

# *Learning disabilities*

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# *Learning disabilities*

## Why highlight this group of people?

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There is considerable evidence that people with learning disabilities have a higher burden of illness than the general population and that, to an alarming degree, their health needs are not being met. It is also clear that regular health checks for this most vulnerable group can be both rewarding and challenging. Real opportunities exist to improve the mental and physical health of this group through early

identification of health problems to reduce future morbidity and mortality. It is estimated that 20–40% of people with learning disabilities also have emotional disorders (Gravestock & Bouras, 1997; Iverson & Fox, 1989). The broad term ‘emotional disorders’ is used to cover psychiatric illness, personality disorder, autistic spectrum disorder (autism) and behaviour problems.

# What is a learning disability?

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The term **learning disability** was adopted by the Department of Health in 1992. It has the same meaning as its predecessor **mental handicap** but is seen as more acceptable, particularly in reducing the confusion with mental illness. However, many service users prefer the term **learning difficulty**.

A person is identified as having a Learning disability if **all** of the following are present:

- ❑ A significantly reduced ability to understand new or complex information, to learn new skills (significantly impaired intelligence) and
- ❑ A reduced ability to cope independently (impaired social/adaptive functioning),
- ❑ Which started before adulthood (onset before 18 years), *and*, with a lasting effect on development

*(Valuing People, Department of Health, 2001)*

(More information on methods for identifying a Learning Disability is in Appendix 1.)

Learning disability may be 'significant' or 'severe' but these adjectives can only very generally suggest the level of disability. People with learning disabilities have many different talents, qualities, strengths and support needs. The approaches that work for the general population are equally effective with most people with a learning disability although most will need ideas communicated in ways that are easy to understand. It is only a minority who face major challenges in communicating their ideas and preferences.

# Why people with learning disabilities have increased psychological needs

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The emotional needs of people with learning disabilities are often overlooked; as in the case of physical illness, the label of being 'learning disabled' frequently overshadows emotional needs. Overall, the areas of psychological need are more similar than different to those of the wider population.

However, people with a learning disability are more likely to experience mental health problems as a result of:

- ❑ Loss and repeated separations
- ❑ Financial and social struggles
- ❑ Little control of their own environments and lives

- ❑ Poor coping skills
- ❑ Communication difficulties
- ❑ Predisposition to mental illness as a result of a particular syndrome
- ❑ Exploitation
- ❑ Family problems
- ❑ Poor relationships and interpersonal skills
- ❑ Low self-esteem
- ❑ Social isolation
- ❑ Societal prejudice

(see appendix for further info)

# Why needs are often not addressed/barriers to health care

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Mental health difficulties may be inadequately addressed in people with learning disabilities for a variety of reasons.

**Recognition of ill health** may be difficult or delayed because of

- ❑ Lack of health awareness on the part of people with learning disabilities.
- ❑ People may be less able to self-report or describe the way they are feeling.
- ❑ ‘Symptoms’ may present in ways that are different to other people as a result of communication or cognitive challenges.
- ❑ Symptoms may exaggerate pre-existing cognitive deficits and get put down to the learning disability.
- ❑ Symptoms such as aggression are obvious and may be brought to the attention of services. Symptoms that are equally significant (e.g. withdrawal, loss of interest) may go unnoticed or be recognised as a problem much less quickly.
- ❑ People with a learning disability or the people that support them may not have the skills and knowledge to obtain health care or to maintain health related behaviour.

**The way services operate** can unintentionally present barriers to good outcomes. Issues include:

- ❑ Physical barriers – e.g. wheelchair accessibility
- ❑ Administrative procedures – e.g. appointment time, waiting rooms
- ❑ Communication difficulties – e.g. professionals not adjusting the way they communicate.
- ❑ Attitudes of health professionals – e.g. lack of confidence, limited experience, negative attitudes and assumptions.
- ❑ Reluctance to consider and provide the same range of treatment options as for the rest of the population because of
  - the inability to see beyond the disability
  - Perceived difficulty obtaining consent
  - Assumptions and negative predictions about how patients might react or co-operate.
- ❑ National targets have been set by the Department of Health (Valuing People 2001) to address and improve health access and outcomes for people with learning disabilities. These include identifying Health Facilitators and developing individual Health Action Plans which are aimed at maintaining and improving the mental and physical health of the person with learning disabilities.

# What helps – recognising emotional disorders

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The presentation of an emotional disorder in an individual with learning disabilities will depend on his or her usual levels of cognitive, communicative, physical and social functioning, and usual behaviour, together with past and present inter-personal, cultural and environmental influences.

