Bristol Community Learning Difficulties Service

Directed Enhanced Service Training

NHS Bristol

Information Pack

NHS
Bristol Community Health

Training Pack coordinated by Simon Jones QN RNLD
Deputy Service Manager
Bristol Community Learning Difficulty Teams 0117 9585666
with thanks to BILD and additional contributions from services users, practitioners and Kim Scarborough from the University of the West of England (UWE)

Contents

Themed Alphabetical Resources List

Introduction

This training pack was commissioned from the British Institute of Learning disabilities (BILD) by Health Facilitators in Staffordshire and Stoke. It has been made available to Bristol Community Learning Disability Service via Valuing People and has been updated and adapted to meet our local needs.

Aims of the information pack and the training sessions

1. To raise awareness and to improve access to Primary Health Care for people with learning disabilities

2. To help participants explore and enhance their knowledge and working practices in meeting the healthcare needs of people with a learning difficulty

3. To build stronger links between service users, carers and health professionals involved in the care of people with a learning difficulty

4. To indicate where accessible resources might be found

CLDT contact details

Bristol North Community Learning Disability Team
(Brentry) 0117 9085000

Bristol Central Community Learning Disability Team
(Stapleton) 0117 9585666

Bristol South Team Community Learning Disability Team
(Withywood) 0117 9878383

Bristol Intensive Response Team via the above teams.

We have an open referral system and a referral form is on our Website:
http://www.bristollearningdifficulties.nhs.uk

Rationale for the DES

Healthcare for All RECOMMENDATION 8

'The Department of Health should direct PCTs to secure general health services that make 'reasonable adjustments' for people with learning disabilities through a DES. In particular, … regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working.' (Michael 2008)

Health Inequalities experience by people with learning disabilities

Great difficulty and barriers in accessing all aspects of Healthcare (Michael 2008)

2.5x more likely to have a physical condition that needs medical intervention
Lack of early intervention/detection
4 times more likely to die of a preventable cause
58 times more likely to die before the age of 50 (Hollins et al 1998)

Health checks are effective

Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial.

- Six-fold increase in the detection of visual impairments
- Thirty-fold increase in hearing testing
- Increase in immunisation updates
- Improvement in women's health screening (Lennox et al 2007)

Previously unidentified, and therefore untreated, morbidity in patients with intellectual disability identified during screening by Baxter et al (2006)

- Diabetes
- Hypertension
- High cholesterol
- Thyroid disorders
- Dental problems
- Cardiac difficulties
- Asthma
- Mental health difficulties

Cooper et al (2006) monitored 100 people with learning disabilities for a year; half received health checks, half did not. They found an average of 4.8 new conditions in the health check group compared to 2.4 conditions amongst control group (240 conditions versus 113 in total).

Diagnostic Overshadowing

When a person presents with a new behaviour or existing behaviours escalate, you should not assume the behaviour is linked to the person's learning disability as behaviour change is often an individual's way to communicate health or life changes that are negatively impacting on them. You should consider possible physical problems such as pain or discomfort, e.g. from ear infection, toothache, constipation, reflux oesophagitis, deterioration in vision or hearing. Also consider psychiatric causes such as depression, anxiety, psychosis and dementia and social causes which might include changes in carers, bereavement or abuse.

Disability Rights Act 1995

It is a legal requirement not to treat people with a disability less favourably than other members of the public but maintain equality of access to your services. To ensure equality may mean treating some people differently, examples are giving longer appointments, accessible health materials and adapting how you communicate verbally with the individual. It is a legal requirement to make "reasonable adjustments" which are often about practices and procedures rather than simply physical access.

What is a Learning Disability?

Learning disabilities means a significantly reduced ability to understand new or complex information, to learning new skills (impaired intellectual functioning). This includes a reduced ability to cope independently (impairment of adaptive/social functioning) which started before adulthood and has a lasting effect on development (Valuing People 2001 DH pg 14-15).

The cause of a person's learning disability is not always known however commonly known causes include prenatal e.g. chromosome, genetics, toxins; perinatal, e.g. birth complications, infections and post natal e.g. infections, trauma including non-accidental injury. There are conditions associated with learning disabilities including Cerebral Palsy, Downs Syndrome, Prader-Willi Syndrome, Fragile X, Tubular Sclerosis, Phenylketonuria (PKU).

