**INTRODUCTION**

**What is a learning disability?**
‘Learning disability’ is an umbrella term covering many different intellectual disabilities. It means that a person’s capacity to learn is affected and that they may not learn things as quickly as other people. Sometimes a learning disability is called a learning difficulty, intellectual impairment or intellectual disability.

A learning disability is not an illness. Some people with a learning disability also experience mental health problems such as depression, but they are not the same thing.

People usually have a learning disability from birth or sometimes from early childhood. Although it is a permanent condition, people with a learning disability can and do learn and develop with the right sorts of support from other people.

**How do learning disabilities vary?**
Learning disabilities are often categorised as mild, moderate or severe. People with a learning disability vary a great deal in the help they may need in meeting their basic needs. Some people may require help with washing and dressing for example, while many others will live quite independently with much less support.

Some people are described as having high individual support needs. They may have a profound learning disability, behaviour that is sometimes challenging, additional sight or hearing difficulties, autism, mental illness or many additional health problems.

**Including people with learning disabilities**
Categorising people with learning disabilities by measuring their IQ alone does not take into account how well they cope day to day or acknowledge their potential. People with learning disabilities often find it difficult to function independently in society and to communicate with other people. It is important to see someone with a learning disability as part of society and to consider what she or he needs from society so they are included. This may be particular kinds of support or positive social attitudes which enable them to reach their potential.

**Health needs of people with learning disabilities**
People with learning disabilities have higher levels of ill-health and much higher rates of premature death than the population as a whole. It is estimated that people with learning disabilities are 58 times more likely to die prematurely. People with learning disabilities have higher rates of obesity, coronary heart disease, respiratory disease, hearing impairment, dementia, osteoporosis and epilepsy. Some 26% of people with learning disabilities are admitted to hospital each year.
The evidence from a series of reports and inquiries, set out below, shows that the health service is not yet commissioning or providing services in ways that adequately meet these health needs. This contributes to preventable ill-health, poor quality of life and – at worst – premature deaths.

The toolkit has been developed to provide knowledge and support for NHS Lothian employees in relation to people with learning disabilities the documents have been colour coded into three sections.

Help and advice is also available from

Learning Disability Hospital Liaison Nurses
The NHS Lothian learning disability liaison nurse exists to promote access to hospital services for people with learning disabilities. They do this by directly supporting people, developing hospital and community systems, influencing strategies and policies and educating hospital staff. They work with any adult and child with a learning disability who requires additional support to access hospital services within NHS Lothian regardless of their geographic location. The Learning Disability Liaison Nurse can assist with:

- Co-ordination of care – at points of attendance, admission and discharge
- Education within clinical areas and contributing to programmes of education
- Support and advice for acute care staff in relation to personalised care and service delivery
- Collaboration between the agencies involved in service delivery to ensure effective seamless care by undertaking domiciliary home based visits.
- Development and enhance standards of care for all patients with a learning disability attending the acute hospital.
- Promotion of effective communication with those involved in the patient’s care – whether they are community or hospital based.
- Support of a relative or a family member with a learning disability who is affected by the patient’s illness/ hospital stay
- Promote safety and minimise risk
- Provide accessible information about treatments
- Promote positive experiences and outcomes
Community Learning Disability Services

Edinburgh City, East, Mid and West Lothian have eight Community Learning Disability Teams.

The learning disability multidisciplinary teams comprise of the following professionals:

- Community Nurses
- Speech & Language Therapist
- Clinical Psychologist
- Occupational Therapist
- Physiotherapist
- Dietitian
- Art Therapist
- Consultant Psychiatrist

The Community Learning Disability Service operates an open referral system and welcomes direct referrals. Referrals to members of the team can be made directly or through the Learning Disability Liaison Nurse.

Patients referred must have a definite diagnosis of a learning disability and they should also be in agreement with the referral.

The Service complements the work undertaken by primary care and does not seek to replace or duplicate this. Further information can be obtained from the Learning Disability Liaison Nurse.