Generally the signs and symptoms of emotional disorders presented by adults with mild learning disabilities and reasonable communication skills are similar but less complex than those presented by adults with average intelligence. However, due to their less well developed cognitive and communication skills, as well as increased risks of physical impairments, adults with moderate and severe learning disabilities are more likely to exhibit disturbed behaviours or physical complaints as presentations of emotional disorders (Fraser & Nolan, 1994).

*Whether current behaviour/emotion/physical condition is different from the person's usual pattern is a key indicator of underlying problems.*

Behavioural problems constitute more than half of all referrals to specialist mental health services for people with learning disabilities. In such cases the possibility of an underlying mental illness is explored as well as the contributions of psychosocial factors such as grief, loss, conflict and adjustment difficulties. Due to interaction between biological and psychosocial factors a multidisciplinary approach is typical.

## What helps:

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### *Top 10 tips for consultations with people with learning disability*

#### **Tip one**

Alert reception staff to the needs of people with a learning disability. Let them know the names of individuals who might need longer appointments.

#### **Tip two:**

Some people with a learning disability cannot tolerate waiting in the waiting room. Alert all staff to their needs – can they wait somewhere else. Offer first appointment in surgery or speed through on arrival.

#### **Tip three:**

How do patients find their way around surgery? Are there any aids you could use to help people with learning disabilities – pictures of staff/big arrows/coloured maps etc.

#### **Tip four:**

Requests for home visits, particularly from learning disability homes, can sometimes be avoided if you can be flexible with appointment times. Sometimes limited staff and the demands of other residents make it difficult to attend during normal surgery times.

#### **Tip five:**

Speak to the person with learning disability first and only then check out with a carer if something is not clear. Involve the person with learning disability as much as possible.

#### **Tip six:**

Use language the client understands at a



simple level, use pictures and symbols. Try to check that the client has understood – ask them to explain in their own words if possible.

 **Tip seven:**

Think about the person's capacity to consent to any proposed intervention. Try to evaluate if you need to obtain the person's consent or if you are proceeding in the 'best interests' of the person.

 **Tip eight:**

Try to obtain as much accurate information about the condition as possible. Ask carers to record what is happening in a simple manner, e.g. Seizure frequency, behaviour, episode of pain etc. If in a home – ask to speak to staff who knows what is happening.

 **Tip nine:**

Try to remember health promotion advice that you would give routinely. There are leaflets about smoking/breast examination/alcohol use/cervical smears, for example, that are specifically, for people with learning disabilities

 **Tip ten:**

Include people with learning disability in all your "quality" initiatives e.g. Diabetes/CHD/asthma etc. Heart disease/hypothyroidism and osteoporosis are all under-diagnosed in people with learning disability.

With thanks to Abbotswood Road Surgery for these tips.

# Appendix 1: Identifying learning disabilities

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About 2% of people in the UK have learning disabilities. In Gloucestershire we estimate that there are between 11–13 thousand people with learning disabilities and statutory services are aware of about 5 thousand of this population.

A person is identified as having a learning disability if all of the following are present:

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- ❑ A significantly reduced ability to understand new or complex information, to learn new skills (significantly impaired intelligence) and
- ❑ A reduced ability to cope independently (impaired social/adaptive functioning),
- ❑ Which started before adulthood (onset before 18 years), *and*, with a lasting effect on development

To clarify the definition further, *the following people are not included* in the accepted definition of learning disability:

- ❑ People who develop an intellectual disability after the age of 18.
- ❑ People who suffer brain injury in accidents after the age of 18.
- ❑ People with complex medical conditions which affect their intellectual abilities and which develop after the age of 18 – for example, Huntington’s Chorea, Alzheimer’s Disease.
- ❑ People with some specific learning difficulties – for example, dyslexia, delayed speech and language development, and those with literacy problems.

## Methods used to identify a learning disability

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People are often referred for an IQ test to measure intelligence. A score of 69 or below is taken as indicative of a significant impairment of intellectual functioning. A score of 50 or below indicates a severe impairment.

However, having an IQ below 70 tells us a limited amount about somebody’s ability to cope (Whitaker, S., 2003) and IQ is not a particularly good predictor of the persons adaptive behaviour/social functioning. For this reason, there has been a major shift in emphasis away from measuring the psychological deficits residing within the person towards methods which focus on evaluating the social and environmental supports, which a person will need in order to achieve success in his or her specific environments.