The WHO identifies levels of disability in the ICD10 as

Mild – IQ between 50 and 70
Moderate IQ – 55- 69
Severe and Profound Learning Disability IQ – below - 55

Valuing people (DH 2001c) stresses that IQ of 70 or below cannot be used in isolation in determining the provision of specialist health and social care. How the person is functioning in their environment needs to be understood.

Medical / Social Model

People with learning difficulties think it is important that professionals understand that society disables people and the Health Trainers in Bristol, who have learning disabilities say

> "We would just like to say on behalf of the health trainers that we do not agree with the description of what WHO and Valuing People says a learning difficulty is. We feel that this medical model, talking about our deficits is insulting to us. Our learning difficulties are not the reason we are not able to take part in society. We actually believe in the social model of disability. For example, being deaf or having a learning difficulty does not exclude us from society. The barriers in society stop us from being included. If our access needs are met we will be as important as everyone else in society and as included as everyone else."
>
> Tracy Hyde, Robert Absalom, Beth Richards 2008

To work within a social model health practitioners can identify and remove barriers to their services and identify methods of working that are inclusive, this should include improving communication skills and having accessible health information so people can be supported to make health choices and decisions.

How many people have Learning Disabilities

National Prevalence of learning disabilities is estimated by the Foundation of People with Learning Disabilities as 2-3% of the population. This means that there are approximately 210,000 people with severe & profound learning disabilities, and 1.2 million people with mild to moderate learning disabilities. It is estimated that this accounts for 25 per 1000 of the population. So how many people with learning disabilities might be accessing your service? A GP surgery with 4000 patients is likely to have 100 people with learning disabilities. Have you identified them all?

How to identify if a person <u>may</u> have a Learning Disability

Firstly you can explore the person's communication skills and understanding. Ask them about the persons Daily Living Skills, do they need help with activities of living and simple domestic tasks. Discuss the person's history, think about education as well as medical history, for example did the person access special or mainstream school? Question what, if any, services, accommodation or support they use, day support, Aspects and Milestones, Key-ring, Supported Living, People First, independent budgets and CLDT are words to listen for as it might indicate a learning disability. If you believe an individual has a learning disability you can contact the CLDT for an assessment.

Common health needs

Common Health Problems

- Respiratory Disease
- Coronary Heart Disease
- Sensory Impairments
- Epilepsy
- Dysphagia
- Helicobacter pylori
- Gastrointestinal Cancer

Dementia

The incidence of dementia is much higher in people with a learning difficulty (especially Downs Syndrome) than within in the general population. Down's Syndrome dementia incidence rises with increasing age and rates vary: Average onset is in the 54th year with 2% of individuals developing dementia aged 30 - 39 years and 55% developing dementia aged 60 - 69 years (Prasher 1995).

Medical conditions associated with causes of learning disabilities - for further list visit 'into the mainstream' website

Down's syndrome-

- Hypothyroidism
- Visual & hearing impairment
- Reoccurring respiratory tract infections
- Sleep apnoea
- Obesity
- Skin disorders
- Dementia
- Depression
- Congenital heart disease
- Low blood pressure and higher MCV

Fragile X Syndrome

- Recurrent otitis media
- Myopia and 'lazy eye'
- Flat feet, joint laxity
- Epilepsy (20% in men)
- GORD
- ADHD in childhood and adolescence
- Autism

Phenylketonuria (PKU)

- Weight loss
- Poor wound healing or bed sores
- Osteoporosis
- Hair loss
- Depressive episodes
- Anxiety
- over activity

Tuberous Sclerosis-

- Epilepsy
- Problem behaviours
- Skin Lesions
- Hypertension
- Renal Lesions
- Polycystic kidney disease
- Pulmonary complications

Prader-Willi Syndrome

- Obesity
- Problem behaviours
- Pain threshold
- Depressive episodes with psychotic symptoms

Community Learning Disability Teams (CLDTs)

The CLDT is a group of professional staff from Bristol Primary Care Trust's provider function "Bristol Community Health" (BCH) who provide assessment, support, advice and therapeutic interventions to people who have learning difficulties. We are co-located with Bristol's City Council's, Health and Social Care, Learning Difficulty Teams.