Areas of work undertaken include:

- Assessment of health care needs
- Advice on management and control of epilepsy
- Management and support for people with mental health needs
- Management and support for people presenting with challenging behaviour
The Community Learning Disability Service is organised into geographical teams. Not all members of the team are permanently located at these bases but initial contact can be made through the team administrators.

### Edinburgh CHP

<table>
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<tr>
<th>NW LHP</th>
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<tr>
<td>T : 537 4261</td>
<td>T : 536 6257</td>
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<tr>
<td>F : 537 4201</td>
<td>F : 536 6260</td>
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<tr>
<td>Pennywell Resource Centre 31-35 Pennywell Road Edinburgh EH4 4P</td>
<td>Leith CTC Junction Place Edinburgh EH6 5JQ</td>
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<tr>
<td>T : 537 7006</td>
<td>T : 536 0532</td>
<td>T : 672 9500</td>
</tr>
<tr>
<td>Sighthill Health Centre 380 Calder Road Edinburgh EH11 4AU</td>
<td>Forteviot 16 Hope Terrace Edinburgh EH9 2AR</td>
<td>Gracemount MC 24 Gracemount Drive Edinburgh EH16 6RN</td>
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<th>Midlothian CHP</th>
<th>East Lothian CHP</th>
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<tr>
<td>T : 01506 433384</td>
<td>T : 537 9924</td>
<td>T : 536 8542</td>
</tr>
<tr>
<td>Suite 4, Shiel House Shiel Place Livingston EH54 5EH</td>
<td>Bonnyrigg Health Centre Quarry Head 109-111 High Street Bonnyrigg EH19 2ET</td>
<td>Dunpender Herdmanflat Hospital Aberlady Road Haddington EH41 3BU</td>
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### Acute Hospital Liaison

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<th>St. John’s / RHSC</th>
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<td>T : 537 4220</td>
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[Map showing geographical areas and contact details.]
The use of mental health and adults with incapacity law in general hospitals

The Mental Health (Care and Treatment) (Scotland) Act 2003 came into effect in October 2005. This sets out the law on the treatment of people with mental illness, learning disability or personality disorder (termed ‘mental disorder’). The Act defines when and how a person with a mental disorder
• can be given compulsory treatment
• can be detained in hospital

The Adults with Incapacity (Scotland) Act 2000 defines how essential decisions, affecting the lives of those with a mental illness, learning disability or dementia, can be made. The Act sets out the arrangements for the
• Giving of medical treatment
• Granting of intervention orders which allow individual decisions to be made on behalf of the person
• Appointment of welfare and financial guardians, who have the authority to make decisions on behalf of a person

Guidance to help mental health practitioners interpret the legal basis for treatment and to give treatment that is in line with best legal and ethical practice [2006]
http://www.mwcscot.org.uk/web/FILES/Publications/Consent_to_Treatment.pdf

Authorizing significant interventions for adults who lack capacity original guidance on the use of the Adults with Incapacity Act by Hilary Patrick, this should only be used in conjunction with the 2006 edition. [2004]
http://www.mwcscot.org.uk/web/FILES/Adults_who_lack_Capacity.pdf

A legal and practical guide - this guidance responds to cases and research evidence that identifies this is an issue for those using and providing mental health and learning disability services in Scotland. The guidance suggests that there may be situations in which covert medication might be necessary to keep an individual from harm. A Covert medication care pathway (.doc) and review (.doc) is provided to support decision making, that is structured and recorded in a way that safeguards that the health, safety and legal rights of the individual. [2006]
http://www.mwcscot.org.uk/web/FILES/Publications/Covert_Medication.pdf
The use of mental health and adults with incapacity law in general hospitals
http://www.mwcscot.org.uk/web/FILES/Publications/Information_for_general_hospitals_%28v2%29.doc

Good practice guidance on how to balance the principle of carer involvement with the patient's right to confidentiality. [2006]
http://www.mwcscot.org.uk/web/FILES/Publications/Carers_Confidential.pdf

Communication and Assessing Capacity A guide for social work and health care. This guide has been produced to support professionals in assessing the capacity of individuals who may come under protection of the Adults with Incapacity (Scotland) Act 2000

Adult Support and Protection
An Act of the Scottish Parliament to make provision for the purposes of protecting adults from harm; to require the establishment of committees with functions relating to the safeguarding of adults who are at risk of harm;

Better Health, Better Care: Action Plan
This Action Plan sets out the Government's programme to deliver a healthier Scotland by helping people to sustain and improve their health, especially in disadvantaged communities, ensuring better, local and faster access to health care. The report is informed by the response to the consultation on Better Health, Better Care: A Discussion Document (August 2007).

Disability Rights Commission Scotland Disability Equality Duty - 45,000 public bodies across Great Britain are covered by the Disability Equality Duty (DED), which came into force in December 2006. The DED is meant to ensure that all public bodies - such as central or local government, schools, health trusts or emergency services – pay 'due regard' to the promotion of equality for disabled people in every area of their work.

The Disability Rights Commission (DRC) produced a range of information on the duty, some of which is available. The DRC closed at the end of September 2007, and was replaced in October 2007 by the Equality and Human Rights Commission.

For introductory information, including the Code of Practice, and guidance on key elements of the duty, such as involving disabled people and impact assessments, see below.
http://www.dotheduty.org/
Getting It Right Together (2005)
Learning how to confidently meet the healthcare needs of people with learning disabilities. Nursing and midwifery practitioners in Scotland will benefit from this learning resource. The material will help increase knowledge and confidence when working with people with learning disabilities and responding to their health care needs.

Learning units
http://www.nhshealthquality.org/nhsqis/files/GIRT_Unit%201.pdf
http://www.nhshealthquality.org/nhsqis/files/GIRT_Unit%203.pdf
http://www.nhshealthquality.org/nhsqis/files/GIRT_Unit%204.pdf

Support material
http://www.nhshealthquality.org/nhsqis/files/GIRT_Self%20Assessment%20for%20resource%20user.pdf
http://www.nhshealthquality.org/nhsqis/files/JustOrdinaryPeople.wmv

The Health Needs Assessment was undertaken in response to the first recommendation of Promoting Health, Supporting Inclusion: The National Review of the Contribution of All Nurses and Midwives to the Care and Support of People with Learning Disabilities.

NHS Quality Improvement Scotland (NHS QIS) was set up by the Scottish Parliament in 2003 to take the lead in improving the quality of care and treatment delivered by NHS Scotland. The purpose of NHS QIS is to improve the quality of healthcare in Scotland by setting standards and monitoring performance, and by providing NHS Scotland with advice, guidance and support on effective clinical practice and service improvements.

This document contains the revised Quality Indicators for Learning Disabilities. These quality indicators were first published in May 2000 and have been used to assess the quality of health services available to children and adults with learning disabilities in Scotland. Subsequently, there have been a number of developments in both policy and legislation relevant to the needs of children and adults with learning disabilities, and the quality indicators have been revised to reflect these.
http://www.nhshealthquality.org/nhsqis/files/Learning%20Disability%20Quality%20Indicators.pdf
Tackling Indifference is a national overview for healthcare services for people with learning disabilities. It is based on the NHS QIS local report for each NHS Board area, and reports on the performance across Scotland against the learning disabilities quality indicators 2 (Promoting Inclusion and Wellbeing) and 3 (Meeting General Healthcare Needs). This overview, together with supporting information.

Promoting Health Supporting Inclusion (2001)
National Nursing Review of the contributions required from all nurses and midwives to meet the health needs of children and adults with learning disabilities, to improve health and support inclusion.

Tackling health inequalities
Equally well report of the Ministerial Task Force on health inequalities. The report brings together thinking on poverty, lack of employment, children’s lives and support for families and physical and social environments, as well as on health and wellbeing.

The same as you?
A review of services for people with learning disabilities.

An Ordinary Death - Update about the service needs of people with learning disabilities who are dying.  
[Update_An Ordinary Death.pdf]

Background - health campaigns - Background to Mencap's local health campaigns pack.  
Download publication (PDF, 35.49 Kb)

Death by indifference - Report about institutional discrimination within the NHS, and people with a learning disability getting poor healthcare.  
Download publication (PDF, 1.69 Mb)

Roddy Donnet FAI [2007]  
Fatal accident enquiry into the sudden death of a man with a learning disability.  
[http://www.scotcourts.gov.uk/opinions/donnet.html]

[http://www.scotcourts.gov.uk/opinions/cb12_02.html]

No ordinary life - A report revealing a shocking lack of support for the parents of children and adults with profound and multiple learning disabilities.  
Download publication (PDF, 164.16 Kb)

Six lives: the provision of public services to people with learning disabilities  
Second report (Session 2008-09)

Contents

Part 1: overview and summary investigation reports (PDF 541KB) (HTML)  
Part 2: the complaint made by Mr Allan Cannon and Mrs Anne Handley (PDF 838KB)  
Part 3: the complaint made by Mr and Mrs Cox (PDF 447KB)  
Part 4: the complaint made by Mrs Jane Kemp (PDF 605KB)  
Part 5: the complaint made by Mrs Iris Keohane in relation to her late brother,  
Mr Edward Hughes (PDF 718KB)  
Part 6: the complaint made by Mrs Vera Ryan (PDF 479KB)  
Part 7: the complaint made by Mr and Mrs Wakefield (PDF 761KB)  

.Treat me right!  
Campaigning report calling for better healthcare for people with a learning disability.  
Download publication (PDF, 748.25 Kb)
Accessible information on health conditions and treatments in audio, video and printed formats.
http://www.easyhealth.org.uk/

Advice for hospitals and health professionals
Short page of tips for healthcare professionals when treating people with a learning disability.
Download publication (PDF, 27.29 Kb)

All About Autistic Spectrum Disorders
A booklet written primarily for parents, carers and other family members when a child has been diagnosed as having an autistic spectrum disorder. It will also be of interest to those who are professionally involved, such as teachers, GPs, speech and language therapists and health visitors. This booklet gives information on some of the most common questions, suggests further publications and gives the details of useful organisations.
all_about_autism.pdf - 254 KB all_about_autism.pdf

Communicating with people with a learning disability:
A guide to communicating with people with a learning disability, including tips on how to be a better communicator and how to support others to communicate.
Download publication (PDF, 392.04 Kb)

Communicating with people with PMLD: a guide
An introduction to communicating with people with profound and multiple learning disabilities (PMLD) including examples of some non-formal communication methods.
Download publication (PDF, 230.09 Kb)

Where to get more help with communication
Clear for All
www.clearforall.co.uk

www.mencap.org.uk

www.saifscotland.org.uk
www.rnib.org.uk
Disdat - general information
This is a distress assessment tool designed by St Oswold's Hospice. It is designed to help health professionals identify distress cues in people who because of cognitive impairment or physical illness have severely limited communication.
Download publication (PDF, 79.17 Kb)

Disdat monitor sheets
Disdat tool - monitor sheets
Download publication (PDF, 111.72 Kb)

Disdat tool
This is a distress assessment tool designed by St Oswold's Hospice. It is designed to help health professionals identify distress cues in people who because of cognitive impairment or physical illness have severely limited communication.
Download publication (PDF, 80.24 Kb)

End of life care - best practice guide
A best practice guide to end-of-life care for people with a learning disability.
Download publication (PDF, 1.33 Mb)

End of life care: key messages
The 12 main messages for ensuring all people with a learning disability receive inclusive end-of-life care services.
Download publication (PDF, 152.02 Kb)

Getting it right
A best practice guide for healthcare professionals.
Download publication (PDF, 261.63 Kb)

Guidance for nursing staff (Royal College of nursing)
A 20 page guide to support nurses treating people with a learning disability.
Download publication (PDF, 1 Mb)

The hospital communication book
Developed with the Surrey Learning Disability Partnership Board, this is a practical guide to help people who have difficulty communicating get an equal service in hospital.
Download publication (PDF, 2.69 Mb)

Working Together:
Easy steps to improving how people with a learning disability are supported when in hospital
Useful and related publications

www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf

Commissioning Specialist Adult Learning Disability Services: Good Practice Guidance, department of Health (2007)
www.dh.gov.uk/en/Publicationsandstatistics/Publications/

Good practice in learning disability nursing, department of Health (2007)
www.dh.gov.uk/en/Publicationsandstatistics/Publications/

www.dh.gov.uk/en/Publicationsandstatistics/Publications/

Information prescriptions
www.dh.gov.uk/en/Healthcare/Patientchoice/choice/

Better Information choices Health/Informationprescriptions/index.htm
Common core principles to support self care: a guide to support implementation, department of Health (2008)
www.dh.gov.uk/en/Publicationsandstatistics/Publications/

Long-term conditions

Better Health, Better Metrics
As part of the better Metrics project, the Foundation for People with learning disabilities published a commissioning Note for PcTs to support better commissioning for health
www.learningdisabilities.org.uk/our-work/improving-service/betterhealth

Health Action Planning and Health Facilitation for people with learning disabilities: good practice
World class commissioning for the health and wellbeing of people with learning disabilities
Recent inquiries have demonstrated the health inequalities faced by people with learning disabilities; and the reasonable adjustments needed to overcome them. This is a practical guide to support commissioners to meet the needs of this group, and ensure they are fulfilling their duty to promote equality.

Download World class commissioning for the health and wellbeing (PDF, 1048K)


Leaflets

Getting older
Down’s Syndrome Scotland
On web: www.dsscotland.org.uk/publications

Let’s talk about getting older
Down’s Syndrome Scotland
On web: www.dsscotland.org.uk/publications

Let’s talk about death
Coping with Loss
Down’s Syndrome Scotland

On web: www.dsscotland.org.uk/publications

Keep Yourself Healthy

A guide to examining your breasts
Fair, Health Education Board Scotland
On website: www.hebs.com

Confidentiality - your rights

Consent - it's your decision

Consent - your rights
How you should be involved in decisions about your health care and Treatment.
(This is a guide for under 16s).
Confidentiality - your rights
How the health service keeps information about you private.
(This is a guide for under 16s).

Websites

Advocacy organisation managed by Enable providing advocacy services to people with learning disabilities living in West Lothian.

ACE Advocacy http://www.enable.org.uk/

Action Group (for Children and Adults with Learning Disabilities and their carers)

Local organisation which campaigns for, and provides community services for people with learning disabilities and their carers in Edinburgh. Services include support and leisure activities, supported housing, care at home services, and supported employment ('Real Jobs') projects, welfare rights and advice.

http://www.actiongroup.org/

Capability Scotland
National charity providing a diverse range of services including community living, day and residential services, employment, respite/short breaks, therapy, education and learning, family support and activities to disabled people of all ages in Scotland.

Children Activities
Education & Learning - Children Respite/Short Breaks - Family Support

Adults Community Living Services - Day Services - Employment Development Services - Residential Services - Adult Respite/Short Breaks
http://www.capability-scotland.org.uk/

Detailed below are some useful references for further reading


Emerson E., Azmi S., Hatton C., Caine A., Parrott R. & Wolstenholme J. (19997) Is there an increased prevalence of severe learning disabilities among British Asians? *Ethnicity and Health* 1 (2) 317 321


Hutchinson C (2005) Addressing issues related to adult patients who lack capacity to give consent. *Nursing Standard* 16, 47–53.