It is absolutely essential when assessing the nature of persons’ abilities, or diagnosing a learning disability, to assess adaptive functioning separately.

## Requesting an assessment

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### *Before making a referral*

Diagnosis is a specialist task but before requesting assessment it should be checked that:

- ❑ difficulties existed prior to age 18 years
- ❑ and there is good reason to believe the person requires support with social functioning.

The need for ‘**Intermittent**’ or ‘**Limited**’ support indicates a *significant* impairment of adaptive/social functioning.

The need for ‘**Extensive**’ or ‘**Pervasive**’ support indicates a *severe* impairment of adaptive/social functioning.

These terms are defined below using the British Psychological Society Guidelines (2001).

- ❑ **Intermittent support:** The person requires support on an “as needed” basis. Characterised by episodic nature, person not always needing the support, or short-term supports needed during life-span transition (e.g. during a transition – job loss, moving home, illness).
- ❑ **Limited support:** The person needs support characterised by consistency over time. It may be time-limited but not of an intermittent nature. It may require fewer...[resources] than more intense levels of support

- ❑ **Extensive support:** The person needs support characterised by regular involvement (e.g. daily) in at least some environments (e.g. work, home) and is not time-limited

- ❑ **Pervasive support:** The person needs support characterised by consistency, high intensity, to be provided across environments, and having a potential life-sustaining nature.

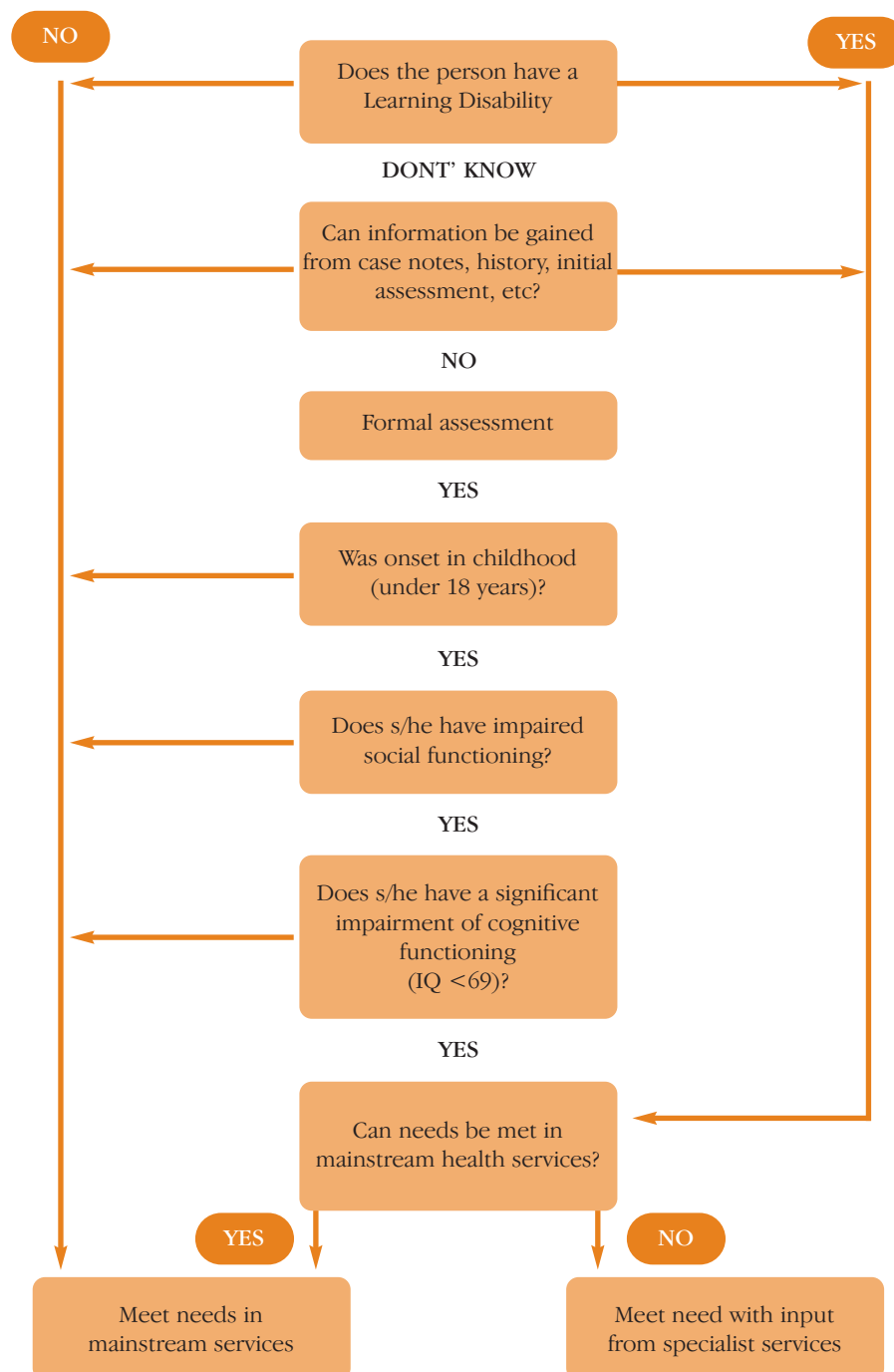
### *Making referrals*

Advice on whether to refer for specialist assessment can be obtained through the Health facilitation team.

Referrals for Specialist assessment should be made to the local Community Learning Disability Team.

# Decision making process for assessment, eligibility and need for specialist learning disability health services

## New Referral to CLDT



# Sources of support and information

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## The Health Facilitation Team for People with Learning Disabilities

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Kevin Elliott & Esia Dean  
Tel: 01452 525652 or  
e-mail 'Name'@glos.nhs.uk

## The Community Learning Disability Teams

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Cheltenham –	01242-272141
Cirencester –	01285-648530
Forest of Dean –	01594-827771
Gloucester –	01452 891363
Stroud –	01453-827161
Tewkesbury –	08454-223989

## Useful websites

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### *MENCAP*

Mencap is the UK's leading learning disability charity. It was formed in 1946 and works with people with a learning disability, their families and carers. They fight for equal rights, greater opportunities and challenge attitudes and prejudice and provide advice and support to meet people's needs throughout their lives. An interesting website with plenty of useful information. [www.mencap.org.uk](http://www.mencap.org.uk)

### *Valuing people support team website*

The Valuing People support team works across England and clearly shows you how to contact your regional advisor and gives you news and events from your region. This website gives

you up to date news, events and links to other useful websites and detailed information on topics they are currently covering. They also produce a monthly newsletter. Lots of information on papers, action plans etc. that the government are working on.

[www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)

### *National Autistic Society*

This is an extremely informative website with information about autism and Asperger syndrome. Providing information about the support and services available in the UK. The National Autistic Society now has a membership of over 12,000 people. The website has a variety of information from volunteering, jobs, news, publications and all the latest research being undertaken to up and coming events. [www.nas.org.uk](http://www.nas.org.uk)

### *Intellectual disabilities*

Useful for healthcare professionals, families, carers and anyone wishing to learn anything about intellectual disability. The site provides answers to frequently asked questions. It gives examples of families and their personal experiences. For the healthcare professionals there is a section on changing values and services and gives top ten tips for effective consultation amongst many other useful items. There are sections covering diagnosis, mental and physical health, complex disability and a 'how to' section which might be a good starting point for visitors to this website.

[www.intellectualdisability.info/home.htm](http://www.intellectualdisability.info/home.htm)

### *Contact a family*

Contact a Family is a national registered charity, founded in 1979, for families with disabled children and is the only UK charity

providing support and advice to parents whatever the medical condition of their child. Offering knowledge about rare disorders, a wealth of personal experience and plenty of useful contacts. There is also a helpful 'in your area' section which will tell you what is happening with Contact a Family near you. A very well structured website which lets you navigate your way around quickly. Lots more information to peruse. [www.cafamily.org.uk](http://www.cafamily.org.uk)

# References and further reading

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Russell, O. (1985) *Mental Handicap*. Edinburgh, Churchill Livingstone Publications.

Szymanski, L. (1994) *Mental retardation and mental health: concepts, aetiology and incidence*. In: Bouras, N., (ed.) *Mental Health and Mental Retardation*. Cambridge, Cambridge University Press.

'*Signpost for Success*' & '*Once a day*'  
Department of Health publications focusing on health needs of people with learning disabilities.

*Adults with Learning Disabilities: A Practical Approach for Health Professionals (1997)*  
J. O'Hara and A. Sperlinger (eds). Chichester, J. Wiley and Sons

*Valuing People: A New Strategy for Learning Disability for the 21st Century* – Department of Health

*Meeting the Health Care Needs of People who have a Learning Disability* – Thompson, J. and Pickering, S. (2001) Edinburgh Baillière Tindall

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