CLDT Eligibility Criteria

In order to establish if a person has a Learning Disability it is essential to refer to the CLDT who will use all or some of the following tools to screen for learning disabilities:-

- ISACA (Initial Screening Assessment Checklist for Adults)
- Psychology Assessments
- Occupational Health assessments
- Speech & Language assessments

Composition of the CLDT

CLDT

- Community Learning Disabilities Nurses
- Psychologists
- Speech & Language Therapists
- Occupational Therapists
- Physiotherapists
- Music Therapists
- Art Therapists
- Drama Therapist
- Dietician
- Bristol Intensive Response Team (BIRT)
- Psychiatrist
- Social Workers
- Administrative and Team Support

Linked to CLDT

- Heath facilitators
- Health trainers
- Hospital liaison nurses
- Transition nurses
- Forensic nurses
- Court liaison nurses

Links to other services

- Lansdowne (AWP)
- Placement crisis Concord House (BCC)
- Independent sector
  - Brandon
  - Aspects and Milestones
  - Shaw
  - Mencap and others

Communication needs

- Communication problems are probably the most significant barrier to services
- Many service users are able to conceal communication and understanding problems
- Please don't assume that if a person is agreeing with you they know what you are talking about!
- People often want to please you by saying what they think you want to hear

Top Tips for Communication

- Use accessible letters to invite people for appointments
- Find out if a reminder before a visit would help people remember to attend the surgery
- Speak directly to the person with learning difficulties
- Take your time – extra time may be needed
- Get advice from the carers regarding how to communicate with a person
- Arrange to have a quiet environment with not too many distractions
- Get the persons attention e.g. use their name / make eye contact
- Use everyday words e.g. heart rather than cardiac
- Use short sentences covering one topic
- Try to avoid questions/statements that the person can simple agree with (as sometimes people will give the answer they think you want.)
- Use clear direct questions e.g. Does this hurt?
- Use pictures or objects and gestures to back up what you are saying
- Some procedures can be demonstrated on the carer first e.g. taking blood pressure, using a stethoscope
- Clarify whether the person has understood by asking them to feedback what you have said so as to test their understanding
- Some people may not remember information about their medication/treatment. Simple written information that they can look at or share with carers may help them remember their appointment with you
- Record communication needs in persons notes
- Learn essentials for any Alternative and Augmentative Communication systems your patients use
- Talk to individual and include carers
- Have pre–prepared
    - Accessible leaflets
    - Pictures to help describe things
    - Objects to help promote understanding
    - DVDs can be very good as well

Consent

Essential facts

- It is a criminal offence to treat a person who has not consented
- No-one can give consent on behalf of another adult
- It must be assumed that a person can give consent i.e. make their own decisions unless proven otherwise
- It is the responsibility of the treatment provider to make a decision about the person's capacity to consent to treatment

Consent

- Everything possible must be done to help someone make their own decision
- If it is decided that someone is unable to make a particular decision, it does not stop that person making other decisions
- Decisions can legally be made for someone thought to lack capacity by: -
  - Those involved in the care and treatment of the person (within the framework of a best interests multi disciplinary meeting)
  - a court
  - a deputy appointed by the court
  - someone chosen by the person to make decisions for them (lasting Power of Attorney)

5 Key principles

- Adults are assumed to have the capacity unless proven otherwise
- A person must be given all available support before lack of capacity is concluded
- People have the right to make unwise decisions
- Anything done for someone without capacity
  - must be in their best interest
  - should restrict their rights and basic freedoms as little as possible

The department of health website has numerous resources to help you achieve best practice in relation to consent and people with learning disabilities.

