

Learning Disabilities

By Liam Black (Physician Associate)

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Aims & Objectives

- What is a Learning Disability?
- Prevalence
- Causes / Risk factors
- Diagnosis
- Associated problems
- Management
- Health / Social inequalities
- Reasonable adjustments
- Q/A

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Definitions

Department of Health

'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' - Department of health

DSM-V - 'Intellectual Disability'

Refers to limited functioning in social, conceptual and practical skills

'Global Developmental Delay' (GDD)

A condition that occurs between birth - 18 years, which prevents a child from reaching key developmental milestones.

NOT 'Specific Learning Difficulties' (e.g. dyslexia) as these do not affect global cognitive functioning.

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Prevalence

UK - ~1.5 million people have a learning disability (~2% population)

Male > Female (3:2)

- Mild 85%
- Moderate 10%
- Severe - Profound 5%

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Causes / Risk Factors

Chromosomal /
Genetic disorders
– e.g. Down's syndrome

Non-genetic congenital
malformations

Prenatal exposures
– e.g. alcohol,
teratogens, infections

Birth complications
resulting in
hypoxic brain injury

Extreme prematurity

Childhood illness
– e.g. meningitis

Childhood brain injury

Childhood neglect and/or
lack of stimulation in
early life

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Diagnosis

01

Significant
impairment in
intellectual
functioning
(IQ <70)

02

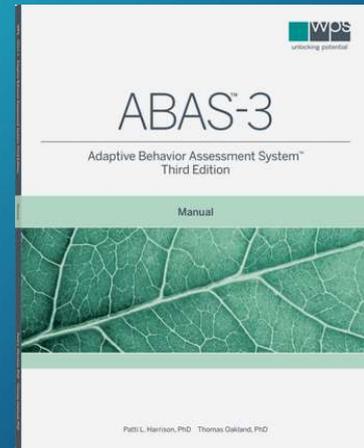
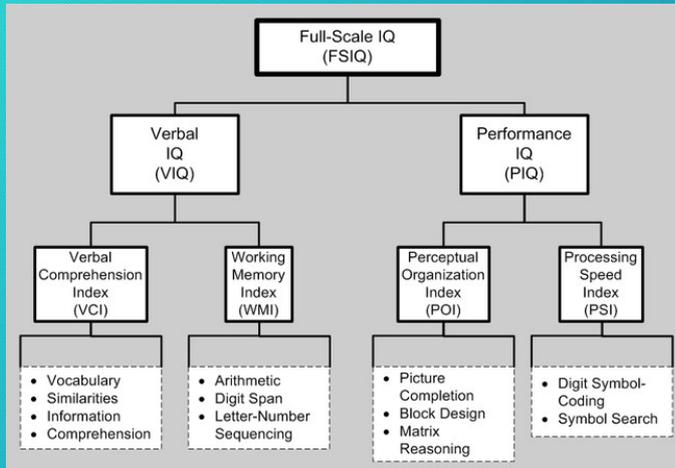
Significant
impairment in
social or adaptive
functioning

03

Onset in childhood
(<18 Years)

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Diagnostic process



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WHO: Classification of severity

Mild - IQ 50 - 69

Moderate - IQ 35-49

Severe - IQ 20 - 34

Profound - IQ <20

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Associated Physical Health Problems

- Epilepsy (x20)
- Sleep disorders
- Mobility difficulties
- Vision / hearing impairment
- Obesity / Malnourishment
- Dysphagia
- Aspiration pneumonia
- Congenital heart problems
- Dyspepsia, Constipation, GORD, Incontinence

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Associated Neurodevelopmental & Mental Health Disorders

- Autism
- ADHD
- Anxiety
- Depression
- Psychosis / Schizophrenia
- Personality disorders
- Dementia - early onset in people with Down's Syndrome
- Eating disorders

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When to consider a mental health problem?

- Loss of skills or requiring more prompting to use skills
- Social withdrawal
- Avoidance
- Irritability / Agitation
- Anhedonia

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Associated 'Behaviours of concern'

- Aggression - verbal / physical
- Self-injurious behaviour
- Stereotypic behaviour - e.g. rituals, compulsions, obsessions, perseveration, repetitive or stereotyped language
- Withdrawal
- Disruptive / destructive behaviour - e.g. violence, arson, sexual abuse (may lead to involvement with the criminal justice system)

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When assessing behaviours of concern...

Think bio-psycho-social!

- Physical health - e.g. toothache, seizures, constipation, infection, GORD
- Sleep problems
- Vision / hearing impairment
- Medication / adverse effects
- Mental health problems
- Communication difficulties
- Social / physical environment - e.g. change in staff or setting, recent life events, lack of meaningful activities

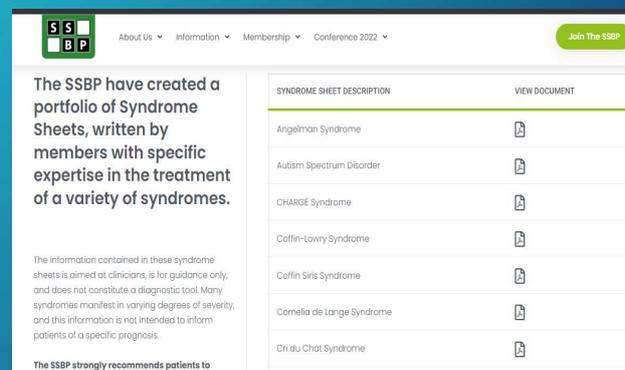
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Behavioural Phenotypes

“Patterns of behaviour that present in syndromes caused by chromosomal or genetic abnormalities.” (O'Brien, 2006)

e.g. people with Down's Syndrome

- Autistic traits (10-15%)
- ADHD traits (6%)
- Conduct / Oppositional disorder (5%)
- Aggressive behaviour (5%)



The SSBP have created a portfolio of Syndrome Sheets, written by members with specific expertise in the treatment of a variety of syndromes.

The information contained in these syndrome sheets is aimed at clinicians, is for guidance only, and does not constitute a diagnostic tool. Many syndromes manifest in varying degrees of severity, and this information is not intended to inform patients of a specific prognosis.

The SSBP strongly recommends patients to

SYNDROME SHEET DESCRIPTION	VIEW DOCUMENT
Angelman Syndrome	View Document
Autism Spectrum Disorder	View Document
CHARGE Syndrome	View Document
Coffin-Lowry Syndrome	View Document
Coffin-Siris Syndrome	View Document
Cornelia de Lange Syndrome	View Document
Chi du Chat Syndrome	View Document

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Associated Social Inequalities

- Living in rented, overcrowded or poor quality accommodation
- Physical, sexual, or emotional abuse
- Less social support
- Difficulties communicating
- Difficulties finding & maintaining relationships
- Difficulties finding employment / voluntary work

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Premature death & Learning disabilities mortality review (LeDeR)

By finding out more about why people died we can understand what needs to be changed to make a difference.

Anyone can report a death here -
<https://leder.nhs.uk/>

Median age of death for different levels of impairment



Source: University of Bristol North Ry Centre for Disability Studies, 2019

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Barriers to accessing healthcare services

- Lack of accessible transport links
- Lack of understanding about learning disabilities
- Failure to recognise that a person with a learning disability is unwell
- Failure to make a correct diagnosis
- Lack of confidence for people with a learning disability
- Lack of joint working from different care providers
- Not enough involvement allowed from carers
- Inadequate aftercare or follow-up care

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Reasonable Adjustments

Healthcare professionals have a **legal duty** to provide reasonable adjustments for disabled people (Public Health England, 2016).

A lack of reasonable adjustments can be a barrier to accessing healthcare settings and to equal healthcare (Ali *et al.*, 2013).

A confidential inquiry into premature deaths of people with learning disabilities (CIPOLD) showed the lack of reasonable adjustments provided to people with a learning disability (especially in accessing clinic appointments and investigations) as a contributory factor in a number of avoidable deaths.

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Communication Tips

- Always greet the person first and explain your role
- Explain what is going to happen during the consultation
- Ensure they know that the accompanying person can leave at any time
- CHUNK information together
- Regularly CHECK their understanding
- Explain any difficult or unfamiliar words
- Consider vision / hearing impairments
- Consider using gestures, visual prompts, practical demonstrations, alternative formats (based on patient preference)
- Review any communication reports prior to the appointment

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Easy Read

Coronavirus

Wash your hands more often

Coronavirus is a serious illness that can make you very ill.

The best way to not catch it is to wash your hands more often for 20 seconds.

Use soap and water or a hand sanitiser when you:

- Get home or into work
- Blow your nose, sneeze or cough
- Eat or touch food

Find out more at nhs.uk/coronavirus

 **PROTECT YOURSELF & OTHERS**

Why we wear PPE

Keeping everybody safe

Health workers may look different. They are wearing extra protection called PPE

- Face mask
- Face shield
- Gloves and gown

Don't be scared

- ✓ PPE helps nurses and doctors work safely.
- ✓ PPE helps stop the coronavirus spreading to other patients.
- ✓ Underneath it is still the same person caring for you.



Top tips for healthy pooing

Eat healthy foods with lots of fibre like fruit and vegetables.

Drink lots of water. Try and have 6 to 8 glasses of water a day.

Do exercise and move a lot.

How to sit on the toilet-

- Relax
- Put your feet on a box
- Lean forwards.



What to do if you are poorly or worried

Please tell someone if you are poorly or worried.

You can talk to family members and carers.

You can call your doctor.

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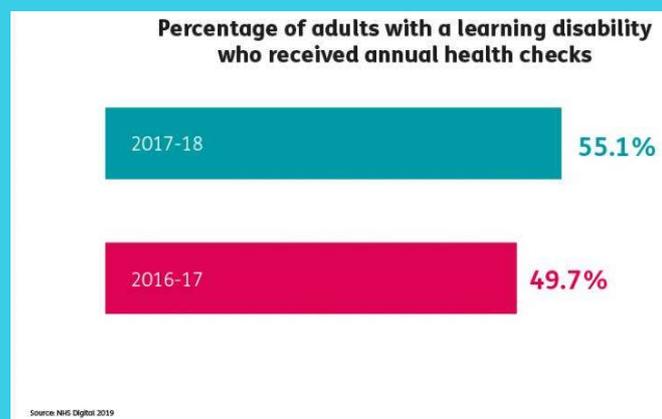
Greenlight Working



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Annual Health Checks

- Physical health review
- Mental health review
- Medication review
- Vaccinations up to date?
- Eligibility for national screening programmes?
- Specific syndrome-related reviews - e.g. dementia screen in down's syndrome
- Lifestyle advice
- Discuss age-related conditions and what to expect as they become older



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Stop Over-Medicating People with LD and/or Autism (STOMP)

Stopping Over-Medication of People with a Learning Disability, Autism or Both

(STOMP)

NHS
England

- Psychotropic medications include - antipsychotics, benzodiazepines, AEDs, mood stabilisers, antidepressants, hypnotics, stimulants and cognitive enhancers.
- Sometimes they are prescribed for 'behaviours of concern'
- They may be appropriate for some people to keep them safe and well.
- Always important to review non-pharmacological approaches before medication.

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Multidisciplinary Team

Learning disabilities service

- Psychiatrists, Physician associates, ACPs, Pharmacists
- Psychologists
- Learning disability nurses / support workers
- SALT
- Occupational therapists
- Physiotherapists
- Dieticians
- Therapy assistants

Close liaison with social care, primary care, other secondary care services and external third sector services.

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Transforming Care

- Winterbourne view hospital scandal
- PwLD and/or autism may sometimes need hospital care but hospitals are not where people should live.
- TC is a national programme aiming to transform services so that pwLD no longer live inappropriately in hospitals but are cared for in line with best practice, based on their individual needs, and that their wishes and those of their families are listened to and are at the heart of planning and delivering their care

(Department of Health, 2011)

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When assessing Mental Capacity

Consider

- Physical / mental health
- Communication needs
- Previous experience in making decisions
- Involvement of others and the possibility of undue influence, duress, or coercion
- Situational, social, and relational factors
- Cultural, ethnic, and religious factors
- Cognitive (including their awareness of their ability to make decisions), emotional, and behavioural factors
- Effects of medication / other substances

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Families & Carers

- Access to a carers assessment
- Register as carer with their GP
- Additional support / services
- Explain the transition from child to adult care
- Access to respite care
- Access to training - i.e. autism, behavioural management training
- Emergency / Crisis contact details
- Access to family advocacy
- How to raise safeguarding concerns or make a complaint

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Social Care

'Social care' can mean support that ranges from a few hours of a week to 24 hours per day depending upon their needs.

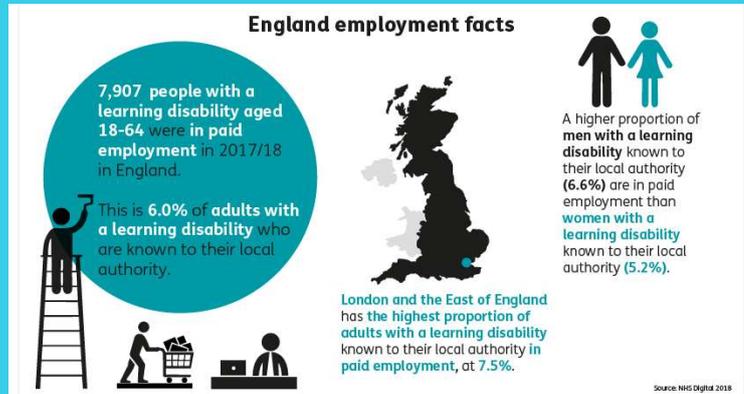
'Support' can be many things, including supporting somebody to get up and get dressed, to develop friendships and relationships, or to do meaningful activities and be part of their local community.

Government spending on social support in England

- Learning disability support (38%) - £5.5 billion
- Physical support (43%) - £6.2 billion
- Memory and cognition support (9%) - £1.3 billion
- Mental health support (9%) - £1.2 billion
- Sensory support (1%) - £0.16 billion

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Employment



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Questions?
Thoughts?
Comments?

Email: liam.black@shsc.nhs.uk

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Further information

- NHS England - <https://www.england.nhs.uk/learning-disabilities/>
- NICE CKS - <https://cks.nice.org.uk/topics/learning-disabilities/>
- NICE Guidance - <https://www.nice.org.uk/guidance/population-groups/people-with-learning-disabilities/products?GuidanceProgramme=guidelines>
- MENCAP - <https://www.mencap.org.uk/>
- BILD - <https://www.bild.org.uk/>
- STOMP - <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>
- Annual Health Checks - <https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/>