

Department of Social Protection

Learning Disabilities

Contents

| | |
|--|-----------|
| 1. Overview and Definition of Learning Disabilities | 5 |
| 1.1 Overview | 5 |
| 1.2 Definition of Intellectual Disability | 5 |
| 1.2.1 Intellectual Disability - Diagnostic and Statistical Manual of Mental Disorders 4 th Edition Text Revision (DSM-IV-TR) Classification | 6 |
| 1.2.2 Intellectual Disability - International Classification of Diseases; 10 th Edition (ICD-10) Classification | 7 |
| 1.2.3 Functional Effects of Intellectual Disability | 7 |
| 1.2.4 American Association of Intellectual and Developmental Disabilities. | 8 |
| 1.3 Learning Disorders | 9 |
| 1.3.1 Specific Reading Disorder - Dyslexia | 9 |
| 1.3.2 Specific Spelling Disorder - Dysgraphia | 10 |
| 1.3.3 Disorders of Arithmetical Skills – Dyscalculia | 11 |
| 1.3.4 Mixed Disorder of Scholastic Skills | 11 |
| 1.4 Other Disorders Which May Affect Learning Ability | 11 |
| 1.4.1 Auditory processing disorder | 11 |
| 1.4.2 Language Based Learning Difficulties | 12 |
| 2. Epidemiology | 13 |
| 3. Aetiology | 15 |
| 3.1 Aetiology of Intellectual Disabilities | 15 |
| 3.1.1 Mild Intellectual Disability | 15 |
| 3.1.2 Moderate to Severe Intellectual Disability | 15 |
| 3.2 Genetic Factors | 15 |
| 3.3 Intrauterine Factors | 16 |
| 3.4 Perinatal Factors | 16 |
| 3.5 Postnatal Factors | 16 |
| 3.6 Environmental Factors | 17 |
| 4. Diagnosis | 18 |
| 4.1 Down Syndrome | 18 |
| 4.1.1 Epidemiology | 18 |
| 4.1.2 Aetiology | 18 |
| 4.1.3 Clinical Features | 19 |
| 4.1.4 Prognosis | 19 |

| | | |
|-----------|---|-----------|
| 4.2 | Fragile X Syndrome | 20 |
| 4.2.1 | Epidemiology | 20 |
| 4.2.2 | Clinical Features | 20 |
| 4.2.3 | Prognosis | 21 |
| 4.3 | Autism Spectrum Disorders | 21 |
| 4.4 | Autistic Disorder | 21 |
| 4.4.1 | Epidemiology | 22 |
| 4.4.2 | Aetiology | 22 |
| 4.4.3 | Core Clinical Features | 22 |
| 4.4.4 | Complications | 22 |
| 4.4.5 | Prognosis | 23 |
| 4.5 | Asperger's Syndrome | 23 |
| 4.5.1 | Epidemiology | 24 |
| 4.5.2 | Aetiology | 24 |
| 4.5.3 | Complications | 24 |
| 4.5.4 | Prognosis | 24 |
| 4.6 | Attention Deficit Hyperactivity Disorder – ADHD | 24 |
| 4.6.1 | Epidemiology | 25 |
| 4.6.2 | Aetiology | 25 |
| 4.6.3 | Core Clinical Features | 25 |
| 4.6.4 | Complications | 26 |
| 4.6.5 | Treatment | 26 |
| 4.6.6 | Prognosis | 27 |
| 5. | Differential Diagnosis and Comorbidity | 28 |
| 5.1 | Differential Diagnosis | 28 |
| 5.2 | Physical Comorbidity | 28 |
| 5.2.1 | Cerebral Palsy | 28 |
| 5.2.2 | Epilepsy | 29 |
| 5.3 | Psychiatric Comorbidity | 29 |
| 6. | Treatment | 31 |
| 6.1 | Treatment Options for Intellectual Disabilities | 31 |
| 6.2 | Management of Learning Disability | 31 |
| 6.3 | Education | 31 |
| 6.4 | Psychological Therapies | 32 |

| | | |
|------------|--|-----------|
| 6.5 | Psychopharmacological Treatments | 32 |
| 6.6 | Family Support | 33 |
| 6.7 | Creative Therapies | 34 |
| 6.8 | Employment Opportunities | 34 |
| 6.9 | Accommodation and Supervision | 34 |
| 6.10 | Self-Help Groups | 34 |
| 6.11 | Prevention | 35 |
| 7. | Prognosis (Main Prognostic Factors) | 36 |
| 8. | Information Gathering at the In Person Assessment | 37 |
| 8.1 | Assessing the Claimant | 37 |
| 8.1.1 | Mild Intellectual Disability | 37 |
| 8.1.2 | Moderate, Severe and Profound Intellectual Disability | 37 |
| 8.2 | Helpful Questions for Assessing the Disabling Effects of Learning Disability | 38 |
| 8.3 | How to Assess the Disabling Effects of ADHD | 39 |
| 9. | Analysis of Effect on Functional Ability | 40 |
| 9.1 | Indicators of Ability/Disability | 40 |
| 9.2 | Ability/Disability Profile | 41 |
| 10. | Summary of Scheme Criteria | 42 |
| | Appendix A - Rare Disorders Reference Table | 43 |
| 11. | References and Bibliography | 45 |

1. Overview and Definition of Learning Disabilities

1.1 Overview

Learning disabilities, in the form of intellectual disability and learning disorders, are one of the most common forms of disability in the United Kingdom (UK) and Ireland; however, there is a lack of terminological consistency in respect to these conditions, which affects the description, diagnosis, treatment and prevalence figures of these conditions.

Terminologies to describe the different ranges of conditions which can be grouped as learning disabilities also vary from country to country, and vary in terms of historical context. In the United States and Canada, the term 'Mental Retardation', which is now considered outdated in the UK and Ireland, continues to be widely used to describe intellectual disabilities. This term is still reflected in the diagnostic classification systems detailed in the Diagnostic and Statistical Manual Version 4 (American Psychiatric Association, 2000) and the International Classification of Diseases 10th Edition (World Health Organisation), although this is expected to change in the next versions of these classification systems.

The terminology used to describe learning disabilities has also changed as this group of conditions have become viewed conceptually as a 'disability' rather than an 'illness'.

For the purposes of clarity, this protocol covers the following areas:

Intellectual Disabilities: where an individual has significant impairment of intellectual functioning and also has impairment in adaptive skills. This includes both developmental and acquired impairment of intellectual function.

Learning disorders: where an individual has a scholastic difficulty which results in a general impairment with respect to learning – for example dyslexia – but does not have an accompanying impairment of adaptive skills.

It should be noted that the content of this protocol concentrates on intellectual disabilities as this is the more significant area for incapacity claims.

1.2 Definition of Intellectual Disability

In both the UK and Ireland, the terminology used to describe individuals with impaired intellectual ability is closely linked to the availability of social and health care services for people affected by this type of disability. This reflects the eligibility and availability of social benefit available to the individual, as much as it does the functional abilities of the individual. This has an effect not only on the definition of the condition, but also in the reporting of prevalence figures (see **section 2**).

The UK Department of Health (2001) has defined learning *disability* as the presence of:

- “A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development.”

Whilst this definition adequately reflects individuals who have had life long learning disabilities, it does not include individuals who have difficulties which are severe enough to have some form of functional impact, with out being severe enough to require the individual to need social support in terms of an actual disability. The definition also excludes individuals who have ‘acquired’ rather than ‘developmental’ difficulties or disabilities which may have occurred after the age of 18 as a result of illness or injury (for example hypoxic brain injury from near drowning, stroke, or drug or alcohol abuse). There are also individuals who have average or higher than average intelligence such as higher level autistic spectrum disorders (e.g. Asperger’s Syndrome) who could be described as having ‘learning difficulties’ but who do not meet the above definition.

In Ireland, the Department of Health and Children use the phrase ‘Intellectual *Disability*’ and describe the condition as involving: “a greater than average difficulty in learning. A person is considered to have an intellectual disability when the following factors are present: general intellectual functioning is significantly below average; significant deficits exist in adaptive skills; and the condition is present from childhood (eighteen years or less) (InclusionIreland, 2009)”.

Both these definitions use the phrase ‘disability’. Although prevalence figures in this protocol refer to the term intellectual disability, the actual number of individuals who have some form of functional impact through learning or intellectual *difficulties* is far greater. However, there has been little or no research either in the UK or Ireland with respect to this group of individuals.

Other terms which have been used to apply to such individuals are no longer in common use in Europe but are still formal terms used within diagnostic classification systems. ‘Mental retardation’ is the term recognised by both the Diagnostic and Statistical Manual of Mental Disorders 4th Edition Text Revision (DSM-IV-TR) Classification published by the American Psychiatric Association (2000) and the International Classification of Diseases: 10th Edition (ICD-10) published by the World Health Organisation.

1.2.1 Intellectual Disability - Diagnostic and Statistical Manual of Mental Disorders 4th Edition Text Revision (DSM-IV-TR) Classification

The DSM-IV-TR (American Psychiatric Association, 2000) classification states three principles for the diagnosis of mental retardation.

- A. Significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgment of significantly sub-average intellectual functioning).

- B. Concurrent deficits or impairments in present adaptive functioning (i.e., the person's effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.
- C. The onset is before age 18 years.

1.2.2 Intellectual Disability - International Classification of Diseases; 10th Edition (ICD-10) Classification

The World Health Organisation (WHO, 2007) in the International Classifications of Diseases; 10th Edition defines mental retardation as 'A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition'.

Further classification can be made of the extent of impairment of behaviour:

- No, or minimal, impairment of behaviour
- Significant impairment of behaviour requiring attention or treatment
- Other impairments of behaviour
- Without mention of impairment of behaviour

1.2.3 Functional Effects of Intellectual Disability

Both the DSM-IV-TR and ICD-10 diagnostic classification systems describe different levels of severity for mental retardation to reflect the degree of functional impairment that the disability causes the individual.

- **Mild Mental Retardation:** approximate IQ level 50 to 70, mental age approximately 9-12 years – This level of severity is not usually associated with abnormalities in appearance or behaviour, and accounts for the majority of individuals with this condition. Language, sensory and motor abnormalities are mild or absent. Because it is mild, the problem is not usually apparent until school age. Individuals will achieve some educational attainment although may have difficulties in academic school work, and can become relatively self sufficient. Adults may have difficulty coping with stress, and may need support with complex functioning such as parenting and handling their finances. However, the majority are able to live independently in the community and manage some form of employment. Those in the higher levels of this severity category will be capable of practical based work such as unskilled or semiskilled manual labour.
- **Moderate Mental Retardation:** approximate IQ level 35 to 50, mental age

approximately 6-9 years –This category accounts for approximately 10% of individuals with this condition, who can undertake work and self-care tasks with supervision. Although fully mobile and physically active, individuals with moderate learning disability are rarely able to live independently in adulthood, but they may learn to wash, dress and feed themselves. This group has limited but useful language skills. Individuals at the higher levels of this severity category will be able to develop basic reading, writing and counting skills. However, receptive skills tend to be better than expressive skills, leading to a high incidence of frustration and challenging behaviour. Help is needed with road sense and finances. In supported work placements, they will be able to perform simple practical tasks. Individuals with this severity category are able to live and function successfully within the community in residential care settings. Moderate learning disability is often associated with epilepsy, neurological, and other physical disabilities. Other psychiatric conditions may co-exist, but limited language skills make these difficult to identify.

- **Severe Mental Retardation:** approximate IQ level 20 to 35, mental age approximately 3-6 years – accounts for around 3-4% of individuals with mental retardation who are only able to undertake basic self-care with supervision. Individuals with this level of severity are likely to need continuous support, and will have varying language skills ranging from no language skills to the ability to take part in simplistic conversations. This group of claimants have very limited verbal and self-care skills. Severe physical handicaps are very common. Epilepsy affects 33%, incontinence 10% and inability to walk 15%. Behavioural disturbance such as purposeless, self-harming or inappropriate sexual behaviour becomes more common with increasing severity of learning disability.
- **Profound Mental Retardation:** IQ level below 20; mental age below 3 years – Around 1% of individuals with mental retardation will be profoundly retarded. They may be able to develop very basic self-care and very basic communication skills but in general are unable to meet their own care needs. Individuals with this level of disability will require a high level of supervised, structured care. Many individuals will be either immobile or have severely restricted mobility, have continence problems, and commonly severe neurological or physical comorbidities. Visual and hearing problems are also common, as is epilepsy. Pervasive developmental disorders also occur frequently.
- **Mental Retardation, Severity Unspecified:** when there is strong presumption of Mental Retardation but the person's intelligence is un-testable by standard tests.

(American Psychiatric Association, 2000; World Health Organisation, 1996; World Health Organisation, 2007)

1.2.4 American Association of Intellectual and Developmental Disabilities.

The AAIDD definition of intellectual disabilities is another commonly recognised diagnostic classification. The definition of intellectual disabilities as 'a disability characterised by significant limitations both in intellectual functioning and in adaptive

behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18' (AAIDD, 2009). Diagnostic classification in terms of assessment of intellectual disability focuses on functions of adaptive behaviour (conceptual, social and practical) skills. The AAIDD are in the processes of defining a new diagnostic classification for intellectual disabilities which will be available in 2010.

1.3 Learning Disorders

The group of conditions described as 'Specific developmental disorders of scholastic skills' by ICD-10 and 'learning disorders' by DSM-IV-TR are typically first noted in childhood and usually occur in individuals who have at least average intelligence, although they can occur in children with lower cognitive function also. Normal patterns of skill acquisition are noticed to be disturbed in children with this range of deficits, usually at the age where such functions become required (e.g. difficulties in learning to read). These disorders do not arise as a consequence of brain injury or disease but as a dysfunction in cognitive processing (Remschmidt and Schulte-Korne, 2009).

The ICD-10 classification system (WHO, 2007) notes that this category of learning disabilities is ill-defined, stating that it is difficult to identify this disorder against normal variations of scholastic achievement; that there are variations in the rate of normal development; there may be underlying external issues with learning, teaching or family environment which affect the ability of an individual to develop scholastic skills or there may be underlying abnormalities in cognitive processing. There are also difficulties in sub-defining such disorders of scholastic skills.

One of the defining features of a 'specific' learning disorder is that there is a particular skill or ability which is uncharacteristically poor in comparison with the general performance level of the affected individual.

Learning disorders occur more commonly in boys than girls, and frequently occur in conjunction with other related syndromes such as attention deficit hyperactivity disorder.

1.3.1 Specific Reading Disorder - Dyslexia

Specific reading disorder or Dyslexia is a significant specific impairment of the development of reading skills, which is not accounted for by mental age, visual problems or inadequate schooling (WHO, 2007). Word recognition skills, comprehension, oral reading skills and performance of tasks which require reading may be affected. The condition can manifest itself in a number of ways, which include omissions, substitutions or distortions of letters or words, slow reading rates, hesitations or 'loss of place' within a text, or reversal of letters or words (WHO, 2007). This can be accompanied by inability to recall information which has been read, or inability to 'digest' or 'process' information in order to draw conclusions from text which the individual has read.

Reading difficulties are often preceded by speech and language difficulties. Emotional and behavioural problems (such as hyperactivity) are also common, and

may contribute to poor school attendance. 40% of children with reading disorders also have some other form of clinical disorder ((Remschmidt and Schulte-Korne, 2009).

In adult life, it is common for spelling difficulties to be more of an impairment than reading difficulties (Remschmidt and Schulte-Korne, 2009). Approximately one third of adults with reading disorder will have other clinical disorders. Emotional and behavioural difficulties may continue in terms of antisocial and delinquent behaviour. Studies show that the rate of unemployment may be three times higher in individuals with reading disorders (Esser and Schmidt, 1994)

Epidemiology

The prevalence of dyslexia is higher in English speakers than in any other language, as English has more differences in the way a letter can be pronounced than most languages, and more inconsistencies in the manner that words are written and sound (Parliamentary Office of Science and Technology, 2004).

Estimates of prevalence vary according to the definition of severity of reading disorders or dyslexia which is used, but can be between 2-15% of the population (Parliamentary Office of Science and Technology, 2004). No official figures exist in Ireland but the prevalence is thought to be around 8% (Skooool.ie, 2009).

Aetiology

Reading disorders are thought to arise from a combination of genetic influences, issues with central information processing, general psychosocial factors and specific learning conditions (Remschmidt and Schulte-Korne, 2009).

Diagnosis

Diagnosis is made using standardised tests of reading accuracy and comprehension.

Treatment

Treatment for reading disorders is usually by individual instruction and teaching sessions which focus on special educational methods which concentrated on basic phonetics. There is no medication therapy which is effective for reading disorders, although medication is sometimes used to control other clinical issues such as attention deficit hyperactivity disorder.

1.3.2 Specific Spelling Disorder - Dysgraphia

This disorder is a significant impairment in the development of spelling skills, in the absence of reading disorder. Children with this condition have difficulty in spelling orally and in writing words (WHO, 2007). Although this condition exists as a diagnosis in the ICD-10 classification system, there is no associated diagnosis in the DSM-IV-TR classification system. The nearest corresponding diagnosis in this system is 'disorders of written expression'.

1.3.3 Disorders of Arithmetical Skills – Dyscalculia

This condition is a specific impairment in arithmetical skills (ICD-10) or mathematics disorder (DSM-IV-TR) which cannot be explained by general intellectual disability or schooling issues (WHO, 2007). The disorder results in a difficulty in learning and remembering numbers, and a difficulty in performing basic calculations such as adding, subtracting etc. There may be difficulty in recognising numerical symbols, or mathematical signs. However, diagnostic guidelines state there is not an accompanying deficit in reading and spelling skills, which are normally within the range expected for the individual's age, although a dual diagnosis of dyslexia and dyscalculia can be made.

Epidemiology

It is estimated that a specific impairment in arithmetical skills affects between 3 to 6% of schoolchildren (Gross-Tsur et al, 1996). Approximately 40% of children with dyslexia also have dyscalculia (Lewis et al, 1994).

Aetiology

There has been little research regarding the cause of dyscalculia (Remschmidt and Schulte-Korne, 2009).

Diagnosis

Diagnosis is made using standardised tests of mathematical accuracy and comprehension.

Treatment

Treatment for arithmetic disorders mirrors that for reading disorders, focussing on individual instruction and teaching sessions delivered by special educational methods.

1.3.4 Mixed Disorder of Scholastic Skills

ICD-10 states this is an ill defined category where individuals have been diagnosed as having either a reading or spelling disorder, as well as an arithmetic disorder.

1.4 Other Disorders Which May Affect Learning Ability

1.4.1 Auditory processing disorder

Auditory Processing Disorder is a condition in which the brain inaccurately processes or interprets the information messages which are heard by an individual (NIDCD, 2004). The cause is often unknown.

Individuals with this condition:

- Have trouble paying attention to and remembering information presented

orally

- Have problems carrying out multistep directions
- Have poor listening skills
- Need more time to process information
- Have low academic performance
- Have behaviour problems
- Have language difficulty (e.g., they confuse syllable sequences and have problems developing vocabulary and understanding language)
- Have difficulty with reading, comprehension, spelling, and vocabulary

Research is still evaluating treatments for this condition. Current thought is that reducing background noise and noise distortion will allow individuals to process the auditory information to the best effect.

1.4.2 Language Based Learning Difficulties

Disorders of language or speech can cause impairment to an individual in terms of communication with others. ICD-10 classifies specific developmental disorders of speech and language as disorders in which normal patterns of language acquisition are disturbed from the early stages of development.

This group of conditions includes:

- **Speech Articulation Disorder** – in which the use of speech sounds is below the appropriate level an individual's mental age, but a normal level of language skills is present
- **Expressive language disorder** - a specific developmental disorder in which an individual's expressive spoken language is markedly below the appropriate level for their mental age, but in which language comprehension is within normal limits
- **Receptive language disorder** - A specific developmental disorder in which an individual's understanding of language is below the appropriate level for their mental age. Expressive language is markedly disturbed and abnormalities in word-sound production are common
- **Acquired aphasia with epilepsy [Landau-Kleffner syndrome]** – arises in childhood (usually between 3-7) where normally developing child, loses both receptive and expressive language skills but retains general intelligence.

2. Epidemiology

Intellectual disability is one of the highest causes of disability in Ireland. In addition to the figures below, which reflect diagnosed cases, potentially another 10% of the population have mild intellectual difficulties which affect their lives in some way, but not severe enough to warrant formal diagnosis or require the support of formal services.

Statistics are collated by the Health Research board in Dublin, for those individuals who receive the support of formal disability services. Such individuals are recorded on the National Intellectual Disability Database. Figures published in August 2009 indicate there are approximately 26,000 individuals who have been diagnosed with intellectual disabilities – equivalent to a prevalence rate of 6.14 per 1,000 of population.

The levels of severity are approximately:

- **Mild** intellectual disability 33%
- **Moderate** intellectual disability 39%
- **Severe** intellectual disability 15.5%
- **Profound** intellectual disability 4%
- **Unverified** 8.5%

There is a slightly higher prevalence of intellectual disabilities in males than females - 6.94/1000 males and 5.33/1000 females.

28.4% of the individuals registered on the NIDD had a coexisting physical and/or sensory disability in addition to their intellectual disability

32% of the individuals registered on the NIDD live in full time residential services

Up to 40% of individuals with intellectual disabilities will suffer some form of mental illness in their lifetime Cooper and Bailey, 2001.

(NAIMH, 2009; Kelly et al, 2009)

Worldwide, socio-economic factors result in the prevalence of intellectual disabilities being higher in developing than developed countries. The most common preventable cause of intellectual disabilities being iodine deficiency.

Genetic counselling in developed countries has reduced the prevalence of intellectual disabilities in groups where consanguineous marriage is common, or hereditary conditions such as Tay-Sachs disease are frequently encountered (Cooper and Smiley, 2009).

Evidence suggests that the number of people with severe learning disabilities may increase by around 1% per annum for the next 15 years as a result of:

- increased life expectancy, especially among people with Down syndrome
- growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood
- a sharp rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have learning disabilities
- greater prevalence among some minority ethnic populations of South Asian origin

Secretary of State for Health (2001).

3. Aetiology

3.1 Aetiology of Intellectual Disabilities

A specific cause for mild intellectual disability can be identified in about half of all cases, and in around 80% of cases of moderate to profound severities of intellectual disability (Kaski, 2009).

However, the cause of intellectual disability is likely to be multi-factorial. Other risk factors for intellectual disability include lower socioeconomic backgrounds, large families, and environmental factors such as overcrowding & poverty..

3.1.1 Mild Intellectual Disability

Factors which are thought to play a part in the development of mild intellectual disability include:

- Perinatal Hypoxia (15-20%)
- Congenital causes (10%),
- Defined genetic cause (5%).

(Newcastle University, 2009)

3.1.2 Moderate to Severe Intellectual Disability

Virtually all cases of severe & profound learning disability are due to organic or pathological reasons:

- Chromosomal 40%
- Genetic 15%,
- Pre & peri-natal 10%
- Post-natal 10%
- Unknown 25%.

Some cases can be related to syndromes such as autism, cerebral malformation or cerebral palsy.

(Newcastle University, 2009)

3.2 Genetic Factors

Genetic factors can manifest in three ways; chromosomal abnormalities, genetic metabolic disorders and genetic neurologic disorders:

- **Chromosomal abnormalities** - Down and Fragile X Syndromes are the commonest chromosomal causes of intellectual disability. Others include Trisomy 13 (Patau's syndrome); Trisomy 18 (Edwards syndrome); Klinefelter's and Turner's syndromes.
- **Genetic Metabolic disorders:** Autosomal recessive disorders such as Phenylketonuria and Tay-Sachs Disease ; Lysosomal defects such as Gaucher's disease; Peroxisomal disorders; X-linked recessive disorders
- **Genetic neurologic disorders:** Tuberous Sclerosis (autosomal dominant), neurofibromatosis.

3.3 Intrauterine Factors

- Antepartum bleeding
- Smoking (resulting in an increased risk of prematurity)
- Substance abuse, alcohol abuse, fetal alcohol syndrome
- Infections: Rubella, Toxoplasmosis and Cytomegalovirus infections are examples
- Illness or injury of the mother, e.g. pre-eclampsia
- Malnutrition

3.4 Perinatal Factors

- Prematurity and/or low birth weight
- Hypoxia
- Intracerebral bleed
- Neonatal infections
- Traumatic Delivery

3.5 Postnatal Factors

- Infection – e.g. meningitis, encephalitis, measles
- Head Injury (accidental or physical abuse) or other trauma
- Malnutrition
- Toxins (e.g. Lead)

- Hypothyroidism

3.6 Environmental Factors

- Extreme poverty and malnutrition (uncommon in developed countries)
- Socio-economic deprivation
- Emotional abuse

4. Diagnosis

Diagnosis is usually made in childhood. In cases of mild intellectual disability, this may not be until school age when educational attainment becomes noticeably delayed. In moderate to severe intellectual disability early identification is common. Intellectual disability is usually detected early when accompanied by physical abnormalities or signs of a condition or syndrome; for example in cases of cerebral palsy, where a cause of intellectual disability can be determined (perinatal hypoxia).

Diagnostic tools include:

- Developmental and intelligence assessment
- Imaging testing
- Genetic testing
- Laboratory investigations

Once a diagnosis of intellectual disability has been made, it is important to try to ascertain the cause, as this may provide further information on expected developmental progress.

The most common causes of intellectual disability are outlined below.

4.1 Down Syndrome

Down syndrome is the commonest specific cause of intellectual disability, and the most common cause of congenital developmental disability in Ireland (Hoey and Murphy, 2006).

4.1.1 Epidemiology

The incidence of Down syndrome is generally falling in European countries because of increased antenatal detection. However, Ireland continues to have one of the highest prevalence rates of 1 in 546 births, due to policy regarding termination of pregnancy (Hoey and Murphy, 2006; Dolk et al, 2005).

Overall risk of Down syndrome rises with maternal age, but as fertility rates are higher in younger women, 80 percent of Down syndrome children are born to mothers under the age of 35 (NDSS, 2009).

4.1.2 Aetiology

The vast majority of cases of Down syndrome are caused by Trisomy 21. A small number of cases are caused when a piece of an additional chromosome 21 has been translocated to another chromosome, most commonly chromosome 14.

It is thought that Down syndrome mosaicism occurs when chromosomes fail to pass

to two separate cells during cell division in the embryo.

Affected women have a 50% chance of having a child who is also affected by Trisomy 21.

4.1.3 Clinical Features

Down syndrome is associated with a typical facial appearance and short stature. Average height is around the 2nd centile at most ages (Hoey and Murphy, 2006)

85% of individuals affected by Down syndrome have moderate or severe learning disability.

5% of individuals affected by Down syndrome have autistic features and 25% have hyperkinetic disorder.

Physical health problems are associated with Down syndrome:

- Congenital heart disease – 40% - 50%, of which half require surgery. Around 30-40% have complete atrioventricular septal defects.
- Visual and hearing impairment – 50%. (Down's Syndrome Association, 2009)
- Hypothyroidism – 20% prevalence at adulthood (Down's Syndrome Association, 2009)
- Oesophageal and duodenal atresia, other gastrointestinal anomalies – 5% (Merk, 2009)
- 20% increased risk of developing infections and leukaemia.
- Atlanto-axial instability.
- Diabetes (especially type 1 diabetes) (Down's Syndrome Association, 2009)

Cognitive decline and dementia (similar to Alzheimer's disease) occurs 30-40 years earlier than in the general population, and affects 25% of people with Down syndrome (Down's Syndrome Society, 2009, National Down's Syndrome Society, 2009).

4.1.4 Prognosis

The prognosis for Down syndrome is variable, dependent on the degree of severity, with average life expectancy around 50 years of age. The aging process appears to be accelerated in individuals with Down syndrome, with degenerative diseases such as Alzheimer's disease appearing at an earlier age than in the general population.

Dependent on the degree of severity individuals with Down syndrome may live independent lives, or in supported accommodation. Individuals affected by Down syndrome are often able to achieve an education, and sustain employment.

(Down's Syndrome Society, 2009, Down's Syndrome Ireland, 2009)

4.2 Fragile X Syndrome

Fragile X syndrome is the second commonest cause of moderate and severe learning disability after Down syndrome, accounting for 20 - 30% of learning disabilities.

Fragile X syndrome is the commonest *directly inherited* cause of learning disability, and can cause language, learning, socialisation, behaviour and emotional difficulties.

4.2.1 Epidemiology

Fragile X syndrome occurs in 1 in 4000 males, and 1 in 8000 females (Fragile X Society, 2008). Symptoms are often milder in women than men.

4.2.2 Clinical Features

Physical

Fragile X syndrome is associated with a typical appearance, including an elongated face, large ears and blue eyes. Other features include flat feet, macro-orchidism and hyper-flexible joints. The physical features usually develop by puberty, with infants often appearing normal. Females only tend to exhibit large or prominent ears.

Cognitive

The degree of learning disability is similar to that in Down syndrome, 80% of males having an IQ between 45 and 80. A very small percentage, with severe or profound fragile X disability, have an IQ less than 40. Only one third of females affected by Fragile X have a sub-normal IQ, most having normal cognitive development, or slight learning difficulties in terms of educational attainment. Males with fragile X syndrome may have problems with language skills ranging from stuttering to severe problems with basic language use. Females are rarely affected in terms of language.

(NICHD, 2006).

Behavioural

Many individuals with Fragile X syndrome have some form of sensory problem, for example an aversion to loud noise or strong smells. Difficulty adjusting to change, (particularly environmental change), and mood instability are also prominent features.

Boys tend to have more behaviour problems and can be aggressive. Typically, girls tend to be shy and socially withdrawn. Girls often suffer from anxiety and depression.

(NICHD, 2006).

Other Related Conditions

Fragile X is associated with a number of other conditions:

- **Autism:** Most males and 30% of females will show behavioural traits typical of autism. Of these, one third will show severe enough symptoms to warrant a diagnosis of autism.
- **Attention Deficit Hyperactivity Disorder:** Up to 90% of males and 50% of females with Fragile X syndrome will have an attention disorder.
- **Seizures:** Up to 20% of affected individuals suffer seizures, usually controllable with medication.
- **Premature Ovarian Failure:** Affected females usually show menopausal symptoms in their 30s.
- **Other related conditions:** Recurrent ear infections and squint are more common, and there is an increased incidence of connective tissue disorders such as hernia.

(NICHD, 2006).

4.2.3 Prognosis

There is no treatment for Fragile X but with appropriate support some of the symptoms can be reduced or eliminated. Behavioural problems tend to improve with age.

Some people with fragile X syndrome are employed and are able to live independently. The majority need day-to-day supervision, and will require work in a sheltered environment, and either live at home or in supported accommodation.

4.3 Autism Spectrum Disorders

The term 'autistic spectrum disorders' is used to describe a group of developmental conditions that affect the way the brain processes information. These conditions are also grouped in a broader category of pervasive developmental disorders. People with autism are severely affected, while Asperger's syndrome describes people at the higher functioning end of the autistic spectrum.

4.4 Autistic Disorder

Autistic disorder (commonly known as autism or classic autism) is a lifelong developmental disability that affects the way a person communicates and relates to people around them. The core feature of an autistic spectrum disorder is a difficulty in "making sense of the world." An autistic person experiences a confusing mass of events, people, places, sounds and sights without order or meaning. Thus, a lot of

time is spent trying to “work out the pattern behind everything”.

The range of intellectual ability extends from severe learning disability to above average IQ.

4.4.1 Epidemiology

The prevalence of autism is about 13 in 10,000, with a higher male prevalence at a ratio of 4:1 (Volkmar and Klin, 2009) The prevalence does not vary with socio-economic class, although ethnic and cultural differences have not been studied.

4.4.2 Aetiology

Autism is thought to arise from a fundamental disturbance in the central nervous system (Volkmar and Klin, 2009).

Twin and family studies suggest that autism is a strongly genetic condition, with families that already have one autistic child having between 2 and 10% recurrence risk (Volkmar and Klin, 2009). Although several studies have shown that autism is associated with organic causes of learning disability, such as complications of pregnancy and birth, it is not clear if these difficulties reflect an existing genetic weakness or a combination of genetic and perinatal factors (Rutter, 2005). Neurochemical studies of autism have reported abnormalities in dopamine and serotonin metabolism, but the significance of this finding is unclear (Anderson, 2005).

4.4.3 Core Clinical Features

Autism is usually apparent by the age of 18 months of age (NICHD, 2008)

- **Abnormal Social Interaction:** There is failure to initiate, develop or respond to social situations, poor grasp of non-verbal social cues and avoidance of eye contact, so people with autism may appear aloof and indifferent.
- **Impaired Language and Communication Skills:** This includes delayed or impaired language development, difficulty maintaining conversation, lack of creativity and lack of imaginative play.
- **Restricted and Repetitive Behaviour:** This includes a “rigid routine”, interests and activities that have a preoccupation with dates or numbers, and a stereotyped behaviour pattern such as hand flapping, nodding or rocking.

Because individuals with Autism can concentrate on a single task for long periods, they can become very proficient in those tasks that interest them. About 10% of children with autistic spectrum disorders have a special skill at a much higher level than the rest of their abilities - for example, music, art, numerical calculations or jigsaw puzzles.

4.4.4 Complications

A significant number of individuals with autism will also have a learning disability.

Prevalence rates of other conditions in specific relation to autism can be uncertain, as they can occur as a coexisting condition to learning disabilities (SIGN, 2007).

Other complications include:

- 1-2% have fragile X syndrome (Volkmar and Klin, 2009)
- Up to 2.8% have tuberous sclerosis (Volkmar and Klin, 2009)
- 5-40% develop epilepsy (Tuchman and Rapin, 2002)
- Mental Health and Behavioural problems are increased
- Visual and hearing impairment (SIGN, 2007)

Problems with communication and difficulty in adjusting to change often cause frustration, which may result in aggressive or challenging behaviour. It is best to talk to the autistic person in unambiguous terms, and maintain a routine. When challenging behaviour does occur, it can sometimes be channelled into harmless activities such as shredding paper or punching a pillow.

4.4.5 Prognosis

Autism typically runs a steady lifelong course. Specialised education and support aim to help a child to maximise their skills and achieve their full potential. With early intervention, around 50% of individuals will achieve a 'good' or 'fair' outcome (Volkmar and Klin, 2009). Although some autistic adults learn to adapt partially to their disability, only 11% gain jobs on the open market, and only 15% achieve independent living.

4.5 Asperger's Syndrome

Asperger's syndrome has the same core features as autism, but is at the high functioning end of the autistic spectrum. People with Asperger's syndrome find it hard to read social signals, and as a result, they find it difficult to communicate and interact with others.

People with Asperger's syndrome can speak fluently, but they may not understand the reactions of the people listening to them. They may talk on and on, regardless of the listener's interest or they may appear insensitive to the listener's feelings. Jokes, turns of phrase and metaphors can be confusing to a person with Asperger's syndrome, because they tend to think in an over-literal way.

People with Asperger's syndrome often develop an obsessive interest in memorising facts about a special subject, such as train timetables. They also prefer a set routine. Any unexpected happening or change in the routine can upset them.

Children with Asperger's syndrome usually have normal or above average intelligence, and they attend mainstream schools. Many seem clumsy; they have poor coordination and difficulties with fine motor control. Adults with Asperger's syndrome can be considered eccentric, and may resemble those with a schizoid or

anankastic personality disorder.

It should be noted that there is some degree of controversy regarding the diagnostic definition for Asperger's syndrome, and the differential between Asperger's syndrome and classic Autism. The ICD-10 definition for Asperger's syndrome is therefore expected to be refined or removed in the next edition of ICD-10 (Volkmar and Klin, 2009).

4.5.1 Epidemiology

The differing approaches to diagnosis affect prevalence figures. Strict definitions lead to a prevalence rate of 1:2000. Prevalence figures rise as less strict criteria are applied and can be as high as one in several hundred (Volkmar and Klin, 2009). Prevalence figures in Ireland have not been determined but an estimate is that there are around 3,750 children with Asperger's Syndrome in Ireland in 2006 (Cheevers, 2009).

4.5.2 Aetiology

Asperger's Syndrome is thought to arise from the same or similar causes to Autism.

4.5.3 Complications

Individuals with Asperger's syndrome have an increased risk of psychiatric disorders including mood disorders, anxiety, depression and psychosis.

4.5.4 Prognosis

Asperger's Syndrome is a chronic illness, without cure. However, with appropriate support affected individuals can live full and unsupported lives. The problems arising from issues with social interaction are the main cause of disability, and can make it difficult for a person with Asperger's syndrome to cope in a working environment.

In the UK, only 12% of adults with high functioning autistic disorder or Asperger's syndrome are in full time paid employment (National Autistic Society, 2009)

4.6 Attention Deficit Hyperactivity Disorder – ADHD

Attention Deficit Hyperactivity Disorder (ADHD), or Hyperkinetic Disorder as it is described by ICD-10, is the most widely researched childhood psychiatric disorder. However, there is still great contention over its definition and diagnostic criteria (SIGN, 2001). The diagnosis of ADHD is based on a 'constellation' of three types of behaviour; over-activity, impulsivity and inattentiveness (Taylor, 2009). Not every individual will have all of these symptoms – they may only show inattentiveness, particularly in adults (NCCMH, 2009).

People with ADHD are creative and intuitive, but their full potential may not be achieved because of poor concentration. If untreated, ADHD interferes with educational and social development and predisposes to mental illness.

In most countries, ADHD is one of the most commonly diagnosed paediatric mental health problems (Taylor, 2009).

The strict diagnostic criteria outlined by the DSM-IV-TR and ICD-10 state that the onset of ADHD should be before 7 years of age. Recent guidance from NICE (NCCMH, 2009) indicates that this limitation is unnecessary, and it is appropriate to make a diagnosis of ADHD in individuals who have symptoms which occur over the age of 7 years or even in adulthood.

The guideline produced by the National Institute of Clinical Excellence (NCCMH, 2009) recommends that a diagnosis of ADHD should only be considered when an individual shows at least moderate symptoms of ADHD, which cause impairment in multiple settings AND are pervasive in multiple settings (e.g. psychological, social, educational or occupational). These criteria are in *addition* to the diagnostic criteria detailed by DSM-IV-TR and ICD-10.

4.6.1 Epidemiology

The prevalence of ADHD varies in different countries due to different diagnostic practices. In general the prevalence is around 5-10% of the population with a higher male:female ratio of 2-3:1 (SIGN, 2001; Taylor, 2009). NICE (2006) suggest 3 in 1000 children were receiving medication for ADHD in the late 1990s. Prevalence is increasing in industrialised societies as more professionals recognise ADHD as a problem.

ADHD occurs in all cultures and all social classes.

In adult life, ADHD has a high prevalence rate of 4% according to surveys (Taylor, 2009). There is a high degree of psychological comorbidity in this group.

4.6.2 Aetiology

The aetiology of ADHD is a mixture of genetic factors; the condition is one of the strongest genetically inherited psychological disorders (prevalence 5 times higher in relatives). Prenatal factors including smoking, alcohol, recreational drug use and prematurity / low birth weight are thought to play a part. Postnatal factors include head injury and brain disease, though these would need to be severe before having a significant effect. Environmental factors include diet and food additives (although there is debate as to the effect these have) and toxins such as lead (Taylor, 2009).

4.6.3 Core Clinical Features

Increasingly ADHD symptoms are being recognised by the ages 3-6, although it is at school age onwards that most ADHD behaviours start to cause significant impairment.

- **Inattention:** Easily distractible, forgetful, difficulty sustaining tasks such as play, learning and work.
- **Overactivity:** Fidgety, reckless, socially disinhibited, inappropriately active, talking excessively.

- **Impulsivity:** Interrupts and intrudes, unable to “wait their turn.”

People with ADHD tend to be clumsy, accident-prone and get into trouble with parents and teachers. Others learn to avoid them, so they become socially isolated.

Most children who have been diagnosed with ADHD no longer meet the diagnostic criteria by the time they reach adulthood; however symptoms of hyperactivity continue leading to a raised incidence of other types of behaviour such as antisocial or aggressive behaviours. Most adults in this group will have some form of functional impairment which is related to hyperactivity (Taylor, 2009)

4.6.4 Complications

Many children diagnosed with ADHD have learning difficulties, including speech, language, social and relationship problems. 25% have co-existent anxiety disorders, and 20% have mood disorders (SIGN, 2001). This can create a complex situation in which the co-existent problems actually appear to be the dominant problem, masking the ADHD (Taylor, 2009).

Young people and Adults with ADHD also have an increased risk of self harm, involvement in traffic accidents, delinquency, substance abuse and academic underachievement (NCCMH, 2009)

It has been suggested that a significant number of adults labelled as suffering from personality disorder are actually suffering from ADHD, and as such are likely to respond to medication.

4.6.5 Treatment

Individuals with ADHD should be offered psychological, behavioural and educational/occupational advice and interventions. This may include cognitive behavioural therapy [CBT] and/or social skills training (NCCMH, 2008).

Drug treatment should only be used in severe ADHD, and as part of a package of advice and interventions as detailed above. The usual drug of choice is Ritalin (methylphenidate) which is an amphetamine-like stimulant. In affected individuals it has the paradoxical effects of decreasing activity level and improving attention. It helps to improve academic performance and relationships, and is recommended when ADHD occurs either without comorbidities, or with comorbid conduct disorder. Should tics, Tourette’s syndrome, anxiety disorder, stimulant misuse or risk of stimulant diversion exist, or methylphenidate either not be tolerated or prove ineffective, atomoxetine can be considered as an alternative

Medication produces a short-lived improvement after each dose, but it is not a permanent cure.

Self help written information, and information about local and national ADHD groups should also be provided. (NCCMH, 2008)

4.6.6 Prognosis

By the second decade, the problems of impulsivity and inattention tend to improve, even without medication. However, the learning difficulties caused by ADHD in childhood have long-term consequences, almost 80% of children with ADHD continue to have the full ADHD syndrome in adolescence and about 60% of adults will continue to experience problems, but usually not as severe. There are high levels of psychiatric co-morbidity, and 20% of individuals with ADHD have two or more comorbid conditions:

Psychiatric co-morbidity:

- ADHD and conduct disorder: 30-50%
- ADHD and oppositional defiance disorder 35-65%
- ADHD and mood disorders or depression: 20-30%
- ADHD and anxiety: 20-30%
- ADHD and antisocial personality disorder: 12%
- ADHD and substance abuse: 20 - 30%

(Brown, 2008)

Adults with ADHD are most likely to succeed in employment where it provides a stimulating, yet structured, environment.

5. Differential Diagnosis and Comorbidity

5.1 Differential Diagnosis

Specific differential diagnoses which should be considered for intellectual disabilities include:

- Antisocial personality disorder
- Pervasive developmental disorders
- Specific developmental disorders

5.2 Physical Comorbidity

Intellectual disability is associated with an increase in other physical and mental health issues. Literature suggests that individuals with intellectual disabilities will pay 1.7 times more visits to a GP than the general population and have up to 4 times the number of prescriptions (Straetmans et al, 2007).

Individuals with intellectual disabilities are recognised as being a group which is vulnerable and socially excluded in society. In addition to genetic vulnerabilities to certain health conditions, they may be reluctant or unable to access health services, unaware of public health awareness campaigns or live in social settings which may not foster healthy lifestyles. In addition, their ability to undertake physical activities may be limited either due to lack of opportunity, or co-existing physical disabilities.

The more severe the learning disability, the higher the prevalence of serious physical disabilities (Davies et al, 2009).

| Physical Impairment | Prevalence in severe learning disability | Prevalence in mild learning disability |
|---------------------------|--|--|
| Cerebral Palsy | 20% | 8% |
| Epilepsy | 35% | 15% |
| Severe Visual Impairment | 8% | 5% |
| Severe Hearing Impairment | 9% | 4.5% |

For a child with learning disability, the prognosis is poorer when there are multiple problems, especially those interfering with social relationships, and those inhibiting learning and play (Puri et al, 1996).

5.2.1 Cerebral Palsy

Cerebral Palsy is a complex group of motor abnormalities and functional impairments that affect muscle coordination. Mild or moderate intellectual

disabilities are common in individuals with cerebral palsy. Around a quarter of affected individuals will have severe intellectual disabilities.

5.2.2 Epilepsy

A substantial minority of individuals with intellectual disabilities have co-existing epilepsy, often resulting from the same causes of the intellectual disability itself. Some syndromes increase the risk for developing epilepsy, such as tuberous sclerosis and Down syndrome.

The prevalence rate of epilepsy is around 10 times higher for an individual with mild intellectual disabilities than in the general population; the prevalence increases from this in line with the severity of the intellectual disability to around 30% of all individuals with intellectual disability (Bernal, 1995).

In individuals with Down syndrome the prevalence of epilepsy is 5-10% (Iivanainen 2009).

5.3 Psychiatric Comorbidity

Psychiatric illness is 2-3 times more common in the intellectually disabled than in the general population. Around 40% of individuals with intellectual disabilities will have coexisting psychiatric disorders (Tonge, 2009), with the risks increasing with the severity of the intellectual disability. Diagnosis of these disorders is difficult, limited speech and intellectual capacity, and lack of differentiation from the causes and effects of intellectual disability itself, make it difficult to diagnose and treat mental illness in this population.

Signs and symptoms of psychiatric illness mirror those of the general population in individuals with mild intellectual disability or borderline traits, however in those who have more significant intellectual disabilities, the symptom pattern can be more diverse and atypical, and therefore less easy to diagnose (Dosen, 2009)

Behavioural issues and hyperactivity decrease as individuals age from child to adulthood, whilst symptoms of depression increase with age.

In adults with intellectual disability, psychosis, major depression, bipolar disorders, anxiety, autism spectrum disorders, and dementia are all more common (Dosen, 2009).

Because of difficulty with communication, those with learning disability may not have the skills to express and describe what they are experiencing, so presentations may differ from those with a normal IQ. The observation of behavioural changes such as psychomotor retardation, agitation and possible responses to hallucinations can be helpful, and information from family and carers is especially important.

| Co-morbid Condition | Effects of Learning Disability |
|-------------------------------|--|
| Schizophrenia | Delusions are less elaborate and hallucinations are simple and repetitive. |
| Depression | Patients are less likely to express depressive ideas. Carers may observe sadness or alterations in behaviour or sleep pattern. The suicide rate is lower. |
| Adjustment Disorders | Common when there are changes to routine, such as loss of carers. |
| Phobias | Easily overlooked because of language difficulties. |
| Obsessive-Compulsive Disorder | More frequent than in the general population. Over-eating and unusual dietary preferences are frequent. |
| Personality Disorder | Common, and can lead to greater management problems. |
| Dementia | Tends to occur at a younger age in those with learning disability. |
| Sleep Disorder | Common, and may cause significant stress in carers. |
| Criminal Behaviour | Mild learning disability is associated with a higher rate than in the general population. Arson and sexual offences (exhibitionism) are particularly common. |

6. Treatment

6.1 Treatment Options for Intellectual Disabilities

The presence of intellectual disability has a number of effects on treatment options:

- The individual may have limited communication skills resulting in subjective observation by clinical staff and family members becoming of higher importance. The relationship becomes indirect, not with the patient.
- The clinical picture can be complicated by overlapping and multiple conditions meaning that a provisional diagnosis may sometimes only be confirmed by a successful response to treatment
- Treatment can have unexpected and ambiguous effects as multiple conditions result in different effects
- Improvements in condition may be due to normal developmental changes rather than a positive effect of treatment (e.g. epilepsy will often show a spontaneous improvement around age 4 in an individual with autism. This is a change in the condition rather than a change in response to treatment)
- There is limited supporting evidence as to the effectiveness of most treatments
- The issue of informed consent may be problematic.

(Berney, 2009)

6.2 Management of Learning Disability

In a specialist child development clinic, the assessment of learning disability begins with interviews with the patient, their parents and other carers. The family history, obstetric history, developmental milestones and schooling history are particularly important. A physical examination includes assessments of vision and hearing. Standardised measures of intelligence, language, motor and social skills complete the assessment.

When children with learning disabilities suffer psychiatric symptoms, drug treatments are used less often than in adult psychiatry. The emphasis is on psychological treatments and working with the whole family to solve problems. In adults with learning disabilities, the treatment of medical and psychiatric problems is similar to that in other patients, but some forms of psychological treatment may not be appropriate, depending on the patient's intellectual abilities.

6.3 Education

Children with mild or moderate intellectual disabilities are usually educated within

mainstream schools. An educational psychologist will assess their educational needs, and an appropriate package of educational interventions which is tailored to the individual will be provided. Individuals with severe disability, (1% of children), may attend a school specialising in the education of children with learning disabilities.

(The classification in this protocol uses medical definitions of mild, moderate, severe and profound learning disability. In other contexts, the terms may have different meaning, and this should be remembered when interpreting medical evidence from an educational professional.)

As well as education in terms of scholastic achievement, educational support is required for individuals with learning difficulties in a number of other areas:

- Independence and self help skills e.g. bathing, dressing, self care
- Communication skills
- Work place support
- Social and sexual relationships, assertiveness training

6.4 Psychological Therapies

Although the communication barriers which are common with individuals affected by intellectual disability have led to an emphasis on observable behaviour (Berney, 2009), suitably modified behavioural and cognitive techniques can be successfully applied to patients with learning disabilities. Programmes focus on two broad areas – providing support for the learning of skills as detailed above, and providing support for unlearning behaviours which are not considered desirable. For example, problems such as wetting and soiling, impulsive behaviour and phobias can be treated by behavioural therapy. This approach works by offering praise and rewards for practising the desired behaviours.

Other areas where behavioural treatments have been shown to be effective are the use of anger management therapies, and techniques designed to reduce anxiety such as relaxation techniques (Berney, 2009).

6.5 Psychopharmacological Treatments

Drug therapies are used widely in individuals with intellectual disabilities. There are two general reasons for use of pharmacological preparations:

- To control co-existing conditions – e.g. epilepsy, attention deficit hyperactivity disorder
- To control symptoms arising from intellectual disability itself – anger, aggression, self-injury, obsessive compulsive behaviours

Neuroleptics

Frequently used in intellectual disabilities to treat a wide variety of symptoms. However, neuroleptics have not been shown to have consistent and specific effects (Berney, 2009). Atypical neuroleptics such as risperidone have been shown to have positive effects in controlling aggression, social withdrawal, inattentiveness and over-activity (Jesner, 2007) but also have reported side effects of sedation, weight gain and possible involvement in the development of metabolic syndromes (Berney, 2009).

Antidepressants

Studies have reported the use of clomipramine and Selective Serotonin Reuptake Inhibitors (SSRIs) to be effective in the management of behaviour disorders among adults with intellectual disability. However, it is possible that the improvement in symptoms of intellectual disability reflects an improvement in depression, anxiety and obsessive behaviour rather than the disability itself.

Beta Blockers

Beta blockers such as propranolol are sometimes used to treat anxiety in individuals with intellectual disabilities, especially where anxiety is an underlying cause of aggression. However, there is some evidence to indicate that they cause lethargy or depression.

Stimulants

Methylphenidate and atomoxetine are used for the treatment of Attention Deficit Hyperactivity disorder. See section 4.6

Mood Stabilisers

Emotional mood swings are more commonly being treated using anti-epileptic medication, particularly where there are outbursts of rage. Lithium is also sometimes used. The primary approach to aggression is psychological.

Opioid Antagonists

There are some theories that opioid excess may underlie autism and related disorders. Autistic disturbance and repetitive self-injury effects have shown responses to treatment with Naltrexone.

Anti-libidinal Drugs

Drugs such as these are used when educational and psychological therapy approaches to supporting an individual to control their sexual emotions is outweighed by the individual's intellectual disability.

(Berney, 2009)

6.6 Family Support

The birth of a child with disabilities puts great strain on most families. The parents

may grieve for the loss of their anticipated healthy child. The additional physical and financial burdens of caring for their child can lead to marital disharmony. However, the majority of families eventually adjust, with support from healthcare professionals, social workers, teachers, family, friends and self-help groups.

6.7 Creative Therapies

Activities such as art, music and drama can help a person with learning disabilities to express themselves.

6.8 Employment Opportunities

Sheltered and supportive workplace schemes allow those with practical skills to develop a routine and a role in society. There are a number of schemes within Ireland aimed at supporting individuals with intellectual disabilities in obtaining suitable employment opportunities.

6.9 Accommodation and Supervision

A large majority of people with mild learning disability are able to live independently or with their families. Institutional care is only required for a minority of adults or those with more significant levels of intellectual disability. Typically, residential accommodation of this type is now provided in small community units. Periods of respite care can provide an essential break for carers.

40% of parents caring for a child with learning disability are over the age of 60, and this figure is increasing.

6.10 Self-Help Groups

People with learning disabilities and their carers can share information and gain support from others with similar experiences. These groups also aim to influence the provision of services and facilities for disabled people.

Groups within Ireland include:

Inclusion Ireland (<http://www.inclusionireland.ie>)
(previously National Association for the Mentally Handicapped of Ireland)

National Institute for Intellectual Disability (<http://www.tcd.ie/niid/>)

People with Disabilities in Ireland (www.pwdi.ie)
This site contains a list of other relevant organisations and information sources at http://www.pwdi.ie/useful_links/index.htm

6.11 Prevention

It has been suggested that 15% of cases of intellectual disability are avoidable (Bertolote, 2009). Measures towards prevention are summarised below.

Down Syndrome

The availability of genetic counselling and antenatal diagnosis of conditions such as Down syndrome has led to a reduction in the incidence of some learning disabilities. This is dependent upon availability of, and attitudes towards, termination of pregnancy, however.

Iodine Deficiency

This is still one of the major worldwide causes of intellectual disability but can be cheaply and easily avoided by adding iodine to salt, milk, water or flour.

Phenylketonuria and Hypothyroidism

The early detection of hormonal or metabolic problems such as hypothyroidism or phenylketonuria allows treatment before learning disability sets in.

Fetal Alcohol Syndrome

This can be prevented by avoidance of alcohol in pregnancy or at least reduction in alcohol intake to a non-toxic level.

Improved Antenatal Care

Appropriate vitamin supplements, folic acid supplements and adequate antenatal care contribute to the reduction of risk of intellectual disabilities.

Improved Perinatal Care

Improved perinatal care reduces the risk of brain damage. Advances in techniques for caring for premature and low birth weight infants have helped reduce the incidence of intellectual disabilities.

Parent Education

There is some evidence that educational intervention in children of mothers with mild learning disability may improve their educational performance, (though not IQ), and reduce the risk of conduct disorders.

7. Prognosis (Main Prognostic Factors)

Intellectual disability is not in general a curable condition, although with appropriate support and intervention, the severity of the symptoms may be lessened.

As individuals with intellectual disabilities often have coexisting physical problems, their life expectancy may be shortened, depending on the specific condition. Also some genetic syndromes which are a cause of intellectual disabilities may be associated with shortened lifespan. In general, life expectancy will reduce as the severity of cognitive disability and number of associated physical problems increase.

Overall, people with intellectual disability are living longer and enjoying a better quality of life because of improvements in health and social provision. Many people with mild to moderate intellectual disabilities can support themselves, can live independently, and can be successful at jobs that require basic intellectual skills

8. Information Gathering at the In Person Assessment

People with intellectual disability all have impaired performance of intellectual tasks such as learning, short-term memory, use of concepts and problem solving. Some may have problems with spatial awareness, which may cause difficulty with dressing, for example. Poor language skills cause problems with social interaction, and are strongly associated with behavioural disorders. Additional disabilities such as epilepsy, impaired vision and hearing and physical problems often compound the disabling effects of intellectual disability. Intellectual disability runs a chronic life-long course.

8.1 Assessing the Claimant

The assessment should be made using all the information available. This includes information from the claimant's file, informal observations, medical history, typical day, appropriate physical examination, and assessment of their mental state.

Some causes of intellectual disability are associated with particular facial appearances or physical features. When present, these may indicate the likely range of disability.

When it is available, information from family or carers accompanying the claimant will be valuable. However, sometimes carers can be over-protective, and it is essential to develop a rapport with the claimant so that their language and social skills can be observed.

If the claimant is not accompanied by a relative or carer, careful questioning will be necessary to ensure that the information obtained is accurate and reliable.

8.1.1 Mild Intellectual Disability

Claimants who are suffering from mild intellectual disability will have attended mainstream schooling. They may be living in their own home, with their family, or in supported accommodation. They will be able to do most things for themselves, although they are likely to need help with managing their finances. Their typical day history will reveal little or no restriction in their activities of daily living: they will be able to travel independently on public transport, do their shopping, enjoy contact with friends and family, and develop interests and hobbies.

It is very rare that a claimant with ADHD meets the criteria for severe intellectual disability.

Dyslexia on its own does not cause significant disability.

8.1.2 Moderate, Severe and Profound Intellectual Disability

Claimants within these categories of intellectual disability will not be able to live independently. Severe intellectual disability may include one or more of:

- An inability to learn more than the most basic skills such as feeding, dressing and using the toilet.
- The need for help with some or all bodily functions.
- A failure to be aware of dangers, thus requiring supervision.
- Severe behaviour problems that require supervision, such as self-harm or violence.

Certain syndromes always cause severe learning disability. Many of these are described in the table in **Appendix A**. Common conditions such as autism and Down syndrome encompass a spectrum of severity, and these cases should be assessed individually.

8.2 Helpful Questions for Assessing the Disabling Effects of Learning Disability

- Who is accompanying the claimant at the assessment? Was their presence necessary? Those with mild intellectual disability may be able to attend an examination centre alone or cope with an assessment at home without a companion.
- Does the claimant also have a physical disability, epilepsy, or a mental illness?
The combined effects of multiple disabilities are likely to be severe.
- What sort of education has the claimant had? Educational assessment as requiring specific educational support is significant, while attendance at a “Special School” indicates a very high level of learning difficulties.
- Where is the claimant living? Do they have a home of their own, are they living with their family, in supported accommodation, or in long-term residential care?
- Is the claimant currently attending support groups or college for further education courses in life skills and independent living? What is the planned outcome: are they aiming to live independently, or to gain work in a sheltered or open environment?
- Is the claimant able to initiate and complete household tasks? Can they plan and prepare a meal? Can they go shopping independently? Can they perform simple arithmetic to check that they have received the correct change?
- How did the claimant travel to the examination centre? Some claimants will be able to travel alone on familiar routes, but would not be able to cope with a journey to an unfamiliar destination.

8.3 How to Assess the Disabling Effects of ADHD

ADHD is a treatable condition, which tends to improve in adult life. Each case should be assessed individually, with special emphasis on the typical day and assessment of the mental state.

9. Analysis of Effect on Functional Ability

Eligibility to the Department of Social and Family Affairs various Illness-related schemes and the Activation Programme, is determined primarily by the degree of Ability/Disability and its expected duration.

The degree of Ability/Disability assessed, using the following Indicators, can be depicted on the Ability/Disability Profile illustrated below.

9.1 Indicators of Ability/Disability

Normal

- Able to live independently in their own home
- Able to manage their own finances and do all their own shopping
- Able to use public transport to travel independently on an unfamiliar route
- Able to attend an examination assessment centre on their own

Mild

- History of education in mainstream school
- Able to plan and prepare proper meals for themselves
- Specific learning disability without comorbidity
- Treated Attention Deficit Hyperactivity Disorder

Moderate

- History of being identified as requiring specific educational help
- Living alone in supported accommodation
- Able to travel alone on public transport but only on familiar routes
- Unable to initiate and complete household tasks
- Requires prompting to get up and washed and dressed in the morning

Severe

- History of attendance at a special school
- Incapable of living independently
- Comorbid physical disability, epilepsy or mental illness
- Requires supervision because of lack of awareness of dangers

Profound

- Need for help with some or all bodily functions
- Severe behaviour problems requiring supervision because of history of violence or self-harm

9.2 Ability/Disability Profile

| Indicate the degree to which the Claimant's condition has affected their ability in ALL of the following areas. | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | Normal | Mild | Moderate | Severe | Profound |
| Mental health/Behaviour | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Learning/Intelligence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Consciousness/Seizures | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Balance/Co-ordination | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Vision | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hearing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Speech | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Continence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Reaching | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Manual dexterity | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Lifting/Carrying | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Bending/Kneeling/Squatting | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sitting | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Standing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Climbing stairs/Ladders | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Walking | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

10. Summary of Scheme Criteria

Scheme eligibility criteria are maintained on the DSP website and are accessible from the following links:

- **Carer's Allowance**
http://www.welfare.ie/EN/OperationalGuidelines/Pages/carers_all.aspx
- **Carer's Benefit**
http://www.welfare.ie/EN/OperationalGuidelines/Pages/carers_ben.aspx
- **Disability Allowance**
<http://www.welfare.ie/EN/OperationalGuidelines/Pages/disall.aspx>
- **Disablement Benefit**
http://www.welfare.ie/EN/OperationalGuidelines/Pages/oib_disableb.aspx
- **Domiciliary Care Allowance**
<http://www.welfare.ie/EN/Schemes/IllnessDisabilityAndCaring/Carers/DomiciliaryCareAllowance/Pages/DomiciliaryCareAllowance.aspx>
- **Illness Benefit**
<http://www.welfare.ie/EN/OperationalGuidelines/Pages/illben.aspx>
- **Injury Benefit**
http://www.welfare.ie/EN/OperationalGuidelines/Pages/oib_injuryb.aspx
- **Invalidity Pension**
<http://www.welfare.ie/EN/OperationalGuidelines/Pages/invalidity.aspx>
- **Respite Care Grant**
<http://www.welfare.ie/EN/OperationalGuidelines/Pages/respitegrant.aspx>

Appendix A - Rare Disorders Reference Table

| Syndrome | Aetiology | Description | Disabling Effects |
|-------------------------------|-----------------------------------|---|-------------------|
| Angelman Syndrome | Chromosome Abnormality | Characteristic happy smile, inappropriate laughter, jerky movements, and wide-based gait. There is severe learning disability without speech but with some ability to sign. Epilepsy occurs in over 80%. The condition is stable. It has an incidence of about 1 in 20,000. | Severe |
| Fetal Alcohol Syndrome | Toxic | There is a typical appearance and growth failure, learning disability (mean IQ 60-70), hyperkinesia and microcephaly. The severity of disability depends on the level of alcohol intake. Incidence is about 1 in 1000 births. | Moderate |
| Klinefelter Syndrome | Chromosome Abnormality | (XXY) Males with an extra X chromosome. Features include gynaecomastia and sparse facial hair. Mild learning disability is associated with a small proportion of cases. | Mild |
| Lesch-Nyan Syndrome | Disorder of uric acid metabolism | This condition affects males. Treatment with allopurinol can control the associated gout, but it cannot prevent the neurological syndrome of choreoathetosis, spasticity, learning disability (IQ 40-65), and self-mutilation. | Severe |
| Niemann-Pick Disease | Disorder of lipid metabolism | Occurs in A, B & C types. Until school age, development is typically normal, then there is severe motor and intellectual deterioration. There is no effective treatment. Affects 1 in 10,000 births. | Fatal |
| Phenylketonuria | Error of phenylalanine metabolism | An autosomal recessive disease, which occurs in 1 in 10,000 births. It is routinely screened for in the UK, and can be controlled by restricting the intake of protein. | None |
| Prader-Willi Syndrome | Chromosome Abnormality | Features include: short stature, small hands and feet, severe obesity and IQ 50-80. The incidence is about 1 in 20,000 births. | Moderate |
| Rett's Syndrome | X chromosome abnormality | This condition begins to cause severe learning disability in the first 2 years of life, and eventually results in severe global disability. "Hand wringing" movements are a typical feature. It affects 1 in 10,000 girls. | Severe |

| Syndrome | Aetiology | Description | Disabling Effects |
|------------------------------|-----------------------------|--|------------------------------|
| Sturge-Weber Syndrome | Sporadic | Facial port wine stain indicates haemangiomas on the ipsilateral cerebral hemisphere. These cause contralateral seizures, often with hemiparesis and hemianopia. Learning disability is common. | Moderate |
| Tay-Sachs Disease | Ganglioside storage disease | Progressive motor weakness from 6 months of age, and seizures, blindness, and deafness. The child dies before it is 5 years old. The incidence is 1 in 2000 in Ashkenazi Jews. Autosomal recessive. | Fatal |
| Tuberous Sclerosis | Chromosome Abnormality | This condition is named after tuber-like growths on the brain and other tissues. It is associated with learning disability, epilepsy, and characteristic skin lesions, including facial angiofibromas. Affects 1 in 8000 births. Normal life expectancy for all sufferers. | 50% have learning disability |
| Turner's Syndrome | Chromosome Abnormality | (45X) These girls lack an X chromosome. They have short stature and a webbed neck. IQ is usually average, but they have impaired verbal and numerical skills and right-left disorientation. | Mild |

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