Health Checks

Preparation for Health Check

- Accessible Appointment Letter
- Health Check Questionnaire (HCQ) sent out
- Pre appointment phone call? Remind to bring Health Action Plan and HCQ
- Carers support required?
- Allocate one hour per patient.
- Plan how and by whom check will be done
- At the end of the health check the last page of the HCQ needs to be complete and agreed with the person with learning disabilities and where appropriate with carers
- Advise CLDT of DNA's on second non attendance

Health Action Plans (HAP)

- Some people may already have a H.A.P which they may bring to their Health Check Appointment
- When the health check is completed the completed page of the HCQ can be added to the individuals HAP
- This document can then work as their revised Health Action Plan

Healthcare for All (Michael 2008) full report

This report was written following an inquiry into the death of 6 people with learning disabilities. Mencap stated in Death by Indifference (2007) that institutional discrimination contributed to their deaths and called for changes in how people with learning disabilities access health services. The recommendation of the Michael report are key for improving access to health care for people who have been demonstrated to have significant unmet health needs.

RECOMMENDATION 1
Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training, must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training.

RECOMMENDATION 2
All healthcare organisations, including the Department of Health should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.

RECOMMENDATION 3
Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that reasonable adjustments are made to enable them to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.

RECOMMENDATION 4
Primary care trusts should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment. They should consult with their Local Strategic Partnership, their Learning Disability Partnership Boards and relevant voluntary user-led learning disability organisations and use the information to inform the development of Local Area Agreements.

RECOMMENDATION 5
To raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.

RECOMMENDATION 6
The Department of Health should immediately amend Core Standards for Better Health, to include an explicit reference to the requirement to make ‘reasonable adjustments’ to the provision and delivery of services for vulnerable groups, in accordance with the disability equality legislation. The framework that is planned to replace these core standards in 2010 should also include a specific reference to this requirement.

RECOMMENDATION 7
Inspectors and regulators of the health service should develop and extend their monitoring of the standard of general health services provided for people with learning disabilities, in both the hospital sector and in the community where primary care providers are located. The aim is to support appropriate, reasonable adjustments to general health services for adults and children with learning disabilities and their families and to ensure compliance with and enforcement of all aspects of the Disability Discrimination Act. Healthcare regulators and inspectors (and the Care Quality Commission, once established) should strengthen their work in partnership with each other and with the Commission for Equality and Human Rights, the National Patient Safety Agency and Office for Disability Issues).

RECOMMENDATION 8
The Department of Health should direct primary care trusts (PCTs) to secure general health services that make 'reasonable adjustments' for people with learning disabilities through a Directed Enhanced Service. In particular, the Department should direct PCTs to commission enhanced primary care services which include regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working. This should include liaison staff who work with primary care services to improve the overall quality of health care for people with learning disabilities across the spectrum of care.

RECOMMENDATION 9
Section 242 of the National Health Service Act 2006 requires NHS bodies to involve and consult patients and the public in the planning and development of services, and in decisions affecting the operation of services. All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included.

RECOMMENDATION 10
All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, 'reasonably adjusted' health services for those people who happen to have a learning disability. This 'adjustment' should include arrangements to provide advocacy for all those who need it, and arrangements to secure effective representation on PALS from all client groups including people with learning disabilities.

FACTSHEET 1: Primary Health Care and People with Learning Disabilities

Information about learning disabilities

The 2001 White Paper Valuing People gives the following definition of learning disabilities:

'Learning disability includes the presence of

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

(DH, p.15)

- Like all definitions that apply to people, this one covers wide diversity in ability, personality and individuality. The term 'People First' has become a familiar one within the population with learning disabilities, signifying their uniqueness as individuals.

- According to Valuing People and more recent documentation, we do not know the exact number of people in England who have learning disabilities but it is generally estimated that there are about 210,000 people with severe and profound learning disabilities and around 1.2 million with mild or moderate learning disabilities.

- People with profound and multiple learning disabilities require continuous and ongoing support with all aspects of daily life; people with severe learning disabilities need significant help with the activities of daily living; people with mild or moderate learning disabilities are generally able to live independently with varying degrees of support.

- Whilst the prevalence of severe and profound learning disability is fairly uniformly distributed across the population, mild and moderate learning disability has strong links with related to poverty and deprivation.

- Some geographical areas have higher numbers of people with severe and profound learning disabilities because of the historical presence of long stay institutions.

- Increased life expectancy means that there are increasing numbers of people with profound and multiple disabilities or with Down's syndrome living longer.

Some of the effects of learning disabilities

The effects of a learning disability will obviously be influenced by its extent. In general, people can have difficulty with the following elements of learning and social functioning, all of which have significance for healthcare:

- Attending to the relevant aspects of a task, event or information
- Processing information and making sense of it
- Relating new information to past experience
- Committing things to memory
- Retrieving information from memory
- Absorbing more than one piece of information at a time
- Understanding and remembering the usual sequence in which things happen
- Understanding the significance of information, events and experiences
- Relating to other people
- Adapting their behaviour to new and different situations
- Transferring learning from one situation to another
- Various aspects of communication and language, including making choices and decisions, expressing opinions and giving consent
- Reading and writing
- Understanding symbols such as pictures and numbers

Some facts about healthcare for people with learning disabilities

- Most people with learning disabilities have greater healthcare needs than the rest of the population. More are likely to experience specific health problems such as epilepsy, chronic health problems, physical and sensory impairments, osteoporosis, obesity, thyroid dysfunction, poor oral health, mental illness (particularly schizophrenia) and complex health needs. With increasing life expectancy age related illnesses such as stroke, heart disease, chronic respiratory disease and cancer are of concern. The death rate for young people with learning disabilities is above average.

- The incidence of cancer is lower than in the general population, but is increasing due to increased longevity. There is a higher rate of gastrointestinal cancer than in the general population.

- Respiratory disease is the most common cause of death amongst people with learning disabilities.

- Coronary heart disease is the second most common cause of death amongst people with learning disabilities. Almost half of all people with Down's syndrome have congenital heart problems.

- Children with Down's Syndrome are at particularly high risk of developing leukaemia compared to the population in general.

- The prevalence of dementia is higher than in the general population. People with Down's syndrome are at particular risk, with age of onset earlier.

- Fewer women with learning disabilities access cervical smear tests and breast cancer screening.

- Research has highlighted inadequate diagnosis and treatment of certain medical conditions, for reasons such as the person's difficulty in recognising and understanding symptoms health, communication difficulties and a tendency for symptoms to be attributed to the learning disability in some situations.

- There are high mortality and morbidity rates in the population with learning disabilities although the life expectancy of people with mild learning disabilities is approaching that of the general population.

- The underlying causes of health inequality for people with mild and moderate learning disabilities particularly include poverty, low educational attainment, unemployment, discrimination and social exclusion.

- People with learning disabilities from minority ethnic communities are at particular risk of discrimination in accessing healthcare.

- There is over-dependence on psychotropic drugs for the management of challenging behaviour and poor outcomes in consequence.

- Health Authorities have been charged with the responsibility of taking account of the needs of people with learning disabilities in planning services and making them accessible to all.

- National Service Frameworks and other health initiatives apply equally to people with learning disabilities.

- Professionals in specialist learning disability services have a responsibility to develop the capacity of colleagues in mainstream services and enable them to support people with learning disabilities.

- Some people with Down's syndrome are prone to cervical spine instability (atlanto-xial instability) or hypothyroidism. Over 90% are thought to have sight problems.

Significant influences on the developments of services for people with learning disabilities in recent years.

- A shift in the way we think about people with learning disabilities

- Over recent years there have been substantial moves to promote the inclusion of People with learning disabilities in mainstream society

- Emphasis is upon rights, empowerment, choice and individuality.

Significant influences have included

Person Centred Approaches to Healthcare

- A holistic, person centred approach to healthcare which means individuals, family carers and healthcare professionals work in partnership, people are active participants in decisions about heir care and healthcare is not restricted by traditional care boundaries or professional demarcations. (Naish, 2004)

- Valuing People has this to say about a person centred approach to planning:

- '… planning should start with the individual (not with the services) and take account of their wishes and aspirations. Person-centred planning is a mechanism for reflecting the needs and preferences of a person with a learning disability…' (p.49)

Advocacy

- The development of the Self Advocacy movement and of other forms of advocacy has been one of the most significant forces for change. Valuing People highlights effective advocacy as a means of transforming the lives of people with learning disabilities and enabling them to play an active part in the planning and design of responsive services. The attached sheet describes the key features of advocacy.

Valuing people: A new strategy or Learning disability for the 21st Century (2001)

- The first government White Paper about people with learning disabilities for 30 years identified people with learning disabilities as amongst the most vulnerable and excluded within society.
- Sets out a programme for improving services and has implications for everyone making provision for people with learning disabilities: health, education, social services, employment and other support.
- Based on four key principles: civil rights, independence, choice and inclusion
- Takes a lifelong, integrated approach which involves close working relationships between Local Authorities and Health Authorities.
- As a result of the White Paper, the Valuing People Support Team was set up to promote the required changes. They do this through Learning Disability Partnership Boards (the vehicles for inter-agency planning in implementing government proposals at local level), local people and organisations and government departments. The Boards operate within the Local Strategic Partnership framework. They bring together public, private, community and voluntary sector organisations to provide effective local co-ordination of strategic planning and development. Local. Boards have to make sure that people with learning disabilities and family carers are supported to participate fully in all aspects of work undertaken.
- Established the post of Health Facilitators and the process of Health Action Planning (HAP) as the key drivers for improved healthcare for people with learning disabilities. (See information about HAP and Health Facilitators on Factsheet 3A)

The government objective in Valuing People which relates specifically to the improvement of health states:

> 'To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary' (p.59).

Recent and current NHS developments

- Inclusive initiatives and policy within the NHS, both such as National Service Frameworks, Quality and Outcomes Framework, developments in clinical governance, National Standards, Local Action, Patient Advice and Liaison Services, Our health, our Care, our say and National Patient Safety Agency initiatives . (The 'Further Reading and Useful Websites' list below provides information about some of the many initiatives which are proving effective in including people with learning disabilities in these mainstream health developments.)
- Developments designed specifically for people with learning disabilities such as Health Facilitation which includes Action Planning and the identification of Health Facilitators for people with learning disabilities.

Some other 'good practice' ideas that might help

- Following up written information about appointments etc with a phone call to remind people.
- Texting reminders where people can manage mobile phones.
- Having checklists of 'best practice' items relating specifically to people with learning disabilities – ease of access, communication, minimising risk factors etc. Ensuring these take account of ethnic diversity.
- Having quick reference materials on learning disabilities available to staff, e.g., 'handy hints' cards on communication, autism etc
- Involving local self advocacy groups in initiatives such as training, surveys, making information and services accessible etc
- Planning and contributing to training events specifically for people with learning disabilities and/or carers
- Partnerships with organisations supporting people from Black and Minority Ethnic groups to help ensure that people with learning disabilities are included in health initiatives Further reading and useful websites

FACTSHEET 2: Health Facilitation

Part 1: Challenges to Healthcare

Many of the challenges faced by people with learning disabilities arise from communication difficulties – both theirs and ours. The suggestions given below include some things you would do as a matter of course in your professional capacity, but you may have to adapt them to suit the individual person. You will be able to add to them from your own experience.

Improving communication

- Many people with learning disability understand more than they can express. People with Down's syndrome, for example, may have difficulty with articulation but often understand a lot more than we expect.
- People with learning disabilities may find it difficult to absorb and process more than one fact at a time. It helps to break information down into single pieces and give people extra time to absorb it. The use of venues, objects and pictures can aid understanding and help allay anxiety, e.g., showing someone the treatment room and equipment beforehand and explaining what will be done. However, some people may find this more worrying, so we need to take account of individual differences and be guided by the person and carers.
- It's always better to address the person, not the carer, but to include the carer in the discussion. Even when people have profound and multiple learning disabilities and you are doubtful about their ability to understand, there are ways of including them, such as making eye contact or using touch. People with profound and multiple learning disabilities are often able to respond to tone of voice and may be able to understand simple words.
- Listen actively – nod, smile, keep eye contact, while paying close attention to the person's face and body signals
- Make sure the person can see your face and mouth as you talk
- As a general rule, start by using easy words and short sentences – you can always increase the complexity if the person is more capable than you first thought.
- Keep checking back to make sure the person understands. If in doubt, rephrase what you say. You can also involve the person's carer if there is one present without excluding the person, e.g., by the way in which you use eye contact, by using inclusive language, such as, 'Do you have any other questions about what I told you?' (while looking at both) or 'There are two things we can do. The first is… The second is…' – and so on.
- Be particularly aware of facial expressions, gestures and body signals used by the person. Some people with learning disabilities use these skilfully to supplement or replace speech. Others may show barely perceptible signals so you have to be well tuned in. Be aware of your own body language – when you can make good use of it and when it would confuse the issue.
- Where possible, avoid jargon. If you have to use it, explain what it means. Use pictures if helpful.
- Even when you think you have given enough time for someone to respond, give even more if there is no response. Some people with learning disabilities take a long time to

process information, formulate and give a response. When you think you have waited long enough, wait even longer.

- Use concrete language based in the present – many people have difficulty with concepts involving the future
- Use key words and phrases – cut down on unnecessary detail
- If the person uses an alternative and augmentative communication system, such as signs or symbols, try to learn the basic ones you will need. If this isn't possible, work with and through the carer or advocate as an interpreter.
- Increasing numbers of books and leaflets which are easy read or without words are being produced for use with and by people with learning disabilities – see the resources section at the end of this factsheet
- Written information can be replaced or supplemented with audiotapes, large print, simple words and sentences, pictures and photographs.
- Physical contact can be an effective way of communicating and is essential for many healthcare procedures, but may carry risks. You need to check out with the person or carer how the person feels about touch, how to approach the task, what signals or responses to be aware of and what they mean. Your professional experience and sensitivity will guide you and alert you to the possibility that the person's response may indicate the possibility of physical or sexual abuse now or in the past.
- Be aware of how context – surroundings, the people present etc – can influence communication
- The person's Health Action Plan is useful as a main vehicle for communication because it encapsulates all health areas and issues which are likely to be of concern.
- The local Health Facilitator, Community Learning Disability Team and Speech and Language Therapists are particularly useful as resource people and may already have resources that can be used or adapted.

The physical and social environments

Health and safety regulations, risk assessment and the requirements of the Disability Discrimination Act will take care of some of the hazards people with limited mobility might face and physical access, but there are other aspects of the environment you might have to think about. For example, instructions to 'Go to door number 4' or to 'Turn right then left' can be confusing for some people.

- Orientation when the person first joins the practice (preferably at a quiet time) can be invaluable for people who have high levels of anxiety, are slow to learn things or have autistic spectrum disorder or challenging behaviour can pre-empt difficulties. This will enable people to feel comfortable as well as get used to the physical lay-out.
- Advice on lighting for people with visual impairment is available from the relevant organisations – see contact details below. The RNIB, for example, has an accessibility consultancy. When decorating, it helps to use to contrasting colours to show people where the walls end and the floor begins, where doors are etc.
- Greeting people by their name, smiling at them and accompanying them to the treatment room are all things that have been identified by people with learning disabilities as helpful for reducing anxiety.

- People with an autistic spectrum disorder can have difficulty with physical environments which are 'busy', e.g., constant movement, noise, notices on walls etc. If possible, make arrangements for consultation and treatment in a place which is familiar to them, such as their own home, place of work, educational establishment or day centre. The same is true of some people with challenging behaviour.
- Using a calm, relaxed approach will help to put people at ease and can defuse any tension.
- Parents and other carers will be able to provide information about the sorts of 'triggers' which can set off or escalate challenging behaviours. In some situations it may be necessary to move other people away from the vicinity of the person with challenging behaviour in order to calm things down. Physical restraint should only ever be used as a last resort and with due attention to duty of care. he British Institute of Learning Disabilities (BILD) provides guidance on physical interventions – see contact details below.

The coordination of healthcare

You might like to consider the following:

- Do all your patients with a learning disability have a Health Action Plan?
- Are you familiar with and involved in the Health Action Plans of the people using your service?
- How do you see your own role in Health Action Planning?
- Do people with learning disabilities have access to regular health checks and screening in the same way as everyone else?
- Do health promotion schemes involve people with learning disabilities?
- Do you know your local Health Facilitator(s) and how are you working with them?
- What steps have you and colleagues taken to make all aspects of your service accessible to the individual needs of your patients or clients with learning disabilities?
- