiently supported by the present system and did not require further assistance. No further conclusions can be drawn about non-respondents as information about them only included age and gender.

Certainly, there were very few people from minority ethnic groups, which directly reflects the social composition of West Essex (WE). All but one of the specific syndrome support groups that were approached were unable to provide any referrals to the study mainly because of lack of membership in the area of interest (WE).

10.2 Other sources of bias

A cross-sectional design, that is collection of data at one point in time, can not determine the direction of cause and effect between variables. It is therefore only possible to report statistical associations, and then to speculate on likely direction of causal relationships between variables.

Psychometric assessment of all participants would have added complementary information about the sample's ability level. Inclusion of older and younger age groups would have been helpful in establishing patterns of onset of psychopathology that could differentiate points for clinical intervention.

10.3 Issues arising from recruitment

The researcher was not allowed to approach families in dispute with Social Services (four cases under investigation at the time of recruitment). Referral rates were generally slow despite active encouragement of professionals to refer individuals. This included talks about the project to local teams as well as personal contacts in my capacity as Consultant Psychiatrist in learning Disabilities in West Essex. Several parents agreed initially, only to withdraw their consent later because they *"could not see a direct benefit to them from the study whilst it was being carried out"*.

Participants were also asked to opt in to the research, therefore, those who agreed to it were more likely to be predisposed positively towards participating in research. .

Much effort was put into engaging the various agencies in the study. Those included

1. Presentations at the local academic programmes (e.g. Child and Family Consultation Service)
2. Presentations at the monthly Social Services seminars and meetings with the team leaders
3. Meetings with the Headteachers of the two local special needs schools (Harlowfields and Oakview-previously St Lukes)
4. Presentations at GP training seminars

A recent systematic review examined ways in which response rates to questionnaires can be improved (Edwards et al, 2002). One particular method which appears to be significantly associated with increased response is that of offering monetary incentives. However, apart from the ethical dilemmas that this strategy raises, including its use in a vulnerable group, it was not considered, as the project did not have external funding. Teachers were also likely to have responded to questionnaires where the adolescent might have presented a problem in the classroom. They also were unable to complete questionnaires for those who were not attending the particular school at the time of the study. Therefore, their response might have introduced systematic bias towards male adolescents.

10.4 Other issues

The record of obstetric complications used in this study is very limited. A fuller assessment of obstetric adversity could have been used to examine association with mental illness in the sample (Eaton et al, 2001).

Chapter 11 Discussion of the findings

11.1 The local picture

West Essex was generally considered to have few resources available for the health and social care of both children and adults with intellectual disability. The Child and Adolescent Mental Health Service had received the contract for service provision to young persons with ID. However, because of the personal interest of the previous incumbent in the post of Consultant Psychiatrist in Intellectual Disabilities, a few children and young persons were assessed and managed by the Community Intellectual Disabilities Service. As far as the researcher is aware there had been discussions between the two services about how to manage referrals and the pathway to either service but there was no clear approach as to how that was to be achieved. Existing budget management arrangements were also contributing to the lack of reciprocal arrangements between the services. Adolescents with ID were likely to be referred to the Learning Disability Service at the age of 16 years, occasionally after the age 19 years but earlier too if they presented with severe problems which required possible admission to hospital. This organisational pattern is common across services in the UK, most of which operate an adults only policy yet others a lifespan one. Communication with the Child and Adolescent Mental Health Service (CAMHS) was not as frequent or close as it should perhaps have been at the time of the study.

11.2 Considerations of prevalence and between group comparisons

This is the first study to examine the prevalence of psychopathology solely in adolescents with ID. The rate of problem behaviours (50.7%) is in line with other published studies that have found high rates of such problems. As mentioned by Linna et al (1999), using both parental reports and clinical interview increased the number of adolescents who were identified as cases (66.7%).

The present study has found a higher prevalence rate for psychiatric disorders in the adolescents with ID than that reported by recent population studies in children with ID including a secondary analysis of a UK wide survey using the Development and Well-Being Assessment Schedule (ONS, 1999) (Emerson, 2003). This is a questionnaire which provides ICD 10 and DSM IV diagnoses of childhood disorders but has not been standardised in children with ID and was unavailable at the time of this study. The 1999 ONS study in addition did not target children and adolescents with ID and the authors used a combination of survey items to ascertain those with ID in that sample. Therefore, the present high prevalence may be a more accurate estimate of psychopathology that is likely to include problem behaviours which are more prevalent in adolescents with moderate, severe or profound levels of intellectual disability.

In keeping with Einfeld & Tonge (1996) and Molteno et al (2001), adolescents with severe and profound ID were more likely to score higher on the self-absorbed subdomain. Gender did not appear to have an effect on psychopathology in this study. Similarly, age was not associated with psychopathology although Einfeld & Tonge (1996) reported a positive correlation between increasing age and scores on the antisocial subdomain of the DBCL; Molteno et al (2001) found that psychopathology was increased in the younger children in his sample; McCormack et al (2000) found age to be associated with the self-absorbed subdomain. Two important subgroups were identified; one with autism and another of older adolescents (in transition). The former was more likely to be identified as cases. The latter, contrary to expectations, did not appear to be significantly different from a younger age sub group.

Epilepsy did not appear to be a predictor of caseness in this study. Only the study by Molteno et al (2001) reported significant associations between epilepsy and total DBCL, self-absorbed and autistic relating scores.

Although most of the recruited adolescents were attending special schools, this is consistent with other recent research (Emerson, communication to AH, 2002) and policy practice in the UK.

There were too few adolescents with Fragile X or Down syndrome to allow for meaningful statistical analyses of the subgroup.

11.3 Checklist versus categorical classification systems

The Practice Parameters of the American Academy of Child and Adolescent Psychiatry (1999) propose that a comprehensive history, patient interview and medical review are important in reaching a diagnostic formulation for children and adolescents with ID and mental disorders. Behavioural questionnaires and observation are additional measures that allow clinicians to build an accurate picture about the person's difficulties. The choice of instruments for this study attempted to combine an interview technique and a clinical interview in order to make appropriate judgments about individuals. There are different schools of thought as to which is the best approach. Einfeld & Tonge (1994) argue strongly for the use of dimensional checklists, which may

"*assist in cases.....by providing quantitative confirmation of clinical evaluation*".

However, this last point also indicates that there is not just one right tradition in measuring psychopathology. Although the continuous and categorical approaches may differ in their conceptualisation of psychiatric disorder, they may also overlap in their understanding of mental health concepts. Thus, they are best viewed as complementary rather than contradictory or conflicting. Therefore, it is reasonable to assume that a combination of techniques will be more useful than relying solely on one type of information (Angold, 1989). It is also now being recognised that adults are often not very good informants on a child's or young person's mental state especially for internalising conditions such as anxiety and depression (Angold et al, 1987). The present diagnostic and classification systems such as the ICD 10 present difficulties in the assessment of psychiatric problems in young persons with ID as indeed in older persons with ID. This is mainly due to the fact that intellectual disabilities and psychiatric disorders are heterogeneous and may have considerable comorbidity (Feinstein & Reiss, 1996). Sovner (1986) described the limitations of the clinical diagnostic interview of a person with ID as "*intellectual distortion*", "*psychosocial masking*" and "*cognitive disintegration*". Therefore, as an alternative to the limited information that can be gained from the interview, the development of rating scales of behavioural symptoms has taken place.

Boyle et al (1997) have argued that checklists and interviews have different qualities, which can balance the information that is sought. For example, checklists offer flexibility in data collection, do not require a lot of time to complete and necessitate only limited training of the interviewer. On the other hand interviews allow the opportunity to build rapport with participants and to ensure that all aspects of information have been obtained. Interestingly, despite the moderate agreement between parental reports and the clinical diagnosis, the majority of the adolescents who were diagnosed with a disorder by either system were able to access some form of help (predictive value of diagnostic accuracy).

Personal interviews cannot be completely replaced in epidemiological research because they provide a "*...conduit for obtaining subtle information of high clinical relevance and for meeting nosological requirements to date the onset and duration of psychiatric symptoms*" (Boyle et al, 1997).

In the present study the use of a *broadband* instrument, such as the DBCL, was appropriate in order to include diagnostic categories that, although known to be prevalent in the population with ID, would not be included in a categorical classification system. The Developmental Behaviour Checklist has been used successfully in several other studies of prevalence internationally. The caseness cut-off score of 46 was not increased as it has been shown by the instrument's developers to denote "definite psychiatric caseness" clinically. It has also been reported that DBCL scores are good predictors of the outcome of a clinical assessment. However, in this instance there was only moderate agreement between the two assessments, though the rates of caseness from parents and researcher were similarly high. It is likely that some parents might have found it difficult to score items on the list, which is a comprehensive account of all the problem behaviours found in young persons with ID.

Comment:

Finally, Feinstein and Reiss (1996) suggest that separating behaviour problems from clinical diagnoses based on a recognized classification system may influence the treatment options available as well as creating the "*conceptual bias in clinicians of diagnostic overshadowing*".

11.4 Health and Social care pathways

There has only been one other study (Einfeld & Tonge, 1996) which has reported on contact with services. The authors found that only 9% of those with psychiatric problems had received specialist assistance. The results of the present study indicate that contact with services does not appear to be dependent on caseness but tends to be long-term albeit with decreasing frequency as the child becomes older. Behavioural problems are the main reason for the carer seeking help. The decision to contact primary care rested with parents. The outcome of several of those appointments was a referral to a secondary service provider. In many cases, referrals for assessment were made by agencies other than primary care (multi-track referral pattern), i.e. school nurses.

Antipsychotic medication was used in a significant minority to treat such disorders. However, the medication in itself may also be the cause of behavioural problems such as somnolence and social withdrawal or parkinsonian side effects which may mimic primary movement disorders, agitation and restlessness.

Referral status to CAMHS has been associated with parental requests and severity of symptoms (Bailey & Garralda, 1989; Garralda & Bailey, 1988) in children of normal intelligence. Certainly, in this study, two families who had been told that their child suffered with autism or autistic features were more active in seeking further contact with health professionals. However, in cases where ID was unexplained or very severe, parents appeared pessimistic about the benefit of further professional contacts for their child. It is the researcher's impression that as the adolescent was becoming an adult, parents appeared more uncertain about what benefit any service could provide and questioned whether any change could be achieved in the future.

It has been shown that lack of or poor identification of mental disorder by primary care can be a serious barrier to accessing adequate specialist care (Sayal et al, 2002). This is an important issue for both younger and older persons with ID as many of their difficulties are often explained away as associated with the intellectual disability rather than comorbid psychiatric disorders which can be treated (White et al, 1995).

Parental reports suggested that they sought help because they perceived a problem in their child, though frequent primary care attenders explained the frequent visits as the result of repeated infections in the young person which needed ongoing treatment.

Despite the possibility of recall bias, parental views on previous consultations also impacted on subsequent service use. Indeed, several parents believed that they had not been heard during previous appointments and either had dropped out of contact with health services altogether or had made complaints against various agencies, mainly Social Services and Education. Some were seeking a second opinion but found that they could not obtain a referral to tertiary services.

Both GPs and specialists were supervising the young persons who were receiving medication.

Chapter 12 Implications and future developments

12.1 Implications for service provision

Thirty-one adolescents were already open to or about to be seen for the first time by Child and Adolescent Mental Health Services. Another four new referrals to CAMHS resulted from the study whilst co-ordination of care improved for those cases that were jointly open to CAMHS and the specialist Learning Disability Service. Adolescents with ID are more dependent on their carers than normal adolescents, for health checks and contact with health services. If indeed, as is suggested by this study, primary caregivers underestimate the size of the problem, it is doubtful how well services are expected to identify those at risk who need specialist assessment and treatment. The presence of ID can be a serious confounding factor in diagnosing mental health problems in adolescents who may face barriers in receiving appropriate treatment.

As the rates of psychopathology in this population remain high, GPs need to be alert to the possibility of an underlying mental health problem. Furthermore, such chronic disorders are more likely to require intensive input and a supportive social care network. In 40% (30/75) of the adolescents the mental health problem was reported to have started in childhood. The examination of the 95% confidence intervals of the prevalence rate in the present study suggests that between a third and two thirds of adolescents with ID could require specialist input. This is a clinically significant issue that has not been anticipated by current service developments, particularly in terms of early intervention. For instance, the newly published NICE[2] (2002) guidance for the treatment of schizophrenia, highlights the importance of early assessment and treatment and contact with appropriate services. In addition, the strategy for people with ID (England, DoH

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[2] NICE: National Institute for Clinical Excellence, UK

2001) emphasizes the need for appropriate health and social care for this population and particularly for the adolescents who enter the transition phase to adult services.

12.2 Directions for future research

It is recognised that adolescents with ID are more vulnerable to develop mental health problems de novo or to suffer from pre-existing psychiatric problems than adolescents of more average intellectual ability. New evidence is emerging about factors that may predict who is most likely to develop a mental health problem.

It is also known that psychiatric disturbance may continue well into adulthood resulting in intractable problems and consequent social exclusion of the individual.

Although most adolescents are seen by services, there is a lack of evidence-based interventions which may prevent further avoidable impairments from occurring. The concept of early intervention for this population has not yet been developed adequately.

Future research should focus on developing appropriate operationalised diagnostic criteria for this population, as accurate diagnosis is paramount, especially as so many people with ID and behavioural problems may receive medication long-term.

Recognised diagnostic categories derived from the administration of behavioural scales also need to be correlated with known and accepted psychiatric disorders in order to facilitate comparisons between studies and generalisability of published findings.

Additional exploration is required to establish factors that may contribute to the onset of psychiatric disorders in the young persons with ID. It would appear that conduct disorders and hyperkinetic syndrome as well as emotional disorders are over-represented in this population.

Research should also focus on assessing the pathways to care employed by parents and primary care before further referral to specialist services is made. Different service models should be evaluated in terms of therapeutic and cost outcomes. Longitudinal studies are also of importance in establishing the course of disorders as the young person matures into adulthood. An additional strand of work will be exploration of the effects of age in the onset and presence of psychopathology in adolescents with ID compared to younger and older individuals with ID as well as with matched cases from the general population.

Another direction is to investigate the barriers to accessing specialist health services and ways in which those barriers can be overcome. It is often the case that families tend to see multiple professionals in several different settings with little tangible benefit. This approach, partly encouraged by lack of locally coordinated services can only perpetuate the fragmentation of child mental health care provision.

Future studies should also consider the inclusion of in-depth interviews with participants. This will provide invaluable insights into what service users consider as important components of an accessible support network that is helpful and meets their needs. Parents and the adolescents themselves can and should contribute to the development of services that deliver high standard psychiatric care.

Chapter 13 Case histories

Preface

The cases presented here are chosen to illustrate the diagnostic complexities inherent in the presentation of emotional problems in adolescents with ID, the extreme problem behaviours that parents have to deal with in some cases without any support and the poor liaison between professionals and agencies who are involved in the clinical management of, at times, very complicated issues. The names have been changed to protect the anonymity of the participants and their families.

Case 1

Mrs E. consented to be contacted by the researcher and agreed to meet for an interview. Michael was the first of two siblings and lived at home. His parents were divorced. Both parents had serious ongoing mental health problems with frequent contact with inpatient services. Michael aged 15-years was attending a school for children with special needs. His 13-year old brother also had learning disabilities (severe), and attended the same school as his brother. Michael appeared to enjoy school but he was very unruly at home. His mother reported that he had temper tantrums, terrorised his younger brother, destroyed furniture and was hyperactive. Furthermore, he had been threatening to his mother. Mrs E had been feeling unable to discipline her son and cope with his behaviour for sometime. She had been offered help by the Child and Family Consultation Service but ended up attending on her own as Michael had refused to participate and after a couple of meetings she dropped out altogether. Michael was not allocated to a social worker as he was not considered a management problem at school and there were no immediate accommodation issues.

At interview, mother was distraught but also resigned. There were dents on the walls caused by Michael's kicking and the door was constituted from different panels as it had been broken following an outburst of aggression by Michael. Michael was rude and argumentative during the interview, which he did not finish. He muttered to himself or did not answer and finally went to his room. As a result of the research interview, Social Services were contacted to express concern about Michael. Eventually a social worker was allocated who conducted a needs assessment of the family. He was also re-referred to the Child and Family Consultation Services where he was found to have labile mood and was prescribed carbamazepine as a mood stabiliser. His mother called in despair to complain that he did not take his medication, his behaviour was as difficult as ever and that he was feeding his tablets to the family dog. Within a month of interview, Michael was taken to the local casualty department in an extremely agitated state, having taken an overdose of carbamazepine and saying that he "wanted to die". He remained in casualty for two days waiting to be admitted to the regional adolescent unit. He was diagnosed with a bipolar affective disorder and hypothyroidism and was discharged home after about three months. The family was open to the Child and Family Consultation Service for continuing support and in parallel a referral was made to the adult service for people with ID.

Case 2

Mr and Mrs R were approached by the school and agreed to be contacted about the research. I met them at their home with all children present. Stephen is 16 years old and the oldest of four siblings. Father was retired and much older than mother. The family had moved to their present address from a neighbouring county in order to access better services. Mr R complained bitterly about his perceived lack of care for his son. The parents reported that Steven was not listening to them anymore, was going out with other young boys who took advantage of him and that he wanted to live independently. His constant preoccupation was about getting his own flat and when told that he was too young to leave home he became verbally aggressive. At interview father was overpowering and belligerent. Steven did not talk much. He had a mild speech impediment and looked downwards throughout. He said that he liked school and was also attending college as part of his further education plan.

He preferred to "hang out" with his friends. His view was that he would eventually learn to look after himself and could not see why his parents were worried about his moving out. Stephen and his parents engaged in an argument about his future. Father mentioned that he had caught Stephen smoking and taking money from his mother's purse, and that he had been returning home very late at night without telling them where he had been. Stephen repeated that he was with his friends. They reported that his behaviour had been difficult for them to manage for a few years though he was much better at school. They were proud of his skills in art, which they displayed in their living room.

Other issues regarding social care and benefit entitlements were mentioned as well as worries about their younger daughter who they thought might also have learning problems. A diagnosis of socialised conduct disorder was made. Following the interview, the parents called in crisis a few weeks later because Stephen was threatening to the family and especially to his father. A referral was made to Social Services and the specialist service for assessment of his social care and mental health needs in order to decide on the support required. Steven was referred to a local Connexions project group for young people with ID which was set up to provide training in coping and social skills.

Case 3

Mrs N was referred by her GP and agreed to participate in the study. Her 16 year old daughter, Nadia, had been living at home for the past two years after she had been suspended from her residential school because her behaviour was unmanageable. Nadia was well known to social services but there was no current involvement. Mother reported that Nadia was unruly, rude to her and the rest of the family, stole money, did not help around the house and that she was physically aggressive towards her and her sister in particular. Nadia was described as a nuisance to neighbours and it was alleged (found to be true) that local children called Nadia names because of her size (was overweight) and argumentative behaviour and threw stones at her windows. Nadia was prescribed carbamazepine for behavioural problems and labile mood for a few years prior to my meeting her but there was no obvious impact to her mental state. Mrs N had been divorced from Nadia's father for several years. There had been a history of domestic violence and father was dismissive of Nadia with whom he only had infrequent and irregular contact.

Mrs N had tried to contact the education authority to ask for a placement for Nadia but somehow no progress had been made. Mrs N, at the end of her tether, was considering whether she should ask Social Services to find Nadia a new residential home.

Nadia was an obese adolescent girl with good language skills and mild ID. She sat on the floor the entire time of the interview and listened attentively to her mother talking about her. She answered questions about herself and how she felt, mainly mosyllabically, but became more articulate and spontaneous when the conversation veered towards her computer games and presents she had been given. Based on her previous history of lack of discipline, opposition, fighting and aggression a diagnosis was made of conduct disorder.

Nadia vandalised a neighbour's front door and was questioned by Police. That was a point of crisis, which led to Nadia's need for increasing support being finally recognised. She was allocated a social worker to work out a transition plan to adult services for people with ID. Other out-of-area placements were also being sought.

A trainee psychologist engaged with Nadia and Mrs N for family work in order to improve Nadia's self esteem and help Mrs N develop better coping strategies. Nadia was placed under the Care Programme Approach. She agreed to attend College for two days a week and became interested in learning more about looking after animals. Nadia was found a community support worker who focussed on improving her social skills and facilitating her return to education by accompanying her to college classes.

REFERENCES

American Academy of Child and Adolescent Psychiatry (1999). Practice Parameters for the Assessment and Treatment of Children, Adolescents and Adults with Mental Retardation and Comorbid Mental Disorders. Journal of the American Academy of Child and Adolescent Psychiatry, Supplement, 38 (12), AACAP Official Action

Angold A (1989). Structured assessments of psychopathology in children and adolescents. In The instruments of Psychiatric Research (ed Thompson C). John Wiley & Sons LTD pp 271-299

Angold A, Weissman MM, Merikangas JK, et al (1987). Parent and child reports of depressive symptoms. Journal of Child Psychology & Psychiatry, 28, 901-915

Audit Commission (1994). Seen but not heard: co-ordinating community child health and social services for children in need. National Report, HMSO

Bailey D & Garralda ME (1989). Referral to child psychiatry: parent and doctor motives and expectations. Journal of Child Psychology and Psychiatry, 30, 449-458

Baranyay EP (1971). The mentally handicapped adolescent: the Slough Project of the National Society for Mentally Handicapped Children. Pergamon Press, Oxford

Bernal J and Hollins S (1995). Psychiatric illness and learning disability: a dual diagnosis. Advances in Psychiatric Treatment, 1, 138-145

Bland M (2000). An Introduction to Medical Statistic (3rd edition). Oxford University Press

Borthwick-Duffy SA, Lane KL and Widaman KF (1997). Measuring Problem Behaviors in Children with Mental Retardation: Dimensions and Predictors. Research In Developmental Disabilities, 18, 415-433

Borthwick-Duffy SA (1994). Epidemiology and prevalence of Psychopathology in People with Mental Retardation. Journal of Consulting and Clinical Psychology, 62, 17-27

Boyle MH, Offord DR, Racine YA et al (1997). Adequacy of interviews vs checklists for classifying childhood psychiatric disorder based on parent reports. Archives of General Psychiatry, 54, 793-799

British Paediatric Association (1994). Services for children and adolescents with learning disability (mental handicap). Report of the BPA Working Party

Brooks D and Bouras N (1994). Adolescents with a learning disability. Psychiatric Bulletin, 18, 606-608

Castle J, Groothues C, Bredenkamp D, Beckett C, O'Connor T, Rutter M (1999). Effects of qualities of early institutional care on cognitive attainment. E.R.A. Study Team. English and Romanian Adoptees. American Journal of Orthopsychiatry, 69, 424-37
Chadwick O, Piroth N, Walker J et al (2000). Factors affecting the risk of behaviour problems in children with severe intellectual disability. Journal of Intellectual Disability Research, 44, 108-123

Chess S & Hassibi M (1970). Behavior deviations in mentally retarded children. Journal of the American Academy of Child Psychiatry, 9, 282-297

Clarke DJ, Boer H, Whittington J et al (2002). Prader-Willi syndrome, compulsive and ritualistic behaviours: the first population based survey. British Journal of Psychiatry, 180, 358-362

Cohen J (1992). A power primer. Psychological Bulletin, 112, 155-159

Corbett JA (1977b). Mental Retardation- psychiatric aspects. In Child and Adolescent Psychiatry (eds Rutter M & Hersov L), p 11-25. Blackwell Scientific Publications

Cormack KFM, Brown AC, Hastings RP (2000). Behaviour and emotional difficulties in students attending schools for children and adolescents with severe intellectual disability. Journal of Intellectual Disability Research, 44, 124-129

Davies M, Udwin O, Howlin P (1998). Adults with Williams syndrome. Preliminary study of social, emotional and behavioural difficulties. British Journal of Psychiatry, 172, 273-276

Dawson B & Trapp RG (2001). Basic & Clinical Biostatistics (3rd edition). McGraw-Hill International Editions, Singapore

Deb S, Thomas M, Bright C (2001). Mental disorders in adults with intellectual disability, I: prevalence of functional psychiatric illness among a community based population aged between 16 and 64 years. Journal of Intellectual Disability Research, 45, 495-505

Department of Health (England and Wales) (2001). Valuing people: a strategy for people with learning disabilities for the 21st century. London: HMSO

Dykens EM (2000). Annotation: Psychopathology in children with intellectual disability. Journal of Child Psychology and Psychiatry, 41, 407-417

Dykens EM, Shah B, Sagun J, Beck T, King BH (2002). Maladaptive behaviour in children and adolescents with Down's syndrome. Journal of Intellectual Disability Research, 46, 484-492

Eapen V, Robertson MM, Zeitlin H and Kurlan R (1997). Gilles de la Tourettes's syndrome in special education schools: a United Kingdom study. Journal of Neurology, 244, 378-382

Eaton LF and Menolascino FJ (1982). Psychiatric disorders in the mentally retarded: types, problems and challenges. American Journal of Psychiatry, 139, 1297-1303

Eaton WW, Mortensen PB, Thomsen PH, Frydenberg M (2001). Obstetric complications and risk for severe psychopathology in childhood. Journal of Autism and developmental disorders, 31, 279-85

Edwards P, Roberts I, Clarke M et al (2002). Increasing response rates to postal questionnaires: systematic review. British Medical Journal, 324, 1183-1185

Einfeld SL & Tonge BJ (1994). Manual for the Developmental Behaviour Checklist: Primary Carer Version (DBC-P). Centre for Developmental Psychiatry, Monash University, Australia

Einfeld SL, Tonge BJ & Florio T (1994). Behavioural and emotional disturbance in fragile X syndrome. American Journal of Medical Genetics, 51, 386-391

Einfeld SL & Tonge BJ (1996). Population prevalence of psychopathology in children and adolescents with intellectual disability: epidemiological findings. Journal of Intellectual Disability Research, 40, 99-109

Einfeld SL, Smith A, Durvasula S et al (1999a). Behaviour and emotional disturbance in Prader-Willi syndrome. American Journal of Medical Genetics, 82, 123-127

Einfeld SL, Tonge B, Turner G (1999b). Longitudinal course of behavioural and emotional problems in fragile X syndrome. American Journal of Medical Genetics, 87, 436-9

Einfeld SL, Tonge BJ, Rees VW (2001). Longitudinal course of behavioural and emotional problems in Williams syndrome. American Journal of Mental Retardation, 106, 73-81

Emerson E (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. Journal of Intellectual Disability Research, 47, 51-58

Epstein MH, Cullinan D, Polloway EA (1986). Patterns of maladjustment among mentally retarded children and youth. American Journal of Mental Deficiency, 91, 127-134

Evans S and Brown R (1993). Perception of need for child psychiatry services among parents and general practitioners. Health Trends, 25, 53-56

Fee VE, Matson JL, Benavidez DA (1994). Attention deficit-hyperactivity disorder among mentally retarded children. Research in Developmental Disabilities, 15, 67-79

Feinstein C & Reiss AL (1996). Psychiatric Disorders in mentally retarded children and adolescents: that challenges of meaningful diagnosis. Child and Adolescent Psychiatric Clinics of North America, 5, 827-852

Flint J and Yule W (1994). Behavioural Phenotypes. In Child and Adolescent Psychiatry: modern approaches (Eds Rutter M, Taylor E, Hersov LA). Oxford, Blackwell Scientific

Flint J and Wilkie AOM (1996). The genetics of mental retardation. British Medical Bulletin, 52, 453-464

Flynn A,, Matthews H, Hollins S (2002). Validity of the diagnosis of personality disorder in adults with learning disability and severe behavioural problems: Preliminary study. British Journal of Psychiatry, 180, 543-546

The Foundation for People with Learning Disabilities (2002). Count Us In (2002). London, UK http://www.learningdisabilities.org.uk

Fryers T (1997). Epidemiology of mental retardation in Seminars in the Psychiatry of Learning Disabilities (ed Russell O), Gaskell Publications, London

Garralda ME & Bailey D (1988). Child and family factors associated with referral to child psychiatrists. British Journal of Psychiatry, 153, 81-89

Gater R, de Almeida-e-Sousa B, Barrientos G et al (1991). The pathways to psychiatric care: a cross cultural study. Psychological Medicine, 21, 761-774

Gath A & Gumley D (1986). Behaviour problems in retarded children with special reference to Down's syndrome. British Journal of Psychiatry, 149, 156-161

Gillberg C, Persson E, Grufman M and Themner U (1986). Psychiatric Disorders in mildly and severelly mentally retarded Urban Children and Adolescents: epidemiological aspects. British Journal of Psychiatry, 149, 68-74

Goodman R (1998). The longitudinal stability of psychiatric problems in Children with hemiplegia. Journal of Child Psychology and Psychiatry, 39, 347-354

Goodman R, Ford T, Richards H, Gartward R, Meltzer H (2000). The Development and Well-Being Assessment: description and initial validation of an integrated assessment of child and adolescent psychopathology. Journal of Child Psychology and Allied Disciplines, 41, 645-656

Goodman R, Ford T, Meltzer H (2002). Mental health problems in children in the community: 18 months follow up. British Medical Journal, 324, 1496-1497

Hardan A & Sahl R (1999). Suicidal Behaviour in Children and Adolescents with Developmental Disorders. Research in Developmental Disabilities, 20, 287-296

Hardan A & Sahl R (1997). Psychopathology in children and adolescents with developmental disorders. Research in Developmental Disabilities, 18, 369-382

Heiman T (2001). Depressive mood in students with mild intellectual disability: students' reports and teachers' evaluations. Journal of Intellectual Disability Research, 45, 526-534

Hepper F & Garralda ME (2001). Psychiatric adjustment to leaving school in adolescents with intellectual disability: a pilot study. Journal of Intellectual Disability Research, 45, 521-525

Heslop P, Mallett R, Simons K, Ward L (2002). Bringing the divide at transition: what happens for young people with learning difficulties and their families? BILD, UK

Hoare P, Harris M, Jackson P et al (1998). A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. Journal of Intellectual Disability Research, 42, 218-227

Howells G (1986). Are the needs of the mentally handicapped adults being met? Journal of the Royal College of General Practitioners, 36, 449-453

Jacobsen JW (1982). Problem behaviors and psychiatric impairment within a developmentally disabled population I: behavior frequency. Applied Research in Mental Retardation, 3, 121-139

Johnson CR, Handen BL, Lubetsky MJ & Sacco KA (1995). Affective disorders in hospitalised children and adolescents with mental retardation: a retrospective study. Research in Developmental Disabilities, 16, 221-231

Joint College Working Party, Section for the Psychiatry of Mental Handicap and Child and Adolescent Psychiatry Section (1989). The training required to provide a psychiatric service for children and adolescents with mental handicap. Psychiatric Bulletin, 326-328

Kiernan C and Kiernan D (1994). Challenging behaviour in schools for pupils with severe learning difficulties. Mental Handicap Research, 7, 177-201

Koller H, Richardson SA, Katz M (1983). Behavior disturbance since childhood among a birth cohort of all mentally retarded young adults in a city. American Journal of Mental Deficiency, 87, 386-395

Lewis JN, Tonge BJ, Mowat DR, Einfeld SL et al (2000). Epilepsy and associated psychopathology in young people with intellectual disability. Journal of Paediatrics and Mental Health, 36, 172-175

Lindsey M (1998). Signposts for success in commissioning and providing health services for people with learning disabilities . Department of Health, London UK

Linna SL, Moilanen I, Ebeling H et al (1999). Psychiatric symptoms in children with intellectual disability. European Child & Adolescent Psychiatry, 8 (Suppl 4), 77-82

Manikam R, Matson J, Coe DA, Hillman N (1995). Adolescent depression: relationships of self-report to intellectual and adaptive functioning. Research in Developmental Disabilities, 16, 349-364

Mansell J L (1993). Services for people with learning disabilities and challenging behaviour or mental health needs. London, HMSO

Masi G, Mucci L, Favilla L & Poli P (1999). Dysthymic disorder in adolescents with intellectual disability. Journal of Intellectual Disability Research, 43, 80-87

Matson JL, Barrett RP, Helsel WJ (1988). Depression in mentally retarded children. Research in Developmental Disabilities, 9, 39-46

McLaren J & Bryson SE (1987). Review of recent epidemiological studies of mental retardation: prevalence, associated disorders and etiology. American Journal of Mental Retardation, 92, 243-54

Meltzer H, Gatward R, Goodman R and Ford T (2000). The Mental Health of children and adolescents in Great Britain. National Statistics, London HMSO

Menolascino FJ (1966). The façade of mental retardation: its challenge to Child Psychiatry. American Journal of Psychiatry, 122, 1227-1235

Menolascino FJ (1969). Emotional disturbance in mentally retarded children. American Journal of Psychiatry, 126, 168-176

Mental Health Foundation (1997). Don't Forget us: children with learning disabilities and severe challenging behaviour. London

Mental Health Foundation (1993). Learning Disabilities: the fundamental facts. London

Molteno G, Molteno CD, Finchilescu G & Dawes RL (2001). Behavioral and emotional problems in children with intellectual disability attending special schools in Cape Town, South Africa. Journal of Intellectual Disability Research, 45, 515-520

National Institute for Clinical Excellence (2002). Core interventions in the treatment and management of schizophrenia in primary and secondary care. Clinical Guideline (UK)

Office of Population Censuses and Surveys (OPCS) (1991). Data on West Essex

Philips I & Williams N (1975). Psychopathology and mental retardation: a study of 100 mentally retarded children: I. Psychopathology. American Journal of Psychiatry, 132, 1265-1271

Quine L (1986). Behaviour problems in severely mentally handicapped children. Psychological Medicine, 16, 895-907

Reid AH (1980). Psychiatric disorders in mentally handicapped children: a clinical and follow-up study. Journal of Mental Deficiency, 24, 287-298

Reiss S, Levitan GW, Szyszko J (1982). Emotional disturbance and mental retardation: diagnostic overshadowing. American Journal of Mental Deficiency, 86, 567-74

Romano E, Tremblay RE, Vitaro F (2001). Prevalence of psychiatric diagnoses and the role of perceived impairment: findings from an adolescent community sample. Journal of Child Psychology and Psychiatry, 42, 451-459

Royal College of Psychiatrists (1998). Psychiatric Services for children and adolescents with a learning disability. Council Report 70.

Royal College of Psychiatrists (2001). DC-LD [Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation]. Occasional Paper 48

Rutter M, Graham P and Yule W (1970). A neuropsychiatric study in childhood. Clinics in Developmental Medicine. London, Heinmann Medical Books

Saxby H & Morgan H (1993). Behaviour problems in children with learning disabilities: to what extend do they exist and are they a problem? Child: care, health and development, 19, 149-157

Sayal K, Taylor E, Beecham J, Byrne P (2002). Pathways to care in children at risk of attention-deficit hyperactivity disorder. British Journal of Psychiatry, 181, 43-48

Schaefer GB & Bodensteiner JB (1992). Evaluation of the child with idiopathic mental retardation. Pediatric Clinics of North America, 39, 929-43

Shepperdson B (2001). Negotiating Adolescence in Transition and Change in the Lives of People with Intellectual Disabilities (ed May D). Jessica Kingsley Publishers. London & Philadelphia, pp55-74

Sparrow SS, Balla DA, Cicchetti DV (1984). Vineland Adaptive Behaviour Scales-Interview Edition. Survey Form Manual, AGS

Steffenburg S, Gillberg C, Steffenburg U (1996). Psychiatric disorders in children and adolescents with mental retardation and active epilepsy. Archives of Neurology, **53**, 904-912

Strømme P & Diseth (2000). Prevalence of psychiatric diagnoses in children with mental retardation: data from a population-based study. Developmental Medicine & Child Neurology, 42, 266-270

Strydom A (2002). A survey of the mental health and other care needs of older people with learning disability. MSc Thesis, University College London, 30

The Children Act 1989 (1991). Guidance and Regulations. Volume 6: Children with Disabilities. HMSO

Tonge BJ, Brereton AV, Gray KM, Eifeld SL (1999). Behavioural and emotional disturbance in high functioning autism and Asperger syndrome. Autism, 3, 117-130

Tonge BJ & Einfeld S (2000). The trajectory of psychiatric disorders in young people with intellectual disabilities. The Australian and New Zealand Journal of Psychiatry, 34, 80-84

Turk J (1995). Psychiatric, psychological and behavioural function of a British sample of boys with fragile X syndrome. MD Thesis, University of London

Turk J (1996). Working with parents of children who have severe learning disabilities. Clinical Child Psychology and Psychiatry, 1, 581-596

Turk J (1998). Fragile X syndrome and attentional deficits. Journal of Applied Research in Intellectual Disabilities, 11, 175-191

Volkmar F & Dyken E (2002). Mental Retardation in Child and Adolescent Psychiatry (eds Rutter M & Taylor E), pp 697-710. Blackwell Publications, Oxford, UK

White MJ, Nichols CN, Cook RS, Spengler PM, Walker BS, Look KK (1995). Diagnostic overshadowing and mental retardation: a meta-analysis. American Journal of Mental Retardation, 100, 293-298

World Health Organisation (1993). The ICD10 Classification of Mental and Behavioural Disorders. WHO, Geneva

APPENDICES

(headed paper)

MENTAL HEALTH PROBLEMS IN YOUNG PERSONS WITH LEARNING DISABILITIES

Consent Form for under 16 years old

Name of young person: ____

Parent's/carer's* consent

***: delete as appropriate**

I have read the information about the study of mental health problems in young persons with learning disabilities by Dr Hassiotis and am willing for me and my child to take part in the study.

I agree for the child's medical records to be examined and for a blood sample to be taken for genetic analysis if possible.

Parent's/carer's signature and name:

____

______________________________________ Date:____________

(headed paper)

MENTAL HEALTH PROBLEMS IN YOUNG PERSONS WITH LEARNING DISABILITIES

Consent form for over 16 years olds

Name of young person: ____

I have read the information about the study of mental health problems in young persons with learning disabilities by Dr Hassiotis and am willing to take part in the study. My parents/carers have also talked to me about it.

I agree for my medical records to be examined and to give a blood sample.

Signature: ____________________________________

Date: ____________________

Parent's/carer's* consent
***: delete as appropriate**

I have read the information about the study of mental health problems in young persons with learning disability. I agree for me and my child to take part in the study.

I agree for ________________(name) medical records to be examined and for a blood sample to be taken for genetic analysis if possible.

Parent's/carer's name and signature:

____ **date** ____________________

(headed paper)

INFORMATION FOR PRINCIPAL CARE-GIVER

Mental health problems in young persons with learning disabilities

The study

The aim of the study is to investigate the rate of psychiatric and behavioural problems in young people (12 to 19 years old) with learning disability. This is to know because we would like to provide services which can best help you and your child.

The study will involve meeting with you and your child to discuss things such as his medical history, development, day to day skills, contact with services and medication.
The interview will last about two hours but can meet again if we need to.

It may be necessary to ask for a blood test to find out whether there is a cause for your child's disability unless that has already been done. I would also like to see your child's medical records held by his GP or other doctors, e.g. Child Development Team. Results of these tests will be shared with you about what to do next.
The face-to-face assessment will only be done once. We can meet at your own home or at the clinic (Spencer Close, St Margaret's Hospital, Epping).

The study may not be of direct benefit to you or your child now but it will help health and social care professionals to become more aware of the needs of adolescents who have mental health problems and to provide better services.

Taking part in the study is voluntary and if you decide not to participate it will not affect the future care or services that will be provided to you. If you decide to take part in the study but change your mind at any time you are free to withdraw without giving a reason. All information that you give us will be treated with confidentiality and will be stored securely. No references will be made to individuals by name in any publications or presentations which arise from this study.

I enclose consent forms for you and you child.

Please feel free to ask if there is anything you do not understand or if you would like more information.

Contact person: **Dr Angela Hassiotis**
Consultant Psychiatrist in Developmental Disorders

(headed paper)

Information sheet for the young person

Young people with learning disability may have emotional problems which doctors and other professionals need to know about. This is because they try to find the best way to help the person and his/her family to deal with them.

I would like to meet with you to talk about any difficulties you may have. I will ask you about how you feel and what you do.

I will also ask you if you could give me a blood sample to find out what caused the learning disability. It can be helpful for people to know the name of what causes their problem.

I will speak with your GP to find out what medicines you take and if you have other help

I would like to meet with you and your parent/carer at your home or at my clinic which is at St Margaret's Hospital.

We will only meet once and our discussion will not be shared with other people but may be used to help teaching other people. If you want we will tell you what we find out.

You can choose to take part or not. If you do agree to take part I would like you to sign the consent form and send it back in the envelope.

If you have any questions please contact:

Dr Angela Hassiotis
Consultant Psychiatrist in Developmental Disorders

(headed paper)

Information sheet for statutory agencies, education and health care professionals

RE: PSYCHIATRIC DISORDERS AND PATHWAYS TO CARE IN ADOLESCENTS WITH LEARNING DISABILITIES

I am carrying out a study to examine the rates of psychiatric disorders in young people with learning disability (also referred to as mental retardation).
This is an important area of research because there are very few studies of this specific age group in terms of psychiatric vulnerability and these disorders may cause considerable suffering to the individual and his/her family and carers.
Emotional and behavioural disorders have serious consequences on the social integration and activities of people with learning disabilities. However we know little of the extent of the problem in adolescence and consequently it is difficult to plan services and appropriate interventions.

The actual investigation comprises (usually) a sole 2 to 3 hour interview with the carer and young person which covers aspects of their developmental history and current problems. Where possible and where there is lack of such information in the records, the young person will be asked to have a blood test for genetic screening. This is provide evidence for the cause of the disability. The interview may take place either at the person's own home or my office (Spencer Close). The participation is entirely voluntary and will in no way jeopardise the care and treatment the person and their family/carers receive. The study has been approved by the West Essex Research Ethics Committee.

I would be grateful for your assistance in identifying eligible persons with a learning disability aged 12 to 19 who may participate in the study. I will be most grateful if you could let me have the names of any families and young persons who have learning disability and/or other disorders provided that the family are happy for their details to be passed on.
I will then approach them to ask their consent to take part in the study.

If you would like more information or wish to discuss the study further please contact me at the above address. All information that you provide will be treated with utmost care and confidentiality. However where necessary i.e. for completion of research data, I may also need to review the medical and social records of those individuals who take part in the study.

With many thanks for your help. I look forward to hearing from you.

Yours sincerely

Dr Angela Hassiotis
Consultant Psychiatrist
Department of Learning Disability Psychiatry

Department of Learning Disability Psychiatry

-[DATE]

-[ADDRESS]

Dear

Re: Adolescents with learning disability and service use project

I would like to offer you an appointment to meet with you and your child (____________) on

_____________[date] at __________ [time] at ______________.[venue].

Please note that the interview is likely to last approximately 2 hours.

If this date is not convenient please let me know at the above number as soon as you can.

I look forward to seeing you.

Thank you for your assistance.

Yours sincerely

Dr Angela Hassiotis
Consultant Psychiatrist in Learning Disabilities

DEPARTMENT OF LEARNING DISABILITY PSYCHIATRY

Individual code number:

Date of interview: - -

Name of interviewee: ____

Name of interviewer: ____

Thank you for agreeing to participate in this project.
We are carrying out interviews with parents/carers of adolescents with learning disability.
During the interview you will be asked questions about you child's health (mental and general), education and the type of services you have been receiving e.g. doctors, social workers, teachers, nurses and others who have been involved with your child and family.

HISTORY INTERVIEW

This questionnaire is designed to provide us with some basic information about the young person and his/her family.

A. Information about the child

1. Date of birth:____/____/____

2. Age: ________years ________months

3. Name&Surname:_________________
4. Gender: ______
5. Country of birth: ________________
6. Nationality: ________________
7. Ethnicity: ______________________
8. Religion: _____________________
9. First Language: ________________

B. Information about the family

10. Marital status of parents:_________________

11. Date of birth of father/age: ___/___/___

12. Ethnicity:___________________

13. Date of birth of mother/age:___/____/___

14. Ethnicity

15. Father's employment status and current occupation:
____

16. Mother's employment status and current occupation:
____

17. History of educational difficulties:
Father: ____________
Mother: ___________

18. Siblings: Number: ____
Full: _______ Twin: _______
Half: _______
Adopted: ________
Age: 1_____ 2______ 3______

4_____ 5______ 6______

19. Health status of siblings (explain)

____

____

20. Does any other siblings suffer with learning disability or epilepsy?

____

21. Does any of the siblings suffer with an inherited or genetic condition? Please specify

____

Coding:	
4. Sex: 1=Male 2=Female	8. Religion: 001= C/E 005= other 002= Christian other 003= Muslim 004= Jewish 006= Not known (these codes apply to parents too)
	9. First Language: 001= English 002= Other
5. Country of birth: 001=UK 002= Ireland 003= West Indies 004= Africa (not South Africa) 005= Cyprus & Greece 006= Commonwealth (Australia, Canada, S. Africa, New Zealand) 007= Asia (India, Pakistan) 008= Asia other 009= Europe other 010= Other 011=Not known (these codes apply to parents too)	10. Marital status: 001= married 002= separated 003= divorced 004= widowed 005= single
	15. Employment status: 001= employed f/t 002= employed p/t 003= housewife 004= retired 005= disabled 006= unemployed
6. Nationality: 001= British 002= Irish 003= West Indian 004= African (not S A) 005= Cypriot & Greek 006= Commonwealth 007= Indian & Pakistani 008= Asian other 009= European other 010= Other 011= Not known	18. Twin status: 001= No 002= MZ 003= DZ 004= Multiple birth 005= twin dead 006= twin alive
	20. Learning disability/epilepsy in sibling: 1= Yes 2= No

(these codes apply to parents too)	
7. Ethnicity (child): 001= White (European all) 002= Asian (all) 003= Black (all) (These codes apply to parents too)	21. Inherited/genetic condition in sibling: 1= Yes 2= No ICD 10 CODE:

C. Accommodation

22. What is the primary place of residence of the child? e.g. family home, in care etc

____

23. Who does the child live with? e.g. parents, carers, adoptive parents etc

____

24. Who is the primary carergiver?____________________

25. What is the legal status of the child? e.g. in local authority care, adopted etc

____

26. If the child lives outside the family home please tell me the name of the home/placement in which they live

____

27. Which local authority does the child live in?

____

28. Which local authority is responsible for providing education and social services to the child?

____

29. Does the child live in the local authority which is responsible for service provision?

____

30. What school does the child attend?

____

Coding:

22. Primary residence of child:
001= family home
002= foster home
003= residential school (f/t)
004= residential school (weekly)
005= local authority home
006= voluntary/private run home
007= hospital/institution
008= other

23. Parental situation for child:
001= both natural parents
002= both adoptive parents
003= mother alone
004= father alone
005= reconstituted family
006= foster parents
007= social services children's home
008= other

25. Legal status of child:
001= no special status
002= legally adopted
003= responsibility of guardian
004= subject of care/supervision order
005= ward of court
006= other
007= not known

26. Local Authority:
001= Epping
002= Harlow
003= Uttlesford
005= Waltham Abbey
006= other

28. Local Authority provider:

29. LA-Res and LA-Prov=same:
1= Yes 2= No

30. Type of school:
001= residential
002= day
003= Emotional and Behavioural disorders
004= NAS
005= Mild Learning Disability
006= Sever Learning Disability

007= Blind
008= Deaf
009= at home with carer
010= other

DEVELOPMENTAL HISTORY

This section of the questionnaire provides information on perinatal and medical history which may be important in contributing to the cognitive difficulties.

A. Prenatal and birth history

31. Did you have any problems during this child's pregnancy? ________________
Please specify ____________________________
32. Duration of pregnancy: ________________ (weeks)
33. Did you use any alcohol, tobacco or other drugs during your pregnancy for this child? ______________________
Please specify ____________________________
34. Was a caesarian section performed? ______________
Was it a breech delivery? ____________________
Were forceps used? _ ____________________
Normal delivery ____________________
35. Was your baby considered premature? ______________________
36. Was your baby placed in intensive care? _________________________
How long: ____________________ (days)
37. Do you remember the baby's Apgar score? What was it?
1 min______ 5 mins ______
38. Did your baby have unusual movements of the head, arms, limbs?
____
39. Did your baby have seizures or convulsions? ____________________
40. Did your baby have breathing problems? ____________________
Was she/she placed in a ventilator? __________________________
41. Did your baby have
swallowing problems? ___________ sucking problems? ___________
feeding difficulties? ____________

B. Medical treatment

42. Has your child had any of the following:
febrile seizures or other type of seizure (describe)? __________ coma?

__________ encephalitis? ______________ meningitis? __________ visual

defects? __________ hearing defects? ____________ poor sleep ?(describe)

____________________________ head injury? ________________
other significant illness? (describe)

____
43. Does your child receive any treatment? ________________
Please specify ______________________________

44. Has your child been diagnosed with an inherited or genetic condition? ________
Please specify ____

Coding:

31. Illness during pregnancy:
1= Yes 2= No 3= Do not know/no prenatal test

Type of illness:
001= Toxaemia
002= High blood pressure
003= Bleeding
004= Hospitalisation
005= diabetes
006= XRays
007= Amniocentesis
008= Other

33. Drugs during pregnancy:
1= Yes 2= No 3= Not known

Type of drugs:
001= Alcohol 002= Tobacco 003=other

34. Type of delivery:
001= Caesarean section 002= Breech delivery 003= forceps delivery 004=normal birth

35. Premature:
1= Yes 2= No

36. Intensive care:
1= Yes 2= No

38. Unusual movements:
1= Yes 2= No

39. Seizures or convulsions:
1= Yes 2= No

40. Breathing problems:
1= Yes 2= No

41. Feeding difficulties:
001= swallowing 002= feeding problems 003= sucking problems

42. Other medical problems:
001= epilepsy (any type)
002= encephalitis
003= meningitis
004= coma
005= sleeping difficulties
006= visual defects
007= hearing defects
008= head injury
009= other significant illness
010= not known

43. Type of treatment:
001= anticonvulsants
002= antipsychotics
003= antidepressants
004= amphetamines
005= special supplements
006= other

44. Syndrome diagnosis:

ICD 10 SYNDROME CODE

45. Investigations:

1= Yes 2=No

Type of:

001= CT scan 002= EEG 003= MRI head 004= genetic screening
005= other

C. **Family Psychiatric History**

46. Does any of the child's biological family suffer with psychiatric illness or learning disability? ________________________________

Please specify ______________________________

Coding:

46. Family psychiatric history:

1= Yes 2= No 3= Not known

If yes:

001= speech/language delay
002= motor difficulties
003= learning disability
004= inherited disorder
005= hyperactivity
006= autism
007= schizophrenia
008= depression
009= manic depressive illness
010= other psychiatric problems
011= Tourette's syndrome
012= Epilepsy
013= head injuries
014= other

FOR THE INVESTIGATOR:

Is there evidence from clinical, educational and social services files on the following:

IQ level and type of test
Genetic screening
Any diagnosis
Enuresis (wetting)
Encopresis (soiling)
Physical examination:
    Appearance
    Tremor
    Fine motor defects
    Weakness
    Spasticity
    Tics
    Dystonia
    Sensory defects
    Abnormal posture
    Cranial nerve defects
    Abnormal gait

SERVICE UTILISATION

47. Is the child registered with a GP? ____________________

48. Has the child visited the GP in last 12 months?
How many times? ___________________

Were the visits directly related to the child's disability? __________________

49. Please name any other professionals who are currently involved in your child's/client's care

____

____

____

50. Do you have a community nurse? ____________________________
51. How often do you see him/her? _______________________________
52. Do you feel that your child benefits from more contact of this sort?

____

53. Is your child seen by a paediatrician? _______________________
54. Reason for treatment: _________________________
55. Is this service community or hospital based? ___________________________
56. Do you feel that your child would benefit from contact of this sort? _________
57. Has your child been referred ever to the Child Psychiatry services?

____
Why? _____________________________
Who referred you? ____
What was the outcome? _____________________________________
58. Do you feel that your child benefits from contact of this sort?

____

59. Has your child been referred to specialist learning disability service?

____
Why? ____
Who referred you? _________________________________
What was the outcome? ____________________________
60. Do you feel that your child has benefits from this contact? ________________
61. Has your child been seen by any other doctor excluding those I have already mentioned? ____
Reason for treatment? ___________________________________
Who referred you? ________________________________
62. Has your child been seen/referred to a psychologist in the past? _____________
Reason for referral? ____________________________
Who referred you? ________________________________
What was the outcome? ___________________________
63. Do you feel that your child would benefit from more contact of this sort? ______
64. If you do not receive any services at all can you tell us why not?

____

Coding:

47. Registered with GP:
1= Yes 2=No 99= do not know

48. Number of visits in last 12 months:
Related to disability:
1= Yes 2=No 99= do not know

49. Other professionals:
01= Paediatrician
02= Neurologist
03= Child Psychiatrist
04= Psychiatrist-LD
05= Doctor other
06= Psychologist
07= Physiotherapist
08= OT
09= Speech therapist
10= Dietician
11= other

50. Community Nurse:
1= Yes 2=No 99= do not know

51. Frequency of CN visits:
1= weekly 2= fortnightly 3= monthly 4= other

52. Benefits from CN contact:
1= Yes 2=No 99= do not know

53. Paediatrician:
1= Yes 2=No 3= do not know

55. Type of service:
01= community based 02= hospital based 99= do not know

56. Benefits of contact:
1= Yes 2=No 99= do not know

57. a) Child Psychiatry referrals:
1= Yes 2=No 99= do not know
b) Outcome:
01= ongoing 02= waiting list 03= discharged 04= referred elsewhere
05= other

58. Would like service:
1= Yes 2=No 99= do not know

59. a) Learning Disability service:
1= Yes 2=No 99= do not know
b) Outcome:
01= ongoing 02= waiting list 03= discharged 04= referred elsewhere
05= other

60. Would like service:
1= Yes 2=No 99= do not know

61. Other doctor:

01= surgeon
02= neurologist
03= ENT
04= Physician
05= Ophthalmologist
06= other

62. a) Psychologist:

1= Yes 2=No 99= do not know

b) Outcome:

01= ongoing 02= waiting list 03= discharged 04= referred elsewhere 05= other

63. Would like the service:

1= Yes 2=No 99= do not know

64. Why not receiving services:

001= not necessary
002= not offered
003= not available (but have asked)
004= on waiting list
005= discharged
006= no benefit (have tried before)
007= other

VINELAND

ADAPTIVE BEHAVIOR SCALES

Sara S. Sparrow, David A. Balla, and Domenic V. Cicchetti
A revision of the *Vineland Social Maturity Scale* by Edgar A. Doll

INTERVIEW EDITION
Survey Form
Record Booklet

ABOUT THE INDIVIDUAL:

Name Sex

Home address

Telephone Grade

School or other facility

Present classification or diagnosis

Race (if pertinent)

Socioeconomic background (if pertinent)

Other pertinent information

AGE: **YEAR** **MONTH** **DAY**

Interview date

Birth date

Chronological age

Age used for starting points

Type (circle one) chronological mental social

REASON FOR THE INTERVIEW:

ABOUT THE RESPONDENT:

Name Sex

Relationship to individual

ABOUT THE INTERVIEWER:

Name Sex

Position

DATA FROM OTHER TESTS:

Intelligence

Achievement

Adaptive behavior

Other

BEFORE BEGINNING ADMINISTRATION, READ THE INSTRUCTIONS IN THE MANUAL CAREFULLY.

General Directions: In each adaptive behavior domain, begin scoring with the item designated for the individual's age. Score each item 2, 1, 0, N, or DK, according to the scoring criteria in the manual (Appendix C). Record each score in this booklet in the designated box. Establish a *basal* of *seven* consecutive items scored *2* and a *ceiling* of *seven* consecutive items scored *0* for each domain. (For reference when totaling scores, the highest possible sums are printed in the upper right corner of the sum boxes.)

COMMUNICATION DOMAIN

ITEM SCORES	
2	Yes, usually
1	Sometimes or partially
0	No, never
N	No opportunity
DK	Don't know

		RECEPTIVE	EXPRESSIVE	WRITTEN
<1	1. Turns eyes and head toward sound.	☐		
	2. Listens at least momentarily when spoken to by caregiver.	☐		
	3. Smiles in response to presence of caregiver.		☐	
	4. Smiles in response to presence of familiar person other than caregiver.		☐	
	5. Raises arms when caregiver says, "Come here" or "Up."	☐		
	6. Demonstrates understanding of the meaning of "no."	☐		
	7. Imitates sounds of adults immediately after hearing them.		☐	
	8. Demonstrates understanding of the meaning of at least 10 words.	☐		
1	9. Gestures appropriately to indicate "yes," "no," and "I want."		☐	
	10. Listens attentively to instructions.	☐		
	11. Demonstrates understanding of the meaning of "yes" or "okay."	☐		
	12. Follows instructions requiring an action and an object.	☐		
	13. Points accurately to at least one major body part when asked.	☐		
	14. Uses first names or nicknames of siblings, friends, or peers, or states their names when asked.		☐	
	15. Uses phrases containing a noun and a verb, or two nouns.		☐	
	16. Names at least 20 familiar objects without being asked. DO NOT SCORE 1.		☐	
	17. Listens to a story for at least five minutes.	☐		
	18. Indicates preference when offered a choice.		☐	
2	19. Says at least 50 recognizable words. DO NOT SCORE 1.		☐	
	20. Spontaneously relates experiences in simple terms.		☐	
	21. Delivers a simple message.		☐	
	22. Uses sentences of four or more words.		☐	
	23. Points accurately to all body parts when asked. DO NOT SCORE 1.	☐		
	24. Says at least 100 recognizable words. DO NOT SCORE 1.		☐	
	25. Speaks in full sentences.		☐	
	26. Uses "a" and "the" in phrases or sentences.		☐	
	27. Follows instructions in "if-then" form.	☐		
	28. States own first and last name when asked.		☐	
	29. Asks questions beginning with "what," "where," "who," "why," and "when." DO NOT SCORE 1.		☐	
3, 4	30. States which of two objects not present is bigger.		☐	
	31. Relates experiences in detail when asked.		☐	
	32. Uses either "behind" or "between" as a preposition in a phrase.		☐	
	33. Uses "around" as a preposition in a phrase.		☐	
		24	42	0

Count items before basal as 2, items after ceiling as 0.

Sum of 2s, 1s, 0s page 2

RECEPTIVE ☐

EXPRESSIVE ☐

WRITTEN ☐

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

		RECEPTIVE	EXPRESSIVE	WRITTEN
	34. Uses phrases or sentences containing "but" and "or."		☐	
	35. Articulates clearly, without sound substitutions.		☐	
	36. Tells popular story, fairy tale, lengthy joke, or television show plot.		☐	
5	37. Recites all letters of the alphabet from memory.			☐
	38. Reads at least three common signs.			☐
	39. States month and day of birthday when asked.		☐	
	40. Uses irregular plurals.		☐	
6	41. Prints or writes own first and last name.			☐
	42. States telephone number when asked. N MAY BE SCORED.		☐	
	43. States complete home address, including city and state, when asked.		☐	
	44. Reads at least 10 words silently or aloud.			☐
	45. Prints or writes at least 10 words from memory.			☐
	46. Expresses ideas in more than one way, without assistance.		☐	
	47. Reads simple stories aloud.			☐
7, 8	48. Prints or writes simple sentences of three or four words.			☐
	49. Attends to school or public lecture more than 15 minutes.	☐		
	50. Reads on own initiative.			☐
	51. Reads books of at least second-grade level.			☐
	52. Arranges items or words alphabetically by first letter.			☐
	53. Prints or writes short notes or messages.			☐
9	54. Gives complex directions to others.		☐	
	55. Writes beginning letters. DO NOT SCORE 1.			☐
	56. Reads books of at least fourth-grade level.			☐
	57. Writes in cursive most of the time. DO NOT SCORE 1.			☐
10 to 18+	58. Uses a dictionary.			☐
	59. Uses the table of contents in reading materials.			☐
	60. Writes reports or compositions. DO NOT SCORE 1.			☐
	61. Addresses envelopes completely.			☐
	62. Uses the index in reading materials.			☐
	63. Reads adult newspaper stories. N MAY BE SCORED.			☐
	64. Has realistic long-range goals and describes in detail plans to achieve them.		☐	
	65. Writes advanced letters.			☐
	66. Reads adult newspaper or magazine stories each week. N MAY BE SCORED.			☐
	67. Writes business letters. DO NOT SCORE 1.			☐

	RECEPTIVE	EXPRESSIVE	WRITTEN	
	2	20	46	
Count items before basal as 2, items after ceiling as 0. 1.				Sum of 2s, 1s, 0s page 3
2.				Sum of 2s, 1s, 0s page 2
3.				Number of Ns pages 2 and 3
4.				Number of DKs pages 2 and 3
	26	62	46	SUBDOMAIN RAW SCORE (Add rows 1—4 above)

DAILY LIVING SKILLS DOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

		PERSONAL	DOMESTIC	COMMUNITY
<1	1. Indicates anticipation of feeding on seeing bottle, breast, or food.	☐		
	2. Opens mouth when spoon with food is presented.	☐		
	3. Removes food from spoon with mouth.	☐		
	4. Sucks or chews on crackers.	☐		
	5. Eats solid food.	☐		
1	6. Drinks from cup or glass unassisted.	☐		
	7. Feeds self with spoon.	☐		
	8. Demonstrates understanding that hot things are dangerous.			☐
	9. Indicates wet or soiled pants or diaper by pointing, vocalizing, or pulling at diaper.	☐		
	10. Sucks from straw.	☐		
	11. Willingly allows caregiver to wipe nose.	☐		
	12. Feeds self with fork.	☐		
	13. Removes front-opening coat, sweater, or shirt without assistance.	☐		
2	14. Feeds self with spoon without spilling.	☐		
	15. Demonstrates interest in changing clothes when very wet or muddy.	☐		
	16. Urinates in toilet or potty-chair.	☐		
	17. Bathes self with assistance.	☐		
	18. Defecates in toilet or potty-chair.	☐		
	19. Asks to use toilet.	☐		
	20. Puts on "pull-up" garments with elastic waistbands.	☐		
	21. Demonstrates understanding of the function of money.			☐
	22. Puts possessions away when asked.		☐	
3	23. Is toilet-trained during the night.	☐		
	24. Gets drink of water from tap unassisted.	☐		
	25. Brushes teeth without assistance. DO NOT SCORE 1.	☐		
	26. Demonstrates understanding of the function of a clock, either standard or digital.			☐
	27. Helps with extra chores when asked.		☐	
	28. Washes and dries face without assistance.	☐		
	29. Puts shoes on correct feet without assistance.	☐		
	30. Answers the telephone appropriately. N MAY BE SCORED.			☐
	31. Dresses self completely, except for tying shoelaces.	☐		
4	32. Summons to the telephone the person receiving a call, or indicates that the person is not available. N MAY BE SCORED.			☐
	33. Sets table with assistance.		☐	
		50	6	10

Count items before basal as 2, items after ceiling as 0.

Sum of 2s, 1s, 0s page 4

PERSONAL

DOMESTIC

COMMUNITY

DAILY LIVING SKILLS DOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

Item	PERSONAL	DOMESTIC	COMMUNITY
34. Cares for all toileting needs, without being reminded and without assistance. DO NOT SCORE 1.	☐		
35. Looks both ways before crossing street or road.			☐
36. Puts clean clothes away without assistance when asked.		☐	
37. Cares for nose without assistance. DO NOT SCORE 1.	☐		
38. Clears table of breakable items.		☐	
39. Dries self with towel without assistance.	☐		
40. Fastens all fasteners. DO NOT SCORE 1.	☐		
5 41. Assists in food preparation requiring mixing and cooking.		☐	
42. Demonstrates understanding that it is unsafe to accept rides, food, or money from strangers.			☐
43. Ties shoelaces into a bow without assistance.	☐		
44. Bathes or showers without assistance. DO NOT SCORE 1.	☐		
45. Looks both ways and crosses street or road alone.			☐
46. Covers mouth and nose when coughing and sneezing.	☐		
6 47. Uses spoon, fork, and knife competently. DO NOT SCORE 1.	☐		
48. Initiates telephone calls to others. N MAY BE SCORED.			☐
49. Obeys traffic lights and Walk and Don't Walk signs. N MAY BE SCORED.			☐
50. Dresses self completely, including tying shoelaces and fastening all fasteners. DO NOT SCORE 1.	☐		
51. Makes own bed when asked.		☐	
52. States current day of the week when asked.			☐
53. Fastens seat belt in automobile independently. N MAY BE SCORED.			☐
7 54. States value of penny, nickel, dime, and quarter.			☐
55. Uses basic tools.		☐	
56. Identifies left and right on others.			☐
57. Sets table without assistance when asked.		☐	
8 58. Sweeps, mops, or vacuums floor carefully, without assistance, when asked.		☐	
59. Uses emergency telephone number in emergency. N MAY BE SCORED.			☐
60. Orders own complete meal in restaurant. N MAY BE SCORED.			☐
61. States current date when asked.			☐
62. Dresses in anticipation of changes in weather without being reminded.	☐		
63. Avoids persons with contagious illnesses, without being reminded.	☐		
	22	14	24

Count items before basal as 2, items after ceiling as 0.

Sum of 2s, 1s, 0s page 5

PERSONAL ☐
DOMESTIC ☐
COMMUNITY ☐

DAILY LIVING SKILLS DOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

		PERSONAL	DOMESTIC	COMMUNITY
9, 10	64. Tells time by five-minute segments.			☐
	65. Cares for hair without being reminded and without assistance. DO NOT SCORE 1.	☐		
	66. Uses stove or microwave oven for cooking.		☐	
	67. Uses household cleaning products appropriately and correctly.		☐	
11, 12	68. Correctly counts change from a purchase costing more than a dollar.			☐
	69. Uses the telephone for all kinds of calls, without assistance. N MAY BE SCORED.			☐
	70. Cares for own fingernails without being reminded and without assistance. DO NOT SCORE 1.	☐		
	71. Prepares foods that require mixing and cooking, without assistance.		☐	
13, 14, 15	72. Uses a pay telephone. N MAY BE SCORED.			☐
	73. Straightens own room without being reminded.		☐	
	74. Saves for and has purchased at least one major recreational item.			☐
	75. Looks after own health.	☐		
16	76. Earns spending money on a regular basis.			☐
	77. Makes own bed and changes bedding routinely. DO NOT SCORE 1.		☐	
	78. Cleans room other than own regularly, without being asked.		☐	
	79. Performs routine household repairs and maintenance tasks without being asked.		☐	
17 to 18+	80. Sews buttons, snaps, or hooks on clothes when asked.		☐	
	81. Budgets for weekly expenses.			☐
	82. Manages own money without assistance.			☐
	83. Plans and prepares main meal of the day without assistance.		☐	
	84. Arrives at work on time.			☐
	85. Takes complete care of own clothes without being reminded. DO NOT SCORE 1.		☐	
	86. Notifies supervisor if arrival at work will be delayed.			☐
	87. Notifies supervisor when absent because of illness.			☐
	88. Budgets for monthly expenses.			☐
	89. Sews own hems or makes other alterations without being asked and without assistance.		☐	
	90. Obeys time limits for coffee breaks and lunch at work.			☐
	91. Holds full-time job responsibly. DO NOT SCORE 1.			☐
	92. Has checking account and uses it responsibly.			☐
		6	22	30

Count items before basal as 2, items after ceiling as 0.

	PERSONAL	DOMESTIC	COMMUNITY	
1.				Sum of 2s, 1s, 0s page **6**
2.				Sum of 2s, 1s, 0s page **5**
3.				Sum of 2s, 1s, 0s page **4**
4.				Number of Ns pages **4, 5, 6**
5.				Number of DKs pages **4, 5, 6**
	78	42	64	**SUBDOMAIN RAW SCORE** (Add rows 1—5 above)

PERSONAL

DOMESTIC

COMMUNITY

SOCIALIZATION DOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

	Item	INTERPERSONAL RELATIONSHIPS	PLAY & LEISURE TIME	COPING SKILLS
<1	1. Looks at face of caregiver.	☐		
	2. Responds to voice of caregiver or another person.	☐		
	3. Distinguishes caregiver from others.	☐		
	4. Shows interest in novel objects or new people.		☐	
	5. Expresses two or more recognizable emotions such as pleasure, sadness, fear, or distress.	☐		
	6. Shows anticipation of being picked up by caregiver.	☐		
	7. Shows affection toward familiar people.	☐		
	8. Shows interest in children or peers other than siblings.		☐	
	9. Reaches for familiar person.	☐		
	10. Plays with toy or other object alone or with others.		☐	
	11. Plays very simple interaction games with others.		☐	
	12. Uses common household objects for play.		☐	
	13. Shows interest in activities of others.		☐	
	14. Imitates simple adult movements, such as clapping hands or waving good-bye, in response to a model.	☐		
1, 2	15. Laughs or smiles appropriately in response to positive statements.	☐		
	16. Addresses at least two familiar people by name.	☐		
	17. Shows desire to please caregiver.	☐		
	18. Participates in at least one game or activity with others.		☐	
	19. Imitates a relatively complex task several hours after it was performed by another.	☐		
	20. Imitates adult phrases heard on previous occasions.	☐		
	21. Engages in elaborate make-believe activities, alone or with others.		☐	
3	22. Shows a preference for some friends over others.	☐		
	23. Says "please" when asking for something.			☐
	24. Labels happiness, sadness, fear, and anger in self.	☐		
	25. Identifies people by characteristics other than name, when asked.	☐		
4	26. Shares toys or possessions without being told to do so.		☐	
	27. Names one or more favorite television programs when asked, and tells on what days and channels the programs are shown. N MAY BE SCORED.		☐	
	28. Follows rules in simple games without being reminded.		☐	
	29. Has a preferred friend of either sex.	☐		
	30. Follows school or facility rules.			☐
5	31. Responds verbally and positively to good fortune of others.	☐		
	32. Apologizes for unintentional mistakes.			☐
	33. Has a group of friends.	☐		
	34. Follows community rules.			☐
6	35. Plays more than one board or card game requiring skill and decision making.		☐	
	36. Does not talk with food in mouth.			☐
	37. Has a best friend of the same sex.	☐		
		40	24	10

Count items before basal as 2, items after ceiling as 0.

Sum of 2s, 1s, 0s page 7

INTERPERSONAL RELATIONSHIPS

PLAY & LEISURE TIME

COPING SKILLS

SOCIALIZATION DOMAIN

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

		INTERPERSONAL RELATIONSHIPS	PLAY & LEISURE TIME	COPING SKILLS
	38. Responds appropriately when introduced to strangers.			☐
7, 8	39. Makes or buys small gifts for caregiver or family member on major holidays, on own initiative.	☐		
	40. Keeps secrets or confidences for more than one day.			☐
	41. Returns borrowed toys, possessions, or money to peers, or returns borrowed books to library.			☐
	42. Ends conversations appropriately.			☐
9	43. Follows time limits set by caregiver.			☐
	44. Refrains from asking questions or making statements that might embarrass or hurt others.			☐
	45. Controls anger or hurt feelings when denied own way.			☐
	46. Keeps secrets or confidences for as long as appropriate.			☐
10,11	47. Uses appropriate table manners without being told. DO NOT SCORE 1.			☐
	48. Watches television or listens to radio for information about a particular area of interest. N MAY BE SCORED.		☐	
	49. Goes to evening school or facility events with friends, when accompanied by an adult. N MAY BE SCORED.		☐	
	50. Independently weighs consequences of actions before making decisions.			☐
	51. Apologizes for mistakes or errors in judgment.			☐
12, 13, 14	52. Remembers birthdays or anniversaries of immediate family members and special friends.	☐		
	53. Initiates conversations on topics of particular interest to others.	☐		
	54. Has a hobby.		☐	
	55. Repays money borrowed from caregiver.			☐
15 to 18+	56. Responds to hints or indirect cues in conversation.	☐		
	57. Participates in nonschool sports. N MAY BE SCORED.		☐	
	58. Watches television or listens to radio for practical, day-to-day information. N MAY BE SCORED.		☐	
	59. Makes and keeps appointments.			☐
	60. Watches television or listens to radio for news independently. N MAY BE SCORED.		☐	
	61. Goes to evening school or facility events with friends, without adult supervision. N MAY BE SCORED.		☐	
	62. Goes to evening nonschool or nonfacility events with friends, without adult supervision.		☐	
	63. Belongs to older adolescent organized club, interest group, or social or service organization.	☐		
	64. Goes with one person of opposite sex to party or public event where many people are present.	☐		
	65. Goes on double or triple dates.	☐		
	66. Goes on single dates.	☐		

Count items before basal as 2, items after ceiling as 0.	1.	16	16	26	Sum of 2s, 1s, 0s page 8
	2.				Sum of 2s, 1s, 0s page 7
	3.				Number of Ns pages 7 and 8
	4.				Number of DKs pages 7 and 8
		56	40	36	SUBDOMAIN RAW SCORE (Add rows 1—4 above)

ITEM SCORES
2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

Note: The Motor Skills domain is for individuals 5-11-30 or under, and optional for older individuals for whom a motor deficit is suspected. See Chapters 4 and 5 in the manual for procedures for administering and scoring the Motor Skills domain for individuals 6-0-0 or older.

		GROSS	
<1	1. Holds head erect for at least 15 seconds without assistance when held vertically in caregiver's arms.	☐	
	2. Sits supported for at least one minute.	☐	
	3. Picks up small object with hands, in any way.		☐
	4. Transfers object from one hand to the other.		☐
	5. Picks up small object with thumb and fingers.		☐
	6. Raises self to sitting position and maintains position unsupported for at least one minute.	☐	
	7. Crawls across floor on hands and knees, without stomach touching floor.	☐	
	8. Opens doors that require only pushing or pulling.		☐
1	9. Rolls ball while sitting.	☐	
	10. Walks as primary means of getting around.	☐	
	11. Climbs both in and out of bed or steady adult chair.	☐	
	12. Climbs on low play equipment.	☐	
	13. Marks with pencil, crayon, or chalk on appropriate writing surface.		☐
2	14. Walks up stairs, putting both feet on each step.	☐	
	15. Walks down stairs, forward, putting both feet on each step.	☐	
	16. Runs smoothly, with changes in speed and direction.	☐	
	17. Opens doors by turning and pulling doorknobs.		☐
	18. Jumps over small object.	☐	
	19. Screws and unscrews lid of jar.		☐
	20. Pedals tricycle or other three-wheeled vehicle for at least six feet. N MAY BE SCORED.	☐	
	21. Hops on one foot at least once, while holding on to another person or stable object, without falling.	☐	
	22. Builds three-dimensional structures, with at least five blocks.		☐
	23. Opens and closes scissors with one hand.		☐
3, 4+	24. Walks down stairs with alternating feet, without assistance.	☐	
	25. Climbs on high play equipment.	☐	
	26. Cuts across a piece of paper with scissors.		☐
	27. Hops forward on one foot at least three times without losing balance. DO NOT SCORE 1.	☐	
	28. Completes non-inset puzzle of at least six pieces. DO NOT SCORE 1.		☐
	29. Draws more than one recognizable form with pencils or crayons.		☐
	30. Cuts paper along a line with scissors.		☐
	31. Uses eraser without tearing paper.		☐
	32. Hops forward on one foot with ease. DO NOT SCORE 1.	☐	
	33. Unlocks key locks.		☐
	34. Cuts out complex items with scissors.		☐
	35. Catches small ball thrown from a distance of 10 feet, even if moving is necessary to catch it.	☐	
	36. Rides bicycle without training wheels, without falling. N MAY BE SCORED.	☐	

Count items before basal as 2, items after ceiling as 0.

	40	32	
1.			Sum of 2s, 1s, 0s page 9
2.			Number of Ns page 9
3.			Number of DKs page 9
	40	32	**SUBDOMAIN RAW SCORE** (Add rows 1—3 above)

GROSS

FINE

Note: The Maladaptive Behavior domain is for individuals 5-0-0 or older. Administration is optional.

ITEM SCORES

2	Yes, usually
1	Sometimes or partially
0	No, never

DO NOT SCORE N OR DK.

PART 1

1. Sucks thumb or fingers.
2. Is overly dependent.
3. Withdraws.
4. Wets bed.
5. Exhibits an eating disturbance.
6. Exhibits a sleep disturbance.
7. Bites fingernails.
8. Avoids school or work.
9. Exhibits extreme anxiety.
10. Exhibits tics.
11. Cries or laughs too easily.
12. Has poor eye contact.
13. Exhibits excessive unhappiness.
14. Grinds teeth during day or night.
15. Is too impulsive.
16. Has poor concentration and attention.
17. Is overly active.
18. Has temper tantrums.
19. Is negativistic or defiant.
20. Teases or bullies.
21. Shows lack of consideration.
22. Lies, cheats, or steals.
23. Is too physically aggressive.
24. Swears in inappropriate situations.
25. Runs away.
26. Is stubborn or sullen.
27. Is truant from school or work.

A. PART 1 RAW SCORE
(Sum of 2s, 1s, 0s Part 1)

PART 2

Note: Part 2 is for individuals who will be compared only with supplementary norm groups.

	Intensity Circle One	
	Severe	*Moderate*
28. Engages in inappropriate sexual behavior.	S	M
29. Has excessive or peculiar preoccupations with objects or activities.	S	M
30. Expresses thoughts that are not sensible.	S	M
31. Exhibits extremely peculiar mannerisms or habits.	S	M
32. Displays behaviors that are self-injurious.	S	M
33. Intentionally destroys own or another's property.	S	M
34. Uses bizarre speech.	S	M
35. Is unaware of what is happening in immediate surroundings.	S	M
36. Rocks back and forth when sitting or standing.	S	M

B. Sum of 2s, 1s, 0s Part 2

PARTS 1 AND 2 RAW SCORE
(Add A and B)

ABOUT THE INTERVIEW:

Respondent's estimate of the individual's functioning

Language used in the interview

Special characteristics of the individual

Estimate of rapport established with the respondent

Estimate of the respondent's accuracy

General observations

Vineland Adaptive Behavior Scales: **INTERVIEW EDITION Survey Form**

Individual's name
Chronological age
Date of interview
Supplementary norm group (if applicable)

Before beginning the score summary, read Chapter 5 in the manual.

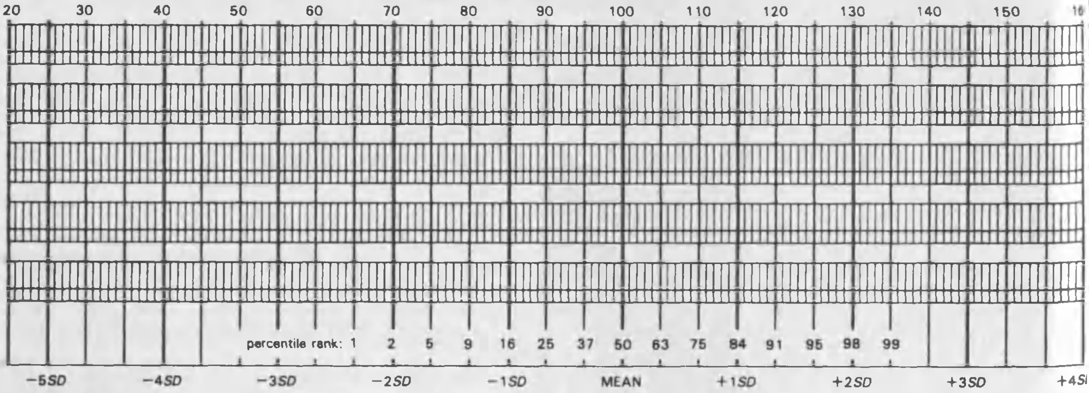
SCORE SUMMARY

SUBDOMAIN	Raw Score	Standard Score $\bar{X}$=100, *SD*=15 Tables B.1 and B.2	Band of Error ___% Confidence Table B.3	National %ile Rank Table B.4	Stanine Table B.4	Supplementary Norm Group %ile Rank Table B.5	Adaptive Level Tables B.6 and B.8	Supplementary Norm Group Adaptive Level Tables B.7 and B.9	Age Equivalen Tables B.1 and B.11
Receptive									
Expressive									
Written									
COMMUNICATION DOMAIN SUM			±						
Personal									
Domestic									
Community									
DAILY LIVING SKILLS DOMAIN SUM			±						
Interpersonal Relationships									
Play and Leisure Time									
Coping Skills									
SOCIALIZATION DOMAIN SUM			±						
(For ages to 5-11-30) Gross									
Fine									
MOTOR SKILLS DOMAIN SUM			±						
SUM OF DOMAIN STANDARD SCORES									
ADAPTIVE BEHAVIOR COMPOSITE			±						

SCORE PROFILE

(See Chapter 5 in the manual to graph scores.)

	Standard Score ± Band of Error
COMMUNICATION DOMAIN	±
DAILY LIVING SKILLS DOMAIN	±
SOCIALIZATION DOMAIN	±
MOTOR SKILLS DOMAIN	±
ADAPTIVE BEHAVIOR COMPOSITE	±



OPTIONAL

MALADAPTIVE BEHAVIOR DOMAIN

(Administer for ages 5-0-0 and older)

	Raw Score	Maladaptive Level: Table B.12	Supplementary Norm Group Maladaptive Level: Table B.13
Part 1			
Parts 1 and 2			

Additional interpretive information (see Chapters 5 and 6 in the manual)

Recommendations

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DEVELOPMENTAL BEHAVIOUR CHECKLIST

(DBC-P)

Some children with developmental delay have problems with their emotions and behaviour. These can sometimes be a problem for their carers.

By completing this checklist, you will help us learn more about these problems. This will assist us to know how the person might respond to help.

Name of Child or Teenager: ....

Date of Birth/Age:..

Sex:..

Person Completing Form: ....

Relationship to Child: ....

Date Completed: ....

Is the Child: (please circle) Unable to see / unable to hear Unable to speak/ speaks very little

Unable to use arms / legs Subject to other serious medical condition.

Please describe: ....

What does he/she do best?

What do other people like about him/her?

What are his/her favourite activities?

Is there anything you feel he/she does as well or better than others?

Have you sought help for any behaviour or emotional problems, apart from slow development, of the child or teenager in your care. Yes/No

If so from whom?

Please continue over the page ➔

Office Use Only

Code No.: ....

Developmental Level (circle one only)

Profound Severe Moderate Mild Unknown

Contact Person: ....

	TBPS
Page 2	
Page 3	
Page 4	
Total	

①	②	③	④	⑤	⑥

Many of the following behaviours may not apply to the child or teenager in your care. For each item that does describe the person in your care, now or within the past six months, please circle the 2 if the item is **very true** or **often true**. Circle 1 if the item is **somewhat or sometimes true** of your child. If the item is **not true** of your child circle the 0.

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

If your child is unable to perform an item, circle the **0.** For example, if your child has no speech, then for the item "Talks too much or too fast" circle the **0**

Underline any you are particularly concerned about

Office Use Only	**Please Circle**			
1. ⑤	0	1	2	Appears depressed, downcast or unhappy
2. ⑤	0	1	2	Avoids eye contact. Won't look you straight in the eye.
3. ⑤	0	1	2	Aloof, in his/her own world.
4. ①	0	1	2	Abusive. Swears at others.
5.	0	1	2	Arranges objects or routine in a strict order. Please describe:
6. ②	0	1	2	Bangs head.
7. ①	0	1	2	Becomes over-excited.
8.	0	1	2	Bites others.
9.	0	1	2	Cannot attend to one activity for any length of time, poor attention span.
10. ②	0	1	2	Chews or mouths objects, or body parts.
11. ④	0	1	2	Cries easily for no reason, or over small upsets.
12. ④	0	1	2	Covers ears or is distressed when hears particular sounds. Please describe:
13. ③	0	1	2	Confuses the use of pronouns e.g. uses "you" instead of "I".
14. ②	0	1	2	Deliberately runs away.
15. ③	0	1	2	Delusions: has a firmly held belief or idea that can't possibly be true. Please describe:
16. ④	0	1	2	Distressed about being alone.
17. ⑤	0	1	2	Doesn't show affection.
18. ⑤	0	1	2	Doesn't respond to others' feelings, e.g. shows no response if a family member is crying.
19. ④	0	1	2	Easily distracted from his/her task, e.g. by noises.
20.	0	1	2	Easily led by others.
21. ②	0	1	2	Eats non-food items e.g. dirt, grass, soap.
22. ④	0	1	2	Excessively distressed if separated from familiar person.
23. ④	0	1	2	Fears particular things or situations, e.g. the dark or insects. Please describe:
24. ⑤	0	1	2	Facial twitches or grimaces.
25. ②	0	1	2	Flicks, taps, twirls objects repeatedly.
26. ④	0	1	2	Fussy eater or has food fads.
27.	0	1	2	Gorges food. Will do anything to get food e.g. takes food out of garbage bins or steals food.
28.	0	1	2	Gets obsessed with an idea or activity. Please describe:
29.	0	1	2	Grinds teeth.
30. ④	0	1	2	Has nightmares, night terrors or walks in sleep.

Please be sure you have answered all items
Continue next page ➔

Office Use Only

TBPS

Subscales

①	②	③	④	⑤	⑥

0 = not true as far as you know   1 = somewhat or sometimes true   2 = very true or often true

Underline any you are particularly concerned about

Office Use Only	Please Circle			
31. ①	0	1	2	Has temper tantrums, e.g. stamps feet, slams doors.
32. ⑥	0	1	2	Hides things.
33. ①②	0	1	2	Hits self or bites self.
34. ②	0	1	2	Hums, whines, grunts, squeals or makes other non-speech noises.
35. ①	0	1	2	Impatient.
36. ①	0	1	2	Inappropriate sexual activity with another.
37. ①	0	1	2	Impulsive, acts before thinking.
38. ①④	0	1	2	Irritable.
39. ①	0	1	2	Jealous.
40. ①	0	1	2	Kicks, hits others.
41.	0	1	2	Lacks self-confidence, poor self-esteem.
42. ⑤	0	1	2	Laughs or giggles for no obvious reason.
43. ⑥	0	1	2	Lights fires.
44. ②	0	1	2	Likes to hold or play with an unusual object, e.g. string, twigs; overly fascinated with something, e.g. water. Please describe: ____________________
45.	0	1	2	Loss of appetite.
46. ②	0	1	2	Masturbates or exposes self in public.
47. ①	0	1	2	Mood changes rapidly for no apparent reason.
48. ⑤	0	1	2	Moves slowly, underactive, does little, e.g. only sits and watches others.
49. ①	0	1	2	Noisy or boisterous.
50. ②	0	1	2	Overactive, restless, unable to sit still.
51.	0	1	2	Overaffectionate.
52.	0	1	2	Overbreathes, vomits, has headaches or complains of being sick for no physical reason.
53. ①	0	1	2	Overly attention-seeking.
54.	0	1	2	Overly interested in looking at, listening to or dismantling mechanical things e.g. lawnmower, vacuum cleaner.
55. ②	0	1	2	Poor sense of danger.
56.	0	1	2	Prefers the company of adults or younger children. Doesn't mix with his/her own age group.
57. ②	0	1	2	Prefers to do things on his/her own. Tends to be a loner.
58.	0	1	2	Preoccupied with only one or two particular interests. Please describe: ____________________ ____________________
59. ⑥	0	1	2	Refuses to go to school, activity centre or workplace.
60. ⑤	0	1	2	Repeated movements of hands, body, head or face e.g. handflapping or rocking.
61. ⑤	0	1	2	Resists being cuddled, touched or held.
62. ③	0	1	2	Repeats back what others say like an echo.
63. ③	0	1	2	Repeats the same word or phrase over and over.
64. ②	0	1	2	Smells, tastes, or licks objects.
65.	0	1	2	Scratches or picks his/her skin.
66. ②	0	1	2	Screams a lot.

Please be sure you have answered all items

Continue over the page ➔

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☐

Subscales

①	②	③	④	⑤	⑥

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

Underline any you are particularly concerned about

Office Use Only	Please Circle	
67.	0 1 2	Sleeps too little. Disrupted sleep.
68. ②	0 1 2	Stares at lights or spinning objects.
69. ⑤	0 1 2	Sleeps too much.
70. ②	0 1 2	Soils outside toilet though toilet trained. Smears or plays with faeces.
71. ③	0 1 2	Speaks in whispers, high pitched voice, or other unusual tone or rhythm.
72. ②	0 1 2	Switches lights on and off, pours water over and over; or similar repetitive activity. Please describe: ______
73. ⑥	0 1 2	Steals.
74. ①	0 1 2	Stubborn, disobedient or unco-operative.
75. ④	0 1 2	Shy.
76. ②	0 1 2	Strips off clothes or throws away clothes.
77. ①	0 1 2	Says he/she can do things that he/she is not capable of.
78.	0 1 2	Stands too close to others.
79.	0 1 2	Sees, hears, something which isn't there. Hallucinations. Please describe: ______
80. ①	0 1 2	Talks about suicide.
81. ③	0 1 2	Talks too much or too fast.
82. ③	0 1 2	Talks to self or imaginary people or objects
83. ①⑥	0 1 2.	Tells lies.
84. ③	0 1 2	Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow.
85. ①④	0 1 2	Tense, anxious, worried.
86. ①②	0 1 2	Throws or breaks objects.
87. ①	0 1 2	Tries to manipulate or provoke others.
88. ③	0 1 2	Underreacts to pain.
89. ③	0 1 2	Unrealistically happy or elated.
90.	0 1 2	Unusual body movements, posture, or way of walking. Please describe: ______
91. ④	0 1 2	Upset and distressed over small changes in routine or environment. Please describe: ______
92. ②	0 1 2	Urinates outside toilet, although toilet trained.
93. ①	0 1 2	Very bossy.
94. ②	0 1 2	Wanders aimlessly.
95. ①	0 1 2	Whines or complains a lot.
		Please write in any problems your child has that were not listed above
	0 1 2	______
	0 1 2	______
	0 1 2	______
96.	0 1 2	Overall, do you feel your child has problems with feelings or behaviour, in addition to problems with development? If not, please circle the 0. If so, but they're minor, please circle the 1. If they're major problems, please circle the 2.

Please be sure you have answered all items

Are there any other comments you would like to make?

______

______

THANK YOU

Office Use Only

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Subscales

①	②	③	④	⑤	⑥

DEVELOPMENTAL BEHAVIOUR CHECKLIST

DBC-T (Teacher Version)

Name of Pupil: ....

Date of Birth/Age:. ....

Sex:. ....

Person Completing Form: .... **Teacher / Teacher's Aide** (please circle)

Date Completed: ....

Type of School & Class: (please circle) Special School/Special Class in Regular School/Regular Class/Other....................

Level of Disability: mild / moderate / severe / profound / other..............................

Is the Pupil: (please circle any that apply) Unable to see/unable to hear Unable to speak/speaks very little

Unable to use arms/legs Subject to other serious medical condition.

Please describe: ....

What programs or activities has the student been unable to participate in due to emotional/behavioural disturbance?

....

....

How much time per week/month is the child absent on account of behaviour disturbance?

....

Of the time the child is in the class, how much is actually spent in productive learning (productive learning could be reduced by, for example, inattention or drowsiness)

(Please circle one)

0	**Most of the time**	1	**About 75%**
2	**About 50%**	3	**25% or less**

Does the pupil require an equal share of your time compared with other pupils?

Class Time (Please circle one)		**Non face-to-face time (Please circle one)**	
0	**Yes, equal time**	0	**Yes, equal time**
1	**Somewhat increased share**	1	**Somewhat increased share**
2	**Greatly increased share**	2	**Greatly increased share**

Please continue over the page ➔

Office Use Only

Code No.: .... Contact Person: ....

	TBPS
Page 2	
Page 3	
Page 4	
Total	

①	②	③	④	⑤	⑥

Below is a list of items that describe pupils. For each item that describes the pupil , now or within the past two months, please circle the **2** if the item is **very true** or **often true**. Circle **1** if the item is **somewhat or sometimes true** of the pupil. If the item is **not true** of the pupil circle the **0**.

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

If the pupil is unable to perform an item, circle the **0.** For example, if the pupil has no speech, then for the item "Talks too much or too fast" circle the 0

Underline any you are particularly concerned about

Office Use Only	Please Circle	
1. ⑤	0 1 2	Appears depressed, downcast or unhappy
2. ⑤	0 1 2	Avoids eye contact. Won't look you straight in the eye.
3. ⑤	0 1 2	Aloof, in his/her own world.
4. ①	0 1 2	Abusive. Swears at others.
5.	0 1 2	Arranges objects or routine in a strict order. Please describe: ____________
6. ②	0 1 2	Bangs head.
7. ①	0 1 2	Becomes over-excited.
8.	0 1 2	Bites others.
9.	0 1 2	Cannot attend to one activity for any length of time, poor attention span.
10. ②	0 1 2	Chews or mouths objects, or body parts.
11. ④	0 1 2	Cries easily for no reason, or over small upsets.
12. ④	0 1 2	Covers ears or is distressed when hears particular sounds. Please describe: ____________
13. ③	0 1 2	Confuses the use of pronouns e.g. uses "you" instead of "I".
14. ②	0 1 2	Deliberately runs away.
15. ③	0 1 2	Delusions: has a firmly held belief or idea that can't possibly be true. Please describe: ____________
16. ④	0 1 2	Distressed about being alone.
17. ⑤	0 1 2	Doesn't show affection.
18. ⑤	0 1 2	Doesn't respond to others' feelings, e.g. shows no response if a family member is crying.
19. ④	0 1 2	Easily distracted from his/her task, e.g. by noises.
20.	0 1 2	Easily led by others.
21. ②	0 1 2	Eats non-food items e.g. dirt, grass, soap.
22. ④	0 1 2	Excessively distressed if separated from familiar person.
23. ④	0 1 2	Fears particular things or situations, e.g. the dark or insects. Please describe: ____________
24. ⑤	0 1 2	Facial twitches or grimaces.
25. ②	0 1 2	Flicks, taps, twirls objects repeatedly.
26. ④	0 1 2	Fussy eater or has food fads.
27.	0 1 2	Gorges food. Will do anything to get food e.g. takes food out of garbage bins or steals food.
28.	0 1 2	Gets obsessed with an idea or activity. Please describe: ____________
29.	0 1 2	Grinds teeth.

Please be sure you have answered all items
Continue next page ➔

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TBPS

Subscales

①	②	③	④	⑤	⑥

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

Underline any you are particularly concerned about

Office Use Only	Please Circle	
30. ①	0 1 2	Has temper tantrums, e.g. stamps feet, slams doors.
31. ⑥	0 1 2	Hides things.
32. ①②	0 1 2	Hits self or bites self.
33. ②	0 1 2	Hums, whines, grunts, squeals or makes other non-speech noises.
34. ①	0 1 2	Impatient.
35. ①	0 1 2	Inappropriate sexual activity with another.
36. ①	0 1 2	Impulsive, acts before thinking.
37. ①④	0 1 2	Irritable.
38. ①	0 1 2	Jealous.
39. ①	0 1 2	Kicks, hits others.
40.	0 1 2	Lacks self-confidence, poor self-esteem.
41. ⑤	0 1 2	Laughs or giggles for no obvious reason.
42. ⑥	0 1 2	Lights fires.
43. ②	0 1 2	Likes to hold or play with an unusual object, e.g. string, twigs; overly fascinated with something, e.g. water. Please describe: ____________________
44.	0 1 2	Loss of appetite.
45. ②	0 1 2	Masturbates or exposes self in public.
46. ①	0 1 2	Mood changes rapidly for no apparent reason.
47. ⑤	0 1 2	Moves slowly, underactive, does little, e.g. only sits and watches others.
48. ①	0 1 2	Noisy or boisterous.
49. ②	0 1 2	Overactive, restless, unable to sit still.
50.	0 1 2	Overaffectionate.
51.	0 1 2	Overbreathes, vomits, has headaches or complains of being sick for no physical reason.
52. ①	0 1 2	Overly attention-seeking.
53.	0 1 2	Overly interested in looking at, listening to or dismantling mechanical things e.g. lawnmower, vacuum cleaner.
54. ②	0 1 2	Poor sense of danger.
55.	0 1 2	Prefers the company of adults or younger children. Doesn't mix with his/her own age group.
56. ②	0 1 2	Prefers to do things on his/her own. Tends to be a loner.
57.	0 1 2	Preoccupied with only one or two particular interests. Please describe: ____________________
58. ⑥	0 1 2	Refuses to go to school, activity centre or workplace.
59. ⑤	0 1 2	Repeated movements of hands, body, head or face e.g. handflapping or rocking.
60. ⑤	0 1 2	Resists being cuddled, touched or held.
61. ③	0 1 2	Repeats back what others say like an echo.
62. ③	0 1 2	Repeats the same word or phrase over and over.
63. ②	0 1 2	Smells, tastes, or licks objects.
64.	0 1 2	Scratches or picks his/her skin.
65. ②	0 1 2	Screams a lot.

Please be sure you have answered all items

Continue over the page ➔

Office Use Only

TBPS ☐

Subscales

①	②	③	④	⑤	⑥

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

Underline any you are particularly concerned about

Office Use Only	Please Circle			
66. ②	0	1	2	Stares at lights or spinning objects.
67. ②	0	1	2	Soils outside toilet though toilet trained. Smears or plays with faeces.
68. ③	0	1	2	Speaks in whispers, high pitched voice, or other unusual tone or rhythm.
69. ②	0	1	2	Switches lights on and off, pours water over and over; or similar repetitive activity. Please describe: ______
70. ⑥	0	1	2	Steals.
71. ①	0	1	2	Stubborn, disobedient or unco-operative.
72. ④	0	1	2	Shy.
73. ②	0	1	2	Strips off clothes or throws away clothes.
74. ①	0	1	2	Says he/she can do things that he/she is not capable of.
75.	0	1	2	Stands too close to others.
76.	0	1	2	Sees, hears, something which isn't there. Hallucinations. Please describe: ______ ______
77. ①	0	1	2	Talks about suicide.
78. ③	0	1	2	Talks too much or too fast.
79. ③	0	1	2	Talks to self or imaginary people or objects
80. ①⑥	0	1	2.	Tells lies.
81. ③	0	1	2	Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow.
82. ①④	0	1	2	Tense, anxious, worried.
83. ①②	0	1	2	Throws or breaks objects.
84. ①	0	1	2	Tries to manipulate or provoke others.
85. ③	0	1	2	Underreacts to pain.
86. ③	0	1	2	Unrealistically happy or elated.
87.	0	1	2	Unpopular with other children.
88.	0	1	2	Unusual body movements, posture, or way of walking. Please describe: ______ ______
89. ④	0	1	2	Upset and distressed over small changes in routine or environment. Please describe: ______ ______
90. ②	0	1	2	Urinates outside toilet, although toilet trained.
91. ①	0	1	2	Very bossy.
92. ②	0	1	2	Wanders aimlessly.
93. ①	0	1	2	Whines or complains a lot.
				Please write in any problems the pupil has that were not listed above
	0	1	2	______
	0	1	2	______
	0	1	2	______
94.	0	1	2	Overall, do you feel the pupil has problems with feelings or behaviour, in addition to problems with development? If not, please circle the **0**. If so, but they're minor, please circle the **1**. If they're major problems, please circle the **2**.

Please be sure you have answered all items

Are there any other comments you would like to make?

______

______

THANK YOU

Office Use Only

TBPS

Subscales

①	②	③	④	⑤	⑥

LOGISTIC REGRESSION ANALYSIS

Logistic Regression

Case Processing Summary

Unweighted Cases[a]		N	Percent
Selected Cases	Included in Analysis	75	100.0
	Missing Cases	0	.0
	Total	75	100.0
Unselected Cases		0	.0
Total		75	100.0

a. If weight is in effect, see classification table for the total number of cases.

Dependent Variable Encoding

Original Value	Internal Value
non case	0
case by dbcl	1

Categorical Variables Codings

		Frequency	Paramete
			(1)
FAMHIS1	no,nk	30	1.000
	yes	45	.000
AUT1	no	63	1.000
	autism pesent	12	.000
PATEMPL1	employed	20	1.000
	unemployed	55	.000
EPILEP1	no	57	1.000
	epilepsy present	18	.000
GENDER1	female	27	1.000
	male	48	.000

Block 0: Beginning Block

Iteration History[a,b,c]

Iteration		-2 Log likelihood	Coefficients
			Constant
Step 0	1	103.959	.027
	2	103.959	.027

a. Constant is included in the model.

b. Initial -2 Log Likelihood: 103.959

c. Estimation terminated at iteration number 2 because parameter estimates changed by less than .001.

Classification Table[a,b]

Observed			Predicted		
			case by DBCL for regression		Percentage Correct
			non case	case by dbcl	
Step 0	case by DBCL for regression	non case	0	37	.0
		case by dbcl	0	38	100.0
	Overall Percentage				50.7

a. Constant is included in the model.

b. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 0	Constant	.027	.231	.013	1	.908	1.027

Variables not in the Equation

			Score	df	Sig.
Step 0	Variables	COMPOSCO	6.107	1	.013
		GENDER1(1)	3.135	1	.077
		AUT1(1)	6.099	1	.014
		PATEMPL1(1)	.205	1	.651
		EPILEP1(1)	.367	1	.545
		FAMHIS1(1)	2.276	1	.131
	Overall Statistics		17.175	6	.009

Block 1: Method = Enter

Iteration History[a,b,c,d]

Iteration		-2 Log likelihood	Coefficients						
			Constant	COMPOSCO	GENDER1(1)	AUT1(1)	PATEMPL1(1)	EPILEP1(1)	FAMHIS1(1)
Step 1	1	85.297	2.585	-.036	-.660	-1.288	.345	.354	-.877
	2	84.443	3.399	-.046	-.791	-1.724	.336	.426	-1.095
	3	84.424	3.545	-.048	-.809	-1.807	.327	.436	-1.128
	4	84.424	3.549	-.048	-.809	-1.809	.327	.436	-1.129

[a] Method: Enter

[b] Constant is included in the model.

[c] Initial -2 Log Likelihood: 103.959

[d] Estimation terminated at iteration number 4 because log-likelihood decreased by less than .010 percent.

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	19.534	6	.003
	Block	19.534	6	.003
	Model	19.534	6	.003

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	84.424	.229	.306

Hosmer and Lemeshow Test

Step	Chi-square	df	Sig.
1	6.644	7	.467

Contingency Table for Hosmer and Lemeshow Test

		case by DBCL for regression = non case		case by DBCL for regression = case by dbcl		
		Observed	Expected	Observed	Expected	Total
Step 1	1	6	7.037	2	.963	8
	2	7	6.214	1	1.786	8
	3	6	5.388	2	2.612	8
	4	3	4.663	5	3.337	8
	5	4	3.950	4	4.050	8
	6	5	3.391	3	4.609	8
	7	3	2.912	5	5.088	8
	8	3	2.135	5	5.865	8
	9	0	1.310	11	9.690	11

Classification Table[a]

			Predicted		
			case by DBCL for regression		Percentage Correct
	Observed		non case	case by dbcl	
Step 1	case by DBCL for regression	non case	25	12	67.6
		case by dbcl	11	27	71.1
	Overall Percentage				69.3

a. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95.0% C.I.for EXP(B)	
								Lower	Upper
Step 1[a]	COMPOSCO	-.048	.021	5.357	1	.021	.953	.916	.993
	GENDER1(1)	-.809	.554	2.132	1	.144	.445	.150	1.319
	AUT1(1)	-1.809	.901	4.037	1	.045	.164	.028	.957
	PATEMPL1(1)	.327	.618	.280	1	.597	1.387	.413	4.656
	EPILEP1(1)	.436	.640	.464	1	.496	1.546	.441	5.422
	FAMHIS1(1)	-1.129	.577	3.827	1	.050	.323	.104	1.002
	Constant	3.549	1.271	7.802	1	.005	34.785		

[a] Variable(s) entered on step 1: COMPOSCO, GENDER1, AUT1, PATEMPL1, EPILEP1, FAMHIS1.

Correlation Matrix

		Constant	COMPOSCO	GENDER1(1)	AUT1(1)	PATEMPL1(1)	EPILEP1(1)	FAMHIS1(1)
Step 1	Constant	1.000	-.499	-.201	-.721	-.058	-.324	-.362
	COMPOSCO	-.499	1.000	.030	.001	-.118	-.165	.157
	GENDER1(1)	-.201	.030	1.000	.010	.093	-.007	.069
	AUT1(1)	-.721	.001	.010	1.000	-.012	.129	.196
	PATEMPL1(1)	-.058	-.118	.093	-.012	1.000	-.132	.182
	EPILEP1(1)	-.324	-.165	-.007	.129	-.132	1.000	-.165
	FAMHIS1(1)	-.362	.157	.069	.196	.182	-.165	1.000

```
Step number: 1
```

```
             Observed Groups and Predicted Probabilities

       4 +                   c           c    c                       +
         |                   c           c    c                       |
         |                   c           c    c                       |
F        |                   c           c    c                       |
R      3 +          cn       nc   c   c  c c  c  c     c              +
E        |          cn       nc   c   c  c c  c  c     c              |
Q        |          cn       nc   c   c  c c  c  c     c              |
U        |          cn       nc   c   c  c c  c  c     c              |
E      2 +   n  c   nn       nn   n   nn c cn nn c c  ccc     c c c   +
N        |   n  c   nn       nn   n   nn c cn nn c c  ccc     c c c   |
C        |   n  c   nn       nn   n   nn c cn nn c c  ccc     c c c   |
Y        |   n  c   nn       nn   n   nn c cn nn c c  ccc     c c c   |
       1 +   n  nn nnn nn ncnnn ccncc nn n nncnnnc nc nnc  c  c cccc  +
         |   n  nn nnn nn ncnnn ccncc nn n nncnnnc nc nnc  c  c cccc  |
         |   n  nn nnn nn ncnnn ccncc nn n nncnnnc nc nnc  c  c cccc  |
         |   n  nn nnn nn ncnnn ccncc nn n nncnnnc nc nnc  c  c cccc  |
Predicted --------------+--------------+--------------+---------------
  Prob:   0            .25            .5             .75             1
  Group:  nnnnnnnnnnnnnnnnnnnnnnnnnnnnnncccccccccccccccccccccccccccccc

          Predicted Probability is of Membership for case by dbcl
          The Cut Value is .50
          Symbols: n - non case
                   c - case by dbcl
          Each Symbol Represents .25 Cases.
```

Casewise List[b]

Case	Selected Status[a]	Observed	Predicted	Predicted Group	Temporary Variable	
		case by DBCL for regression			Resid	ZResid
45	S	c**	.104	n	.896	2.941

a. S = Selected, U = Unselected cases, and ** = Misclassified cases.

b. Cases with studentized residuals greater than 2.000 are listed.