

Psychiatry of Learning Disability

Medical Undergraduate Training Programme

Contents	Page
Introduction	2
Terminology	4
Classification	5
Aetiology of Learning Disability	8
Clinical Syndromes	10
Essential Healthcare	12
Epilepsy	16
Communication	18
History and Mental State Examination	22
Mental Illness	26
Challenging Behaviour	31
Autism	35
Psychotropic Medication	38
Consent to Treatment	41
Services for People with Learning Disability	43

INTRODUCTION

Welcome to the Learning Disability component of the undergraduate training programme in Psychological Medicine. We hope that it will be an informative and enjoyable experience.

You will meet and care for individuals with a Learning Disability throughout your medical career. Our aim is not just to improve your knowledge of health care issues in relation to individuals with Learning Disability, but also to help you examine and challenge your attitudes and fine-tune your skills in relation to the care of all individuals with disabilities.

Attitudes:

- ❖ To treat people with a Learning Disability as equals
- ❖ To look beyond the disability and see the person first
- ❖ To have respect and appreciation of the equal rights of people with Learning Disability
- ❖ To be open to examine one's own attitude
- ❖ Respect for carers' information and opinions
- ❖ Respect the wishes and beliefs of people with Learning Disability and their families

Skills:

- ❖ Skills relating to communicating with people who have Learning Disability and their families
- ❖ Examination, assessment and diagnosis in people who have Learning Disability
- ❖ Appropriate referral to and ability to liaise with community organisations and specialists
- ❖ Obtaining information from carers and other sources

Knowledge:

- ❖ Knowledge about the nature, frequency and causes of Learning Disability
- ❖ Common health and behavioural problems of people with Learning Disability
- ❖ The impact of a Learning Disability on the individual and his/her family
- ❖ Community resources, services and useful medical and non-medical referrals
- ❖ Principles and philosophies of health care for people with Learning Disability

These objectives are challenging and it is inevitable that we will not be able to meet them all within the limited time set aside for you to study the Psychiatry of Learning Disability. Therefore, it is essential that you consider the needs of individuals with Learning Disability in the context of all other aspects of your clinical training and remain open to future learning as your career proceeds. Within the Psychological Medicine block you will receive a one-hour lecture within the Introductory Week.

You will then receive either one or two sessions of Learning Disability Speciality Teaching during your Psychiatric placement. The exact configuration of this teaching will vary between locations. However, there are common objectives:

Speciality Teaching

- ❖ Meeting individuals with Learning Disability (and family / carers if appropriate)
- ❖ Developing awareness of communication issues
- ❖ Explanation of relevant health and social issues
- ❖ Debriefing with senior Learning Disability Psychiatrist

This handbook is designed as a brief introduction and aide-mémoire. The more interested student will also benefit from exploring the references and suggested reading. We have attempted to include relevant Web links as appropriate. However, this is not a formal textbook and should not be seen as a substitute for studying the recommended texts.

References / Further Reading:

Paichaud J. (2002) *Teaching Learning Disability to Undergraduate Medical Students, Advances in Psychiatric Treatment, Volume 8, pages 334-341*

Introductory Texts:

Fraser W. and Kerr M. (2003) *Seminars in the Psychiatry of Learning Disabilities (2nd edition)*. Royal College of Psychiatrists. London, Gaskell Press.

Reed S. G. (Editor) (1997) *Psychiatry in Learning Disability*. London, W. D. Saunders Company Ltd.

Relevant Websites offering general information:

www.idbook.co.uk/Book.htm

www.intellectualdisability.info
www.intellectualdisability.info/home

TERMINOLOGY

You may come across a variety of terms relating to the individuals with what we currently call Learning Disability.

Mental Retardation: Is the term used in the World Health Organisation's International Classification of Mental and Behavioural Disorders (ICD 10, 1992).

Learning Disability: Was introduced by the Department of Health in 1991 to replace the term Mental Handicap. Described as "a change of emphasis in the philosophy of care and in the values which form our thinking". The new term emphasises learning potential and equality of citizenship and "a commitment to thinking of people with Learning Disabilities as individuals in their own right".

Learning Difficulty: There is considerable confusion over the use of this term. In an international context it is used to denote specific learning impairments such as dyslexia. However, some agencies in the United Kingdom use it as a general term synonymous with learning disability. They feel that this places less of an emphasis on the disability which they consider results as much from environmental as pathological factors.

Mental Impairment: This is the term used in the 1983 Mental Health Act. It stipulates abnormally aggressive or seriously irresponsible conduct in addition to social and intellectual impairment and is, therefore, not synonymous with Learning Disability.

Intellectual Disability: This is a term used increasingly by the International Scientific Community. The diagnostic criteria are analogous to those for **Mental Retardation**.

The terms Mental Deficiency and Mental Subnormality were used in the 1913 Mental Deficiency Act and the 1959 Mental Health Act respectively. They are no longer considered appropriate.

CLASSIFICATION

The World Health Organisation uses the term Mental Retardation, which is defined as “a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities. Retardation can occur with or without any other mental or physical conditions”. Intellectual abilities and social adaptation may change over time and, however poor, may improve as a result of training and rehabilitation, diagnosis should be based on the current level of functioning.

Mental Retardation (Learning Disability)

- ❖ Significantly sub-average intellectual functioning; an IQ of approximately 70 or below on an individually administered IQ test.
- ❖ Concurrent deficits or impairments in present adaptive functioning (i.e. the person’s effectiveness in meeting the standard expectations 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.
- ❖ Onset is in the development period (before the age of 18-years).

Degrees of Learning Disability (Mental Retardation) are conventionally estimated by standardised intellectual tests though this will also depend on the overall assessment of intellectual functioning by a skilled Diagnostician.

Mild Mental Retardation:

(IQ 50-69) (80% of Learning Disability population) (1.5% of general population).
(Developmental skills roughly comparable with someone of a chronological age of 9-12 years).

Pen Picture

Susan is married and works in a local factory. Her conversational skills are on par with a child of age 10. She is able to read, write and has basic numeric skills but requires help to understand and complete forms and with more complex budgeting. She is short sighted and wears glasses but is otherwise physically fit. Susan is prone to developing depression following periods of change in her life, she can be naïve in social interactions and her coping skills are limited, but with practical and psychological support is able to enjoy an independent lifestyle.

Moderate Mental Retardation:

(IQ 35-49) (12% of Learning Disability population) (0.3% of general population).
(Developmental skills roughly comparable with someone of a chronological age of 6-9 years).

Pen Picture

James has Down's syndrome and has lived with his parents all his life. He understands simple language and communicates using short sentences. He is able to write his name and address but literacy skills are very limited. James is able to purchase items in a shop but would not be aware if he had been given the incorrect change. He attends a day centre where he is very proud to work in the kitchen under supervision. He has epilepsy but is seizure free on anticonvulsant medication, and has impairments to both vision and hearing which are addressed by glasses and a hearing aid. James is usually very contented, but during periods of stress he can appear to overreact to seemingly minor triggers and become agitated and verbally aggressive.

Severe Mental Retardation: (IQ 20-34) (7% of Learning Disability population) (0.2% of general population). (Developmental skills roughly comparable with someone of a chronological age of 3-6 years).

Pen Picture

Linda lives in shared residential accommodation where she receives 24-hour support. She has limited comprehension and a vocabulary of only 5-10 words and communicates mainly using gestures. Linda has cerebral palsy secondary to birth asphyxia and is incontinent and has limited mobility. She still experiences occasional seizures despite taking two different anticonvulsants.

Linda enjoys a variety of activities at various settings on a timetable negotiated between her care staff and the Case Manager from her Community Learning Disability Team. However, she can become anxious and upset by changes in her familiar routines.

Profound Mental Retardation: (IQ below 20) (1% of Learning Disability population) (0.05% of general population). (Developmental skills roughly comparable with someone of a chronological age of under 3 years).

Pen Picture

Sarah lives at home with her parents with daily support from care workers. She has cerebral palsy secondary to birth asphyxia and is incontinent and unable to stand without support. She has no spoken language skills and minimal comprehension, but is able to smile at people she recognises appropriately. She still experiences frequent seizures despite taking three anticonvulsants. Sarah appears to enjoy listening to music, but when frustrated or over stimulated may scream to indicate discontent.

References / Further Reading:

ICD-10. Classification of Mental and Behavioural Disorders. (1994) World Health Organisation. Geneva.

American Association on Mental Retardation (2002) Mental Retardation Definition, Classification and Systems of Support (10th Edition).

Fryers and Russell (2003) *In: Seminars in the Psychiatry of Learning Disabilities (2nd Edition)*. Royal College of Psychiatrists. London, Gaskell Press.

AETIOLOGY OF LEARNING DISABILITY

A learning disability is not a disease entity in itself but the developmental consequence of some pathogenic process. Aetiology may be grouped into prenatal, perinatal and postnatal, depending on the timing of the brain insult or development of pathology. The effect of the process upon the brain may have physical, cognitive and social consequences.

PRENATAL

Genetic disorders

Chromosomal abnormalities e.g. Down's Syndrome

Autosomal dominant e.g. Tuberous Sclerosis

Autosomal recessive e.g. Phenylketonuria (PKU)

X linked e.g. Fragile X

Maternal infections

e.g. Rubella

Intoxication

e.g. Alcohol

Physical Damage

Endocrine Disorders

PERINATAL

Delivery factors

e.g. Trauma, hypoxia, hypoglycaemia

Kernicterus

POSTNATAL

Infection

e.g. meningitis, encephalitis

Brain Injury

Intoxication

e.g. lead

Malnutrition

Metabolic

Epilepsy

In approximately 30% of people with severe Learning Disability and 50% with mild Learning Disability a cause is not identified. This is a reflection of the limitations of diagnostic techniques as opposed to lack of causation.

Syndrome Specific Checklist

The presence of a specific genetic disorder can predispose the individual to a variety of somatic (physical) and cognitive/behavioural manifestations. This does not mean that all individuals with a given genetic condition will inevitably display these impairments but that there is a predisposition. Similarly, the degree of impairment will vary greatly in different individuals. The following Syndrome Specific Checklist is a brief aide memoir. It is not exhaustive and because of the ever-evolving nature of medical genetics we would recommend that those interested consult an up to date text when seeking more detailed information. Websites are quoted for each disorder and there are two more general sites which are a valuable source of information.

www.cafamily.org.uk/

[www.ncbi.nlm.nih.gov/entrez.query.fcgi?db=OMIM](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM)

CLINICAL SYNDROMES ASSOCIATED WITH LEARNING DISABILITY

	Down's Syndrome	Prader Willi	Fragile X	22q 11 (Velocardio Facial Syndrome) Deletion Syndrome	Phenylketonuria	Neurofibromatosis	Tuberous Sclerosis (Epiloia)
Inheritance	TRISOMY Chr 21 94%non-dysjunction 3-5% translocation 1-3% mosaicism	70% sporadic (deletion on Chr 15 of paternal origin) 25% uniparental disomy (2 maternal Chr 15) *IMPRINTING	X- linked (FMR-1 gene has expansion of trinucleotide repeats at fragile site on X Chromosome) *ANTICIPATION	Usually sporadic, may be autosomal dominant (microdeletion Chr 22)	Autosomal Recessive (Inborn error of metabolism) (Chr 12)	Usually Autosomal dominant. May be sporadic (Chr 17 + 22)	Usually sporadic. Autosomal dominant. (Chr 9,11,16)
Cognitive Phenotype	Most Moderate LD (IQ 20 – 75, mean IQ 50)	Maybe normal IQ or Mild – moderate LD	LD Borderline, Mild or moderate usually. (Females tend to have higher IQ than males)	Learning Disability in 30% (usually mild)	Variable IQ + Social disability (progressive brain damage in un- treated PKU with ^ 50 point IQ ↓ by 1 year)	Variable IQ Learning Disability in <10%	Variable IQ (dep. On site + severity of tubers in brain) approx. 50% have LD (most severe-profound)
Psychiatric Phenotype	Alzheimer's dementia (45% > 45 years) Depression OCD	Cycloid/atypical Psychosis OCD. Anxiety.	Depression	Schizophreniform psychosis (< 25%) Bi-polar affective disorder. Anxiety. Depression.	Anxiety		Depression. Anxiety. Specific phobias Psychosis (Epilepsy related)
Behavioural Phenotype - i.e. Predisposition to certain patterns of behaviour	Sociable Good-natured Stubborn`	Hyperphagia Self -injury (skin picking) Stubborn Poor impulse control Sleep problems Emotional lability	Hyperactivity Social avoidance Gaze aversion Shy Autistic features Hand flapping + biting.	Hyperactivity Autistic features	Autism Poor concentration Hyperactivity Irritability	Hyperactivity	Autism Hyperactivity Self-injury Sleep problems Aggression
Weblink	www.downs-syndrome.org.uk	www.pwsa.co.uk	www.fragilex.org	www.geneclinics.org/profiles/22q11deletion	www.ncbi.nlm.nih.gov → OMIM	http://www.ninds.nih.gov	http://www.nlm.nih.gov/medlineplus/tuberousclerosis.html www.ninds.nih.gov

Chr = Chromosome

(Somatic Phenotype)	Down's Syndrome	Prader Willi	Fragile X	22q 11 (Velocardio Facial Syndrome) Deletion Syndrome	Phenylketonuria	Neurofibromatosis	Tuberous Sclerosis (Epiloia)
CNS	Epilepsy (mostly linked with Alzheimer's)	Microcephaly	Epilepsy		Microcephaly Epilepsy Spasticity	< 10% Epilepsy variable clinical phenomena, dep. On tumour sites	Epilepsy (70%) Cerebral astrocytomas
Cardio-vascular	Congenital heart disease (40-60%) AV canal defect. Tetralogy of Fallot	Heart failure may arise (2° to obesity)	Aortic dilation. Mitral valve prolapse.	Congenital heart disease (>70%) esp.conotruncal malformations	Poor peripheral circulation	Dep.on site of neurofibroma	Cardiac Rhabdomyomas
Endocrine	Thyroid disorder in 25% (esp.hypothyroid) Advise annual TFT	NIDDM (2° to obesity) Hypothyroidism		Hypo calcaemia (50%)		Depending on site of Glioma	
Audiovisual	Visual impairment Hearing impairment (both multifactorial; advise annual checks).		Visual impairment (multifactorial) Hearing impairment	Hearing impairment (multifactorial)		Visual/hearing impairment (Glioma affecting optic/auditory nerve) Iris hamartomas	Retinal tumours
Muscular/ Skeletal	Atlanto-occipital and atlanto-axial instability Hypotonia	Short stature Scoliosis Hypotonia Small extremities	Connective tissue disorder. Scoliosis High-arched palate. Macrocephaly	Polydactyly	Hypotonia	Skeletal abnormalities, esp.Kyphoscoliosis	
Other	Blood dyscrasias Skin Disorders GI disorders GU disorders Obesity Sleep apnoea Recurrent infections esp.respiratory Leukaemia	Severe obesity Undescended testes Hypogonadism Sleep apnoea	Herniae (CT-related) Large ears Macro-orchidism Speech & language abnormalities	Cleft lip/palate Thymic dysplasia Hypernasal speech. Immune problems Characteristic facies. Dysphagia. Renal anomalies. Go reflux. Juvenile RhA.	Variable clinical picture dep. On variable deficiency of phenylalanine Hydroxylase enzyme. Eczema Light skin pigmentation	Variable, dep. On neurofibroma location. Tumours susceptible to malignant change. Other varieties of tumours may be associated. Café au lait spots	Kidney + lung Hamartomas Polycystic kidneys Skin lesions (fibromas, fibrous plaques, hypomelanotic macules, shagreen patch. Adenoma sebaceum Café au lait spots)

ESSENTIAL HEALTH CARE

Learning Disability is by definition related to some form of cerebral trauma in the developmental period. This is rarely confined to just those areas of the brain responsible for cognitive and social function alone, therefore, there are potentially a variety of concurrent physical impairments which can lead to additional health needs over and above those experienced by the general population. There is generally a graduation with the prevalence and severity of physical problems usually increasing from people with mild to those with more severe Learning Disability.

A series of surveys both in the UK and abroad have identified considerable health deficits in people with Learning Disability.

- ❖ Sight Problems
- ❖ Hearing Problems
- ❖ Dental Disease
- ❖ Epilepsy
- ❖ Psychiatric Illness
- ❖ Eating Disorders
- ❖ Sleeping Disorders
- ❖ Challenging Behaviours
- ❖ Obesity
- ❖ Poor Diet
- ❖ Communication Problems
- ❖ Respiratory Function Disorders
- ❖ Skin Conditions
- ❖ Foot Care Problems

People whose Learning Disability is caused by a specific genetic syndrome will be predisposed to recognised patterns of physical impairment associated with the underlying condition. This is called the somatic phenotype. For example, people with Down's Syndrome have particular susceptibility to Cardiovascular Disease, Sensory Impairment and Thyroid Dysfunction. In recent years there has also been increased interest in the concept of Behavioural Phenotypes where by certain challenging behaviours are also felt to be associated with the underlying genetic condition. A frequently cited example of this is the condition Prader-Willi Syndrome where there is an increased prevalence of specific behaviours including food-seeking behaviour and self-injury.

Somatic Phenotypes	Behavioural Phenotypes
e.g. Down's Syndrome <ul style="list-style-type: none"> ❖ Cardiovascular Disease ❖ Respiratory Disease ❖ Sensory Deficits (Vision, Hearing) ❖ Alzheimer's Disease ❖ Hypothyroidism 	e.g. Prader-Willi Syndrome <ul style="list-style-type: none"> ❖ Food Seeking ❖ Poor Impulse Control ❖ Sleep Abnormalities ❖ Psychiatric Illness ❖ Self Injury (skin picking)

The few surveys of health care of people with Learning Disability in the community have consistently shown three main findings.

Community Health Surveys

- ❖ High prevalence of morbidity in people with Learning Disability
- ❖ Apparent deficits in recognition of health deficits
- ❖ Reduced participation in generic health promotion initiatives

It has also been shown that people with Learning Disability are less likely to have their medication adequately reviewed and that unaddressed health needs provided a barrier to the process of de-institutionalisation.

Whilst recent attention on the process of de-institutionalisation has highlighted the primary health care needs of people with Learning Disability, the majority have always lived in the community with their families and accessed their health care through the primary care system. The GP is officially designated as the key identifier of health needs in the UK and most readily accept that this includes the health care of people with Learning Disability. Despite frequent misconceptions, the primary care consultation rates of people with Learning Disability are, in general, lower than the average for the general population. They do, however, have higher levels of consultation with specialist services.

The primary health care system for adults in the UK is largely reactive. That is, a health contact usually depends upon initiation by the individual. This model is not well suited to those people who have poor communication or are poor advocates for their own health, and the Learning Disability experience is mirrored in the poor health care uptake of other groups with similar difficulties, for example, people with chronic Mental Illness and ethnic minorities. The greater the level of Learning Disability, the less likely the person is to be able to identify and adequately communicate deficits in their own health. In those totally dependent upon others the presenting problem may be overlooked due to the

complexity of the person's physical condition or may be considered less important as compared to other major health problems. Finally, and inevitably, the readiness of the person, or their carers, to seek and maintain involvement with health care services is dependent upon their previous experiences in this area.

The likelihood of a positive and effective consultation will depend upon a number of factors. Firstly, interaction is assisted by advance consideration in an optimum setting. Similarly, the health care team should be made aware of any communication difficulties and how best to overcome them. The presence of an advocate would also be extremely valuable especially if they provide quality objective information. Difficulties with examination can often be reduced by previous explanation and, if necessary, desensitisation to a location or procedure. Capacity to consent is often an area of considerable uncertainty and anxiety both for carers and medical practitioners, though it is hoped that this will become less problematic within the statutory framework of The Mental Capacity Act 2005. Finally, consideration of time constraints in the initial discussion with administrative staff can often avoid rushed appointments and lessen stress on all parties. Such planning and communication forms a bedrock for the development of an effective therapeutic alliance between the person with Learning Disability and health care professionals. The specialist knowledge of Community Learning Disability Teams is an extremely effective, and sadly often under-utilised, resource to facilitate this process.

- ❖ Environment
- ❖ Communication
- ❖ Quality of Information
- ❖ Examination Difficulties
- ❖ Capacity to Consent
- ❖ Time Constraints
- ❖ Therapeutic Alliance

Recognition that people with Learning Disability are not optimally served by our current primary health care systems led to calls for more proactive system of care and a case for formal health checks in people with Learning Disability is compelling.

- ❖ Identify unrecognised illness
- ❖ Ensure health promotion
- ❖ Record health gain or loss through
- ❖ Systematic questioning
- ❖ Structured physical examination
- ❖ Syndrome specific checks

References / Further Reading:

Physical Health of Adults with Intellectual Disabilities (2002). VP Prasher and NP Janicki (Eds) Blackwell.

Baxter, Morgan and Kerr (2003) *In: Seminars in the Psychiatry of Learning Disabilities (2nd Edition).* Royal College of Psychiatrists. London, Gaskell Press.

(European Association of Intellectual Disability Medicine)
www.mamh.net/

EPILEPSY IN PEOPLE WITH LEARNING DISABILITY

Epilepsy is the most common medical condition seen in people with learning disabilities – and both the disorder and its treatment can have significant impact upon an individual's physical health and psychological well being.

EPIDEMIOLOGY

Estimated prevalence varies from 6% amongst those with mild learning disability to as high as 40% for those with more severe Learning Disability. This compares to a general population figure of between 0.5 and 1%.

AETIOLOGY

In the learning disabled population it is likely that the underlying pathological cause for the intellectual disability may also have given rise to the seizure disorder. Therefore, identification of the cause for the intellectual disability may have important implications for the management of the epilepsy.

DIAGNOSIS

Assessment may be complicated by a variety of factors. Communication difficulties of the patient and reliance upon the accounts of witnesses unable to attend appointments such as support workers and day centre staff impede accurate history taking. Co morbidities such as mental illness, physical disorder and challenging behaviour may figure high upon a list of differential diagnoses. Events should be investigated appropriately, as in the general population. A prolonged or overnight EEG recording may be necessary and use of video telemetry may be useful where attempting to distinguish events of behavioural origin from those which are seizure related. In some cases neuroimaging will be required and facilities for sedation or general anaesthesia should be available for those whom may have difficulty co-operating with the procedure.

Where possible a diagnosis of seizure type and syndrome should be made as these have important implications for treatment and prognosis. Many individuals with learning disability will be found to experience more than one seizure type.

TREATMENT

Treatment is usually initiated after an individual has experienced 2 or more seizures. The aim is to achieve optimum seizure control with minimum adverse effects. Seizure freedom on monotherapy is the ideal but only 60 – 70% of those with seizure disorder will achieve an adequate response to a single anticonvulsant, and treatment resistance is more common amongst the learning disabled population. Few randomised controlled trials have been conducted specifically in those with intellectual impairment, therefore choice of anticonvulsant will need to be guided from evidence based on the general population. An accurate diagnosis of seizure type is important – some anticonvulsants may worsen certain types of seizure. For example Carbamazepine or Phenytoin exacerbate absence or myoclonic seizures.

The presence of common co morbid conditions such as obesity, dysphagia or reflux oesophagitis may influence the choice of drug or preparation. Other factors such as psychiatric illness or behavioural disorder also need to be taken into account when initiating treatment. Knowledge of the side effect profiles is of particular importance as the learning disabled may be both more likely to develop these adverse effects and less likely to effectively express their discomfort.

A proportion of patients will exhaust all medication options and continue to experience dangerous or disabling seizures; for these the possibility of surgery or vagal nerve stimulation must be considered.

IMPACT OF SEIZURES

The standardised mortality ratio (SMR) is increased both in those with epilepsy and those with a learning disability. For those with both, the figure may be as high as 5 times that of the general population. People with epilepsy are at greater risk of accidents and hospitalisation; the fracture rate of those with LD and epilepsy is double that of those with intellectual disability alone.

A chronic seizure disorder may also impact upon intellectual functioning – repeated head injury may result in permanent neurological damage, a cognitive decline may occur after prolonged status epilepticus, or anticonvulsant medications themselves may exacerbate existing cognitive impairment.

There is significant over representation of psychiatric disorder in those with epilepsy. However, in the learning disabled, where psychiatric morbidity is also comparatively common it is has been difficult to establish a causal relationship.

References / Further Reading:

Learning Disability and Epilepsy. Edited by Michael Trimble. Clarius Press Ltd.

Kerr. (2003) *In: Seminars in the Psychiatry of Learning Disabilities (2nd Edition).* Royal College of Psychiatrists. London, Gaskell Press.

Clinical Guidelines for the Management of Epilepsy in Adults with an Intellectual Disability. Seizure (2001) 10, 401-409.

(National Society for Epilepsy)

www.epilepsynsc.org.uk/

(British Epilepsy Association)

www.epilepsy.org.uk/

COMMUNICATION

Good communication is essential in all health care settings where people are often feeling unwell, are in an unfamiliar environment and are trying to understand and retain medical information. This may limit communication, comprehension and social skills. A person with Learning Disability will have difficulty in all these areas in anticipation of a health care consultation, so extra needs regarding communication should be anticipated. Careful planning should optimise co-operation and reduce the likelihood of distress and challenging behaviour.

The many Cognitive, Sensory and Developmental Impairments, which are intrinsic to the clinical condition of most individuals with Learning Disability, must be borne in mind when assessing and adjusting to an individual's communication needs.

Cognitive Impairment:

- ❖ Attention
- ❖ Memory
- ❖ Processing of Information

Sensory Loss:

- ❖ Hearing
- ❖ Vision

Language Development:

- ❖ Delayed
- ❖ Disordered

Disorders of Speech:

- ❖ Cranio-Facial Anomalies (*e.g. Cleft lip / Palate*)
- ❖ Dysarthria (*Motor speech impediment*)
- ❖ Verbal Dyspraxia (*Impaired programming of articulation*)
- ❖ Verbal Fluency (*e.g. Stammer*)
- ❖ Phonological Disorders (*Immature or Deviant*)
- ❖ Pragmatics (*Rules governing use of language*)

One must also consider the effect of some specific conditions on communication. Some specific syndromes may be associated with particular characteristic communication problems independent of the individual's level of Intellectual Impairment. For example, the communication phenotype of Williams Syndrome (Infantile Hypercalcemia) is described as "Hyperlinguistic in advance of the individual's overall IQ". Individuals

with Fragile X classically display gaze avoidance etc. One must also consider the effect of Autistic Spectrum Disorders where abnormalities in communication and social interaction are an integral part of the diagnosis.

It is important to remember that communication is not just about speech. Non-verbal communication is an important component of any interview, but becomes increasingly important when an individual lacks speech. This could occur in relation to specific brain damage, e.g. Athetoid Cerebral Palsy or in relation to the individual's level of Intellectual Impairment. Individuals with an IQ below 50 generally lack the verbal skills for conventional psychiatric interview. There are a variety of augmentative strategies which the individual may use:

- ❖ Objects of reference
- ❖ Signs
- ❖ Symbol-based systems
- ❖ Communication aids
- ❖ Total communication approach

Interview Skills:

Preparation for interviewing a person with Learning Disability should involve consideration of the environment. Is the person liable to find the setting intimidating or uncomfortable? Are there distractions and, if the individual has a history of challenging behaviour, is the environment set in an appropriate configuration? Background information is also important. Are you aware of the individual's level of cognitive functioning, interpersonal skills? What are the primary means of communication and do they use a specific communication system? If an informant is present what is their relationship, their depth of knowledge of the individual and do they have a specific agenda? Time management is also important. Do you need to factor in the time taken to speak to both the individual and the informant / interpreter? Do you need to take breaks and what is the individual's capacity for waiting?

The initiation of a consultation will also be important. Time taken to appropriately greet the individual, introduce yourself including any necessary explanations or reassurance will be time well spent. This is also the time to clarify the roles of any third parties present during the consultation and to check the appropriateness of positioning. This will include consideration of any requirements of the patient in relation to vision, hearing, your proximity in relation to personal contact and/or safety and an opportunity to observe any groupings/alliances between parties.

Much of the advice has been given as if describing a homogeneous group of patients. The difference in presentation between individuals with mild and more severe Learning Disability can be considerable. Whilst there are indeed some shared requirements it is

also useful to consider the somewhat separate interview techniques which one may use when consulting individuals with mild or more severe Learning Disability.

Consultation with People with Mild Learning Disability:

- ❖ Establish rapport (know something about the person)
- ❖ Use short sentences
- ❖ Speak slowly and clearly
- ❖ Pause between sentences
- ❖ Avoid jargon
- ❖ Check regularly that they understand
- ❖ Augment with gesture, facial expression
- ❖ Break enquiries down into simple steps (don't overload)
- ❖ Use open questions (avoid "yes/no" answers)
- ❖ Offer either/or options
- ❖ Be aware of difficulties with
 - ❖ Tense
 - ❖ Time/sequence
 - ❖ Numeracy/literacy
- ❖ Use pictures, diagrams, symbols (both in enquiry and instruction)
- ❖ If you don't understand ask him/her to
 - ❖ "say it again"
 - ❖ "say it slowly"
 - ❖ "say it in different words"
 - ❖ "show me what you mean"
- ❖ Monitor their emotions, comprehension and attention
- ❖ Consider appearance and observe behaviour throughout
- ❖ Sum up

Finally, remember

- ❖ Compensatory strategies (the struggle to maintain face)
- ❖ Suggestibility
- ❖ Acquiescence

Consultation with People with Severe Learning Disability:

- ❖ Establish rapport (make it enjoyable)
- ❖ Keep it informal
- ❖ Be an opportunist (maintain a flexible approach)
- ❖ Use consistent labels
- ❖ Cue by name
- ❖ Progress stepwise (with regard to level of development)
- ❖ Augment by visual cues (photos, symbols etc.)
- ❖ Use signals, facial expression, touch etc.
- ❖ Monitor mood and attention
- ❖ Check understanding
- ❖ Give sufficient time to answer
- ❖ Relate to developmental level not chronological age (but with regard to dignity)
- ❖ Monitor appearance and behaviour (remember behavioural equivalents)

Finally, remember that “all behaviour has meaning”.

References/Further Reading:

Scotland and Fraser (2003). In: *Seminars in the Psychiatry of Learning Disabilities (2nd Edition)*. Royal College of Psychiatrists. London, Gaskell Press.

HISTORY AND MENTAL STATE EXAMINATION

The classical questions asked in relation to an individual with Learning Disability are much the same as those for any individual. However, as outlined above the individual's intellectual and communication level may limit their capacity to give an effective history. Here the use of a well informed informant can be particularly beneficial. Other areas which differ somewhat from the classical psychiatric interview are the emphasis on functional analysis of behaviour, i.e. seeing a particular act in relation to antecedents and consequences is particularly important. There is also a strong emphasis on developmental history given the frequency of Pervasive Developmental Disorders in individuals with Learning Disability. Information on schooling and functional ability may also give clues in relation to the presence and/or severity of Learning Disability. Information in relation to the type, duration, efficacy and side effects of medication is particularly important given that this is an acquiescent population which does not typically question the actions of authority figures such as doctors.

In the Mental State Examination there is obviously less in the way of subjective information. Therefore, it is particularly important that detailed observations are made in relation to appearance, behaviour and communication. Contribution of a well-informed informant can be critical especially if the person's presentation is a deviation from their normal state.

Finally, whilst a History and Mental State Examination is a pre-requisite to an effective formulation, it must be remembered that the presentation of Psychiatric Illness in individuals with Learning Disability is atypical and communication barriers often preclude the use of conventional diagnostic criteria. There have been recent initiatives within the specialist Learning Disability services in the United Kingdom to develop more appropriate diagnostic systems. For example, Learning Disability Psychiatrists in the United Kingdom have developed the Diagnostic Criteria for Learning Disability (DCLD), which is a tailor made diagnostic system for individuals with learning disability with cross reference, when appropriate, to the conventional international mental health coding systems. There are also interview schedules or checklists designed specifically for the screening and/or diagnosis of mental illness in individuals with learning disability, e.g. the Psychiatric Assessment Schedule for Adults with Developmental Disability (PASADD).

HISTORY AND MENTAL STATE EXAMINATION: LEARNING DISABILITY

Personal Details

Name
Age
Occupation
Ethnic Origin
Marital Status
Domicile

Informant Details
(If applicable)

Name
Age
Relationship
Length of Acquaintance

Presenting Complaint (Verbatim)

History of Presenting Complaint

Spontaneous/Upon Further Enquiry
Onset
Course
Severity
Associated Features
Exacerbating / Relieving Factors
Lifestyle Changes
Sources of Assistance
Attempted Treatment (and effect)

Functional Analysis of any Challenging Behaviour with reference to:

A - Antecedents
B - Behaviour
C - Consequences

Personal History

Parental age at Birth
Complications of Pregnancy or Birth
Condition at Birth
Neonatal Illness
Childhood Illness
Significant Separations

Family History (Draw a Family Tree)

Parents Age / Date of Death
Occupation
Health
Relationship
Contact
Consanguineous?

Milestones (average)

<u>Motor</u>	Sit	9 months	
	Crawl	9 months	
	Stand	1 Yr)	
	Walk	18 months	
<u>Communication</u>	Babble	6 months	
	Words	18months	
	Sentence	2 Yrs.	
<u>Social</u>	Dry by Day	2 Yrs.	
	Dry by Day + Night	5 Yrs.	

Sibs Age
Relationship
Contact
F/H of: Mental Illness; LD;
Other Familial Conditions

Note any delay

Current Functional Ability

Communication Level
Social Support Needs:
Daily Life: Personal Hygiene. Dressing, Feeding
Financial
Occupational
Vulnerability
Safety:
Domestic
Road Safety
Sexuality

Schooling

Academic Social Progress
Conduct Relationship Peers/
Teachers
Special Education
Scholastic Achievement
Literacy / Numeracy
School Psychology involvement

Occupational History

Number,nature, length
Reason for leaving

Sexuality (if appropriate)

Inclination, activity level,
vulnerability, inappropriate
behaviour. History of abuse

Current Medication

Type and Duration
Efficacy
Side effects
Compliance

Substance Abuse

Smoking
Alcohol
Illicit Drugs

Past Medical History

Inc Investigation of Aetiology/Genetics
Systems Enquiry (Inc Syndrome
Specific Vulnerability)

If Epilepsy: Seizure Type(s)
Frequency
Duration
Exacerbating Factors

Forensic History

Premorbid Personality

Character Attitude/Relation to Others
Affective Stability
Concentration/impulsivity
Hobby Interests
Rituals/Obsessions
React to Stress/Frustration/Illness
Activity Level

Mental State Examination

Appearance and Behaviour

Level of Co-operation
Manner
Dress / Self Care
Posture / Movements
Facial Expression etc.
Rapport / Appropriateness
Gesture / Non verbal communication

Mood

Objective and Subjective;
Biological Features;
Cognitive, Inc. Suicide

Thought Content

Concerns / Preoccupations
Obsessions / Compulsions

Abnormal Perception

(Avoid leading questions!)

Cognition (Adapted to Ability)

Orientation Time/Place/Person
Concentration for example: Serial 7s / Months of
Yr Forward + reverse
Days of wk Forward + reverse

Memory Immediate Recall / STM

Insight Ill?; Need Rx?; Attitude to Rx?

Past Psychiatric History

Inc Psychometric Assessments

Specific Behavioural Problems

Aggression
Over activity
Pica
Sleep Disturbance
Absconding
Self Injury

Talk / Communication

Nature / Speed
Structure / Complexity
Repetition
Vocabulary
Disorders of speech
(Dysarthria, Dyspraxia,
Fluency, etc)

Abnormal Beliefs:

Fixed?
Cultural/Developmental
Appropriate?
Acted Upon?
Concerning: Environment
Self
Control

General Knowledge / Intelligence

Receptive / Expressive ability
Constructional Dyspraxia
Execution of Sequential Task
Literacy Numeracy

Physical Examination

(If Appropriate)

References / Further Reading:

Scotland, J., Fraser, W., (2003) *Communicating with People with Learning Disability*. In: *Seminars in the Psychiatry of Learning Disabilities (2nd Edition)*. Royal College of Psychiatrists. London, Gaskell Press.

DC-LD (Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation) (2001) Royal College of Psychiatrists Occasional Paper 48. Gaskell Press. Diagnostic criteria suggested for people with moderate or severe Learning Disabilities.

PSYCHIATRIC ILLNESS IN LEARNING DISABILITY

Individuals with Learning Disability can experience the full range of psychiatric disorders, as seen in the general population.

- Prevalence of psychiatric disorder 3-4 x higher c.f. general population.
- Prevalence of psychiatric illness among adults with Learning Disability is 10 to 50%
- Psychiatric morbidity in over 60% of adults with Learning Disability aged over 65 years.

You need to be aware of the concept of 'diagnostic overshadowing' i.e. the presence of Learning Disability obscuring the diagnosis of a mental health problem.

PATHOGENESIS / AETIOLOGY

There are a number of potential factors that increase the vulnerability of individuals with Learning Disability to psychiatric disorders:

1) BIOLOGICAL

Genetic e.g. Down's syndrome - increased prevalence of Alzheimer's Disease,
Lesch Nyhan syndrome - associated with severe self-injury.

- Physical illness may present as behavioural disturbance.
- Motor phenomena - individuals with Learning Disability have increased motor disorder, e.g. Cerebral Palsy and misinterpretation of symptoms is common.
- Epilepsy - psychiatric illness is 5 x more likely if there is CNS disorder. Approximately 20% of individuals with Learning Disability have lifetime history of epilepsy.
- Sensory impairment increases the risk of psychiatric illness.
- Polypharmacy - misinterpretation of side effects of psychotropic medication.

2) PSYCHOLOGICAL

- Impaired memory / judgment due to brain damage.
- Communication difficulties.
- Low self esteem from repeated failure / rejection.
- Poor coping mechanisms / problem solving.

- Lack of emotional support.

3) SOCIAL

- Stigma / lack of integration with wider society.
- Life events e.g. bereavements and other losses.
- Under or over-stimulating environment.
- Lack of social support / changes in care environment.
- Conflict with family members / residents / staff.
- Increased risk of abuse.
- Difficulty in developing fulfilling relationships.

SPECIFIC PSYCHIATRIC DISORDERS IN ADULTS WITH LEARNING DISABILITY

Some psychiatric disorders are more prevalent in people with Learning Disability. Here are some key facts about mental disorders in Learning Disability, including details of how their presentation differs from the population in general.

Schizophrenia

- Point prevalence in Learning Disability 3% (c.f. 0.4% in general population)
- Difficult to reliably diagnose if IQ<45, or in someone with limited verbal skills / self-awareness, as first rank symptoms of schizophrenia require self-reporting of symptoms.
- Aetiology similar to general population but increased risk may be partly through higher rates of obstetric complications and genetic risk factors
- Consider psychosis if recent history of loss of skills and bizarre behaviour.
- Often more treatment resistant in Learning Disability, but responds to antipsychotics. Avoid polypharmacy and follow NICE guidelines.
- Non-drug treatment possible in more able individuals.

Depression

- Possibly higher rates in individuals with Downs syndrome
- Under diagnosed in severe and profound Learning Disability
- May present as aggression, irritability, self-injury, anhedonia, social withdrawal or loss of skills.
- In severe Learning Disability, biological symptoms may be only guide.
- Treatment primarily with antidepressants; consider using more sedating antidepressant if sleep disturbed (common), but be aware of risk of cognitive impairment. Start low, go slow.
- Non-drug interventions e.g. Cognitive Behavioural Therapy (CBT) possible,

but evidence base is, so far, limited in Learning Disability.

Bipolar Affective disorder

- Hypomania often presents with irritability, aggression, disinhibition, increased verbal communication and volume, and insomnia.
- Mixed affective states commoner presentation of bipolar affective disorder in Learning Disability c.f. general population.
- Rapid cycling disorder may be more common in Learning Disability.
- Some with Learning Disability may show cyclical changes in behaviour, associated with altered mood.
- Exclude episodic pain (e.g. UTI, GI reflux).
- Mainstay of treatment mood stabiliser +/- atypical antipsychotic.

Anxiety disorders

- At least as common as the general population.
- Generalised Anxiety disorder, simple phobia and social phobia most commonly reported.
- Fears may be similar to those of children, at the equivalent developmental level: separation, natural events, injury, animals, the dark.
- May present as aggression, agitation, self-mutilation, obsessive fears, ritualistic behaviours, somatisation, insomnia.
- Anxiety associated with autism may respond to low-dose antipsychotics. SSRI may be helpful. Benzodiazepines must only be used with caution and in the short term because of risks of paradoxical excitation and dependence. Modified anxiety management, daily diaries and information and other non-pharmacological interventions are also important.

Dementia

- Occurs earlier and at higher rates in Learning Disability
- 30-80% of adults aged 65 years or older with Learning Disability (but without Downs syndrome) show Alzheimer's neuropathology.
- Most adults >40 yrs of age with Downs syndrome display Alzheimer's neuropathology (but not necessarily equivalent clinical presentation).
- Clinical symptoms in Downs syndrome 30% by age 50.
- May present as loss of skills and language, memory problems, new onset epilepsy.
- Exclude pseudodementia / reversible causes.
- Cholinesterase inhibitors may be helpful (evidence base very limited). Treat comorbid epilepsy.

Personality disorders

- Learning Disability population prevalence 25-30%
- Difficult to make diagnosis in Learning Disability, virtually impossible in severe Learning Disability.
- Individuals with mild Learning Disability and dissocial / borderline personality disorder can present a significant challenge to health / social / criminal justice system
- Emotionally unstable commonest PD identified in Learning Disability.
- Boundaries, consistent approach, staff debriefing to minimise splitting. Individual / group / family therapy / DBT may help.
- Drug treatment may be helpful for specific symptom management e.g. mood stabilisers / antipsychotics / SSRI depending on presentation.

TREATMENT MODALITIES IN LEARNING DISABILITY

- **Psychotropic Medication:** used in Learning Disability for treatment of mental illness, developmental disorders (e.g. autism, ADHD), challenging behaviour and epilepsy. This group presents particular challenges as consent is often lacking, side effects are more prominent but communication difficulties hinder their reporting.
- **Behavioural Therapy:** is targeted at both skill development and the reduction of challenging behaviours. The reasons for challenging behaviour are varied and complex. The basis of behavioural therapy is thorough assessment (functional analysis) to identify the key

bio/psycho/social factors that may predispose or maintain such behaviours: this underpins the use of planned behavioural interventions.

- **Couselling and Psychotherapy:** individual, group and family work may all be used in people with Learning Disability; from the levels of support / counselling / education / information provision to deeper levels of more active psychodynamic therapy where the individual's inner traumas and conflicts are explored (the latter should only be practiced by experienced clinicians, usually under supervision).
- **Cognitive Behavioural Therapy:** use of CBT in schizophrenia, depression, anxiety disorders, as well as anger and aggression, are all possible in Learning Disability, but the evidence base is currently limited. Modified forms of CBT that take into account the level of language and cognitive ability may reduce anxiety and depression in adults with Learning Disability.
- **Arts therapy (Art, Drama, Music):** arts therapies offer a way for individuals to express and explore thoughts, needs and feelings. Music and Drama therapy may be helpful in those with communication difficulties unable to benefit from conventional speech and language therapy.
- **Family Therapy:** family functioning may be helped by therapy focusing on education, communication skills, conflict resolution, parenting skills as well as reflecting on sensitive issues such as a coming to terms with having a child with a disability and 'letting go'. Parents should usually be integrally involved in the delivery of behavioural, education, communication and physiotherapy programmes.

References / Further Reading:

Vanstraelen, Holt and Bouras, Hollins (2003). *In: Seminars in the Psychiatry of Learning Disabilities. (2nd Edition). The Royal College of Psychiatrists. London, Gaskell Press.*

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Bouras N. (editor) (1999) *Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation. Cambridge, Cambridge University Press.*

Deb, Matthews, Holt et al (2001). *Practice Guidelines for the Assessment and Diagnosis of Mental Health Problems in Adults with Intellectual Disability*. Brighton: Pavilion Publishing.

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CHALLENGING BEHAVIOUR

People with Learning Disability may exhibit a variety of behaviours which provide a challenge to those caring for them. Various terms have been used to describe these behaviours. However, increasingly it is recognised that this must be seen in the context of the individual's personal experience and the influence of their environment and not just as an isolated event.

The term 'challenging behaviour' was defined in 1995 by Emerson as '*...culturally abnormal behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities..*'

Whether a behaviour is viewed as challenging or not may therefore be governed by a number of factors;

- the social context in which it is seen
- the ability of the individual to account for their behaviour
- the beliefs held by others as to the cause of the behaviour
- the capacity of the setting to manage the consequences of the behaviour

EXAMPLES OF CHALLENGING BEHAVIOUR

Verbal aggression	Inappropriate personal habits
Physical aggression	Stereotypies
Destruction of property	Hyperphagia
Self-injurious behaviour	Pica
Inappropriate sexual behaviour	30 Overactivity
Severe non – compliance	

EPIDEMIOLOGY

The prevalence of challenging behaviour is estimated to be 10 - 15% of all those with intellectual disabilities and it is a common reason for referral to the learning disability services. A significant number (25%) of those exhibiting challenging behaviour may do so across more than one of the domains of aggression, self-injury and property destruction. The risk of challenging behaviour appears to be increased in the following;

- males
- age range 15 – 34
- greater severity of intellectual impairment
- poor mobility
- visual or hearing impairments
- psychiatric illness
- institutional care

Some specific syndromes may also be associated with a higher than expected prevalence of particular types of challenging behaviour (see table of clinical syndromes).

THE IMPACT OF CHALLENGING BEHAVIOURS

Individuals displaying challenging behaviours are at risk of a number of consequences to their own and others health or quality of life. Repeated self-injury can lead to infection, malformation or even loss of function. Aggression may result in injury to others or to the individual concerned secondary to defensive or restraining responses. Social responses to such behaviour may include exclusion from community activities and services and the development of stigma. Challenging behaviour is also known to be a risk factor for abuse and neglect.

AETIOLOGY

The aetiology of challenging behaviour is often complex and multifactorial, and one particular behaviour may relate to different causal mechanisms at different times. When attempting to establish the reason for behavioural change the factors listed in the table below may need to be considered in the context of the individual's level of intellectual and emotional development. Particular consideration may also need to be given to the person's communication skills and presence or absence of comorbid developmental disorders such as attention deficit or autistic spectrum disorder.

BIOLOGICAL FACTORS	e.g. Physical illness, medication effects, sensory
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	impairments, hunger, pain, sleep deprivation.
PSYCHIATRIC ILLNESS	e.g. Psychosis, hypomania, depression, OCD, Tourette's Syndrome.
EMOTIONAL FACTORS	e.g. Grief, jealousy, excitability
ENVIRONMENTAL FACTORS	e.g. Over or understimulation, crowds, noise, change of staff
OPERANT CONDITIONING PROCESSES	e.g. Positive, negative or automatic reinforcement

FUNCTIONAL ASSESSMENT

This type of assessment aims to identify the behavioural processes responsible for maintaining a person's challenging behaviour. The first step is to select the behaviours to which intervention is to be targeted based on their current level of impact. There are many ways in which the function of these behaviours may then be explored but the simplest involves an observational method and the recording of ABC charts. Here the observer records antecedent events (A), the target challenging behaviour (B) and consequent events (C). These recordings are then used to examine any relationship between challenging behaviour and environmental events, biological states of the individual, preceding social interaction and the subsequent social response. Hypotheses may then be generated with regard to potential trigger factors and reinforcers.

BEHAVIOURAL APPROACHES TO MANAGEMENT

A number of behavioural approaches to intervention may be taken, dependent on the result of the functional assessment. Some examples include;

- modification of biological trigger factors
- changing the nature of preceding activities
- changing the nature of concurrent activities
- environmental enrichment and noncontingent reinforcement (rewards)
- functional displacement ie the introduction and reinforcement of new socially acceptable behaviours which serve the same purpose as the challenging behaviours.
- differential reinforcement ie reinforcement of a behaviour which is physically incompatible with the challenging behaviour.
- extinction ie modification of the reinforcing outcome of the challenging behaviour.

PHARMACOLOGICAL APPROACHES TO MANAGEMENT

It is good practice to carry out a thorough assessment of the possible aetiological factors mentioned above before considering the use of psychotropic medication for the purpose of attenuating challenging behaviour. Despite a poor evidence base for the use of medication primarily for behaviour disorder, psychotropic drugs, particularly antipsychotics are widely prescribed.

The strongest evidence for the use of antipsychotic medication is in the reduction of stereotypy. As antipsychotic use may be associated with significant long-term effects such as Tardive dyskinesia, the potential risks and benefits to prolonged use should always be assessed. It is hypothesized that self-injurious behaviour is reinforced by the increase in endogenous opiate activity. Naltrexone, an opiate antagonist has been used with the aim of reducing the behaviour but evidence of its effectiveness has been limited. Benzodiazepines, SSRI's, lithium and beta blockers have all been used to treat aggressive behaviour but there are few controlled trials to support their efficacy. The use of Carbamazepine and Valproate has been shown to be effective in certain cases of aggressive behaviour but again this has been in uncontrolled studies only.

References / Further Reading:

Severe Learning Disabilities and Challenging Behaviours. (Editors Emerson and McGill). Chapman and Hall.

Jahoda and Espie. *In: Seminars in the Psychiatry of Learning Disabilities. (2nd Edition). The Royal College of Psychiatrists. London, Gaskell Press.*

Santosh and Baird (1999) *Psychopharmacotherapy in Children and Adults with Intellectual Disability. Lancet 354:231-240.*

Autistic Spectrum Disorders

Autistic Spectrum Disorders (ASD), also called Pervasive Developmental Disorders (PDD's) are umbrella terms to include disorders such as childhood autism, atypical autism and Asperger's Syndrome. All classification systems are to some extent based upon the so-called "Triad of Social Impairments".

Core Features

- Abnormalities in reciprocal social interaction.
- Abnormalities in communication.
- A restricted, repetitive or stereotyped repertoire of interests or activities.

Although many of the individuals with autism will also have learning disability this is not universal and some such as those with Asperger's Syndrome or High Functioning Autism will have intellectual function in the normal range. Both major international diagnostic categories (ICD 10 and DSM IV) adopt similar criteria for childhood autism consisting of features of the triad of impairments combined with the stipulation that onset is before the age of three years. In Asperger Syndrome there should be abnormalities in social interaction and restricted, stereotyped or repetitive interests and activities. However in contrast to childhood autism there should not be any general delay in language or cognitive development. The diagnosis of atypical autism is made if one of the triad of impairments is not present. This diagnosis is often used in an individual with a more severe level of learning disability where the presentation of the triad of impairments may be difficult to delineate.

Typical Features of Autistic Spectrum Disorders

Failure to use eye gaze, facial expression, body posture and gesture to regulate social interactions.

Failure to develop peer relationships that involve mutual sharing of interests, activities and emotions.

Lack of socio-emotional reciprocity as shown by lack of modulation of behaviour.

Lack of spontaneous seeking to share enjoyment or interests.

Delay in, or total lack of, development of spoken language.

Relative failure to initiate or sustain conversational interchange.

Stereotyped repetitive use of language.

Restricted repetitive and stereotyped patterns of behaviour.

Compulsive adherence to routines.

Repetitive mannerisms.

The development of reliable and valid diagnostic criteria remains a challenge and whilst there is extensive research into the aetiology of autism the findings remain inconsistent. In some individuals the autistic spectrum disorder is associated with the recognised syndromes such as Tuberous Sclerosis or Fragile-X. In others impairment is secondary to medical conditions such as Herpes Encephalitis or Congenital Rubella. However in the majority of cases no identifiable syndromes or conditions are found. There is strong evidence from twin and family studies that genetic factors play a role in the development of autistic spectrum disorders. However like many complex neuropsychiatric disorders the exact mechanisms remains elusive. Similarly studies in other areas such as structural functional neuroimaging, neuropathology and neurochemistry have not shown consistent findings.

Of the many psychological hypothesis those with the greatest influence at present relate to the “theory of mind” and “central coherence”. The theory of mind hypothesis is that individuals with autistic spectrum disorders have impaired ability to think about or understand other people in terms of their thoughts, ideas and mental state. Central coherence refers to the question of perceptions. This suggests that individuals with autistic spectrum disorders may have ultra strengths in the focusing on details of perceptions but find it more difficult to bring together these individual pieces of information to construct a more coherent understanding of the overall picture.

Epidemiology

There is considerable debate over the prevalence of autistic spectrum disorders and whether they have been increasing. So far there is not a consensus on this issue. The prevalence of childhood autism is generally considered to be between 2 and 5 per 10,000 of population. The prevalence for the wider category of autistic spectrum disorders has been considered to be in the order of 60 per 10,000 population. These are however

consistent findings of a male to female ratio of approximately 4 to 1 but the exact reason remains unclear.

Prognosis

There have until recently been relatively few studies following children from early life to adulthood. It is becoming increasingly clear that individual's measured IQ and language abilities are important positive predictors of outcome and it is important to recognise that individuals do have the potential to make significant developmental progress. This serves to emphasise the importance of early and intensive interventions. Such interventions involve not just maximising the practical skills but also addressing any maladaptive behaviours or concurrent physical or psychological disorders.

Common Co-Morbidity

Learning Disability

The prevalence of ASD increases with the severity of learning disability.

Epilepsy

Approximately thirty per cent of individuals with ASD have epilepsy. The prevalence of epilepsy increases with severity of Learning Disability.

Psychological Disorders

- Attention Deficit Disorder
- Schizophrenia
- Affective Disorders

Sleep Problems

Interventions

There is a limited evidence base in relation to potential interventions. This is further complicated by the fact that autism is, in effect, a final common pathway for disorders of diverse aetiology. Therefore there will inevitably be subgroups of individuals who are more responsive to specific interventions than others. While there is a consensus that making an early diagnosis and ensuring intensive multidisciplinary input to address

problems with communication, socialisations and adaptive behaviour is beneficial there remains relative paucity of high quality clinical studies to evaluate the relative effectiveness of the various models of intervention. Similarly there is a lack of evidence base in relation to the use of psychotropic medication to address the core features of autism. However should individuals within the autistic spectrum disorder develop new symptoms and behaviour suggestive of a recognised psychiatric or psychological disorder then this should be assessed and any appropriate treatment initiated.

References / Further Reading:

Mental Health Aspects of Autism and Asperger Syndrome. Ghaziuddin. Jessica Kingsley Publishers.

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www.nas.org.uk/

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PSYCHOTROPIC MEDICATION

The term Psychotropic Medication refers to any drug that is prescribed to stabilise or improve mood, mental status, or behaviour. Psychotropic medication may be prescribed for people with Learning Disability for a number of reasons. For example, treatment of clearly diagnosed Psychiatric Illness, Epilepsy or as sedation prior to stressful clinical procedures. However, the relatively widespread use of psychotropic medication to modify severe dysfunctional behaviour remains controversial. (See section on Challenging Behaviour).

Reasons for Prescribing

- Treatment of Mental Illness
- Treatment of Epilepsy
- Sedation prior to stressful clinical procedures
- Modification of severe dysfunctional behaviour

Short term

Long term

The use of newer psychotropic agents gives greater options for tailored prescribing taking into consideration the specific needs and vulnerabilities of individuals with Learning Disability. For example, the newer atypical antipsychotics have less of a tendency to cause extra pyramidal side effects, and SSRIs are less likely to reduce the seizure threshold compared to Tricyclic antidepressants. Similarly, the use of newer anticonvulsants offers comparable efficacy against seizures, but with less potential for sedation as compared to conventional agents. However, it must be acknowledged that

people with Learning Disability are often excluded from the clinical trials of new agents and the inevitable extrapolation of data derived from the general population is potentially flawed.

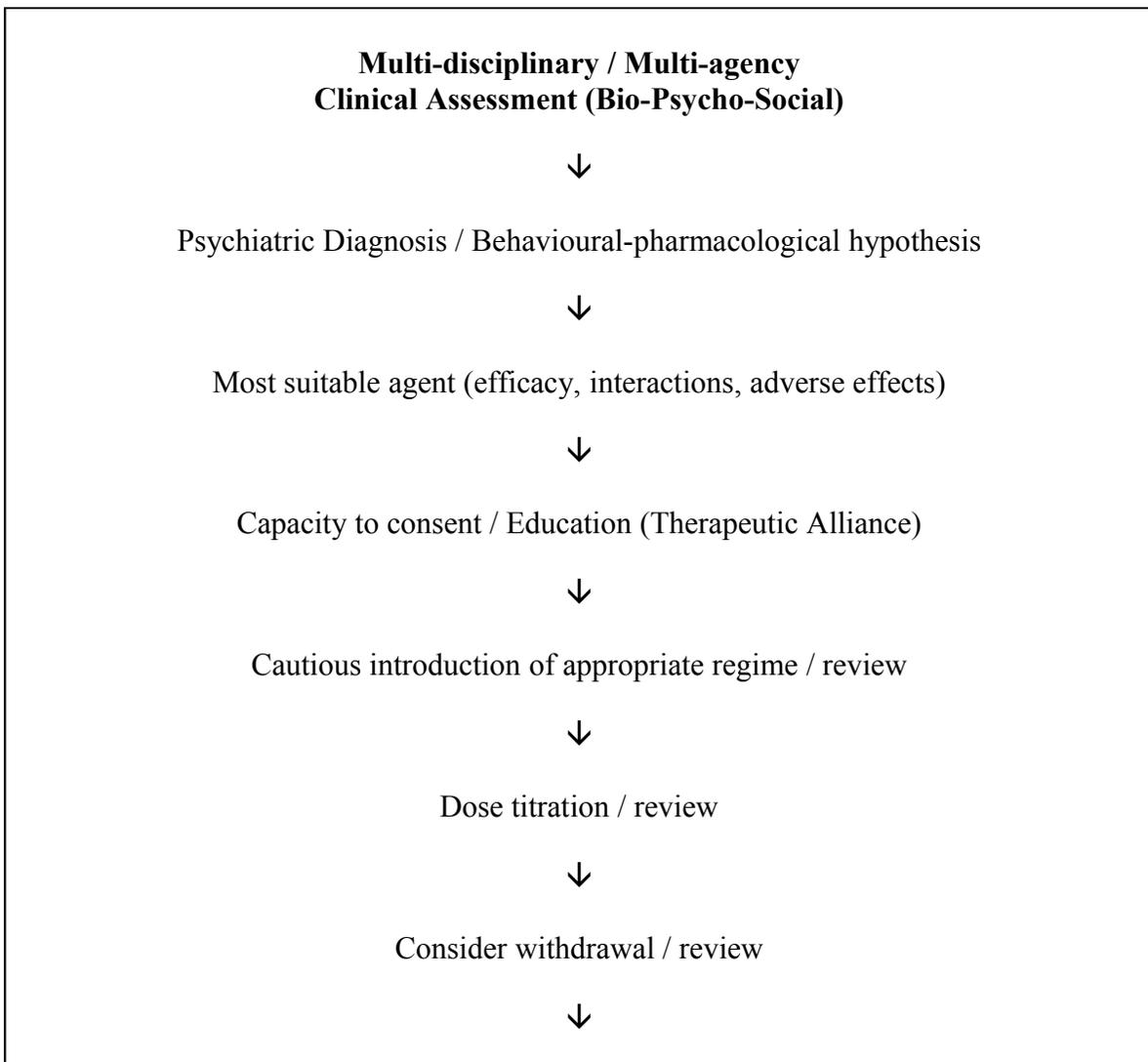
Specific risk factors for people with Learning Disability taking psychotropic medication include vulnerability to neurological side effects of which Cognitive Impairment and extra pyramidal side effects, especially Tardive Dyskinesia, are particularly relevant. It must be remembered that people with Learning Disability have inevitable difficulties advocating for their health and psychotropic medications once prescribed are often inadequately reviewed. It is also important to remember that individuals with Learning Disability often have complex health care needs and that medication prescribed for physical illness can often have potential psychological side effects. When reviewing the psychological side effects of medication it is important to consider any possibility of drug interaction, drug withdrawal and the potential use of “over the counter” medication, including herbal remedies. The use of illicit recreational drugs is less common in individuals with Learning Disability, but must not be automatically discounted.

An international consensus panel on psychopharmacology (Ohio 1995) produced guidelines for the use of psychotropic medication. They included the following recommendations:

- Psychotropic medication should not be used excessively, as punishment, for staff convenience, as substitute for meaningful psychosocial services, or in quantities that interfere with an individual’s quality of life.
- Psychotropic medication must be used within a co-ordinated multidisciplinary care plan designed to improve the individual’s quality of life.
- The use of psychotropic medication must be based on a psychiatric diagnosis or a specific behavioural / pharmacological hypothesis resulting from a full diagnosis and functional assessment.
- Appropriate consent must be obtained from the individual, if competent, or relevant legal advocate (if appropriate) before use and must be periodically reviewed.
- Specific index behaviours and quality of life outcomes should be objectively defined, quantified, and tracked ... in order to monitor psychotropic medication effectively.
- An individual must be monitored for side effects on a regular and systematic basis using accepted methodology including standardised assessment instruments.
- Psychotropic medication must be reviewed on a regular and systematic basis (including side effects) to determine if it is still necessary or, if it is, if the lowest “optimal effective dose” is prescribed.

- Psychotropic medication regimes should be as simple as possible in order to enhance compliance and minimise side effects.

In summary, the prescription of psychotropic medication in individuals with Learning Disability should be carried out on a systematic basis and tailored to the needs of the individual.



References / Further Reading:

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Einfield (2001). *Systematic management approach to pharmacotherapy for people with Learning Disability. Advances in Psychiatric Treatment. 7 (1), 43-49.*

Consent to Treatment or Examination and Capacity

It is the personal responsibility of any Doctor or Dentist proposing to treat a patient to determine whether the patient has the capacity to give valid consent. Valid consent requires that the patient voluntarily (i.e. without being subjected to coercion or unreasonable influence) agrees to the treatment and is capable of taking that decision.

The Mental Capacity Act (which is due to be introduced in April 2007) applies to adults who lack capacity and it enshrines in statute law a number of common law principles.

Common Law Principles

- The presumption of capacity
- The right for individuals to be supported to make their own decisions.
- The right to make eccentric or unwise decisions if they have capacity
- Best Interests – anything done for or on behalf of people without capacity must be in their best interests.
- Least restrictive option – anything done for or on behalf of someone lacking capacity should be the least restrictive of their basic human rights.

If it is suspected that someone lacks capacity for a particular decision then the capacity test must be applied. It is not anticipated that capacity assessment will necessarily be the remit of psychiatrists, but psychiatrists may have a role in providing an opinion as to whether an individual has the capacity to participate in making certain decisions. A person may be assessed as lacking capacity for a particular decision if at the time they are:

Factors indicating incapacity

- Unable to understand the information relevant to the decision.
- Unable to retain the information (long enough to reach a decision).
- Unable to use the information relevant to the decision as part of the process of making the decision.
- Unable to communicate the decision (by any means)

The degree of capacity required will depend upon the seriousness of the decision to be made. It is anticipated that anyone working with a person who they believe may lack capacity for a certain decision would apply the capacity. It is not anticipated that capacity assessment will be the remit of psychiatrists although there may be cases where a specialist opinion would need to be sought.

If the patient cannot give valid consent then it is the responsibility of the medical team to consult with family, donees of lasting power of attorney, court appointed deputies, anyone interested in the patients welfare (i.e. unpaid carers) or nominated by the patient or independent mental capacity advocates (in the case of those with no relatives/unpaid carers) to decide what will be in the patients best interests and whether this is the least restrictive option before signing the appropriate consent form.

Until April 2007 when the Mental Capacity Act comes into force, no one is legally entitled to give consent on behalf of an adult and if a learning disabled adult does not have the capacity to make a treatment decision, under common law, a decision must be made in the patients best interest. After April 2007, donees of lasting power of attorney, court appointed deputies, anyone engaged in caring for that person or interested in their welfare should be included in best interest decisions

The legal situation with regard to consent will change when the Capacity Bill is enacted in that someone with capacity may nominate another to take health, financial or welfare decisions on their behalf when they lose capacity in the future. For someone who lacks capacity the court of protection may nominate a deputy to take decisions on behalf of that person and there will be an expectation that those with an interest in the welfare of someone who lacks capacity will be included in any discussion of best interest actions on behalf of the incapacitated person. A provision widely welcomed by people with Learning Disability is the presumption of capacity which should reduce the frequency of people being defined as lacking capacity solely on the basis that they have a learning disability.

The Mental Capacity Bill applies to adults, the law remains the same in relation to minors (regardless of whether they have or don't have a Learning Disability).

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Current Services for People with a Learning Disability

The progressive closure of large Learning Disability institutions since the 1970's has coincided with the development of specialist multidisciplinary community Learning Disability teams (CTLD). These teams provide advice and support to people with Learning Disability, their families and carers.

COMPOSITION OF TYPICAL CTLD:

- Social workers
- Community (Learning Disability) nurses
- Occupational therapists
- Speech & language therapists
- Physiotherapists
- Learning Disability Psychiatrists
- Clinical Psychologists
- Support workers
- Administrative Support
- Others (e.g. Arts Therapists)

Much emphasis over recent years has been placed on 'care management' - an integrated process involving multidisciplinary working - as a process of organising and managing the care that an individual needs. Most health services for children with Learning Disability are provided by paediatric services in the UK. Some children may access child & adolescent mental health services, but provision across the UK is patchy, due to lack of resources and skills. Some specialist Learning Disability services provide a life-span service.

There is now a statutory recognition that people with Learning Disability have the same rights of access to general NHS health services as anyone else. People with Learning Disability should be supported to access generic health services as much as possible, and to access specialist health services as need be. Recent policy statements in the UK regarding services for people with a Learning Disability are largely based around the principles of human rights. The All Wales Strategy (1983) was at the forefront of the move towards more modern and enlightened services for people with Learning Disability.

ALL WALES MENTAL HANDICAP STRATEGY 1983: CORE VALUES:

People with a Learning Disability have a right to:

- live an 'ordinary' life in the community
- be treated as individuals
- receive support to achieve their maximum potential

These core values have been more recently re-iterated in policy documents such as 'Valuing People' (Department of Health 2001) and 'Fulfilling the Promises' (Welsh Learning Disability Advisory group 2002).

OTHER COMMON THEMES (VALUE-BASE):

- person-centred planning (with the person at the centre of decision-making regarding his / her care)
- information availability
- advocacy support
- ordinary housing and employment
- care-coordinators to co-ordinate and manage care
- support for carers
- accessing mainstream health and social services with support from specialist services as required
- better training for carers
- direct payment schemes (to allow individuals to plan / manage their own supports and care)
- multidisciplinary multi-agency care planning, involving users and carers.

In summary, the current focus for specialist health services for this patient group is based around the CTLD. Team staff may provide support to individuals in accessing mainstream NHS and social services. People with Learning Disability also have a right to access mainstream mental health inpatient services. In practice there can be considerable practical

barriers and much of this care is still provided by specialist Learning Disability services. Most areas in the UK have specialist Learning Disability assessment and treatment beds providing for acute psychiatric care when individuals cannot be safely or effectively cared for in their home environment. Some individuals presenting complex diagnostic or care needs may require the input of specialist tertiary services on a regional basis. There is also likely to be for the foreseeable future some residual provision of NHS continuing care beds particularly for those with high levels of mental health needs / challenging behaviour. However, currently, most people with Learning Disability who are in contact with services reside with their families, in family placement settings or in small community group homes.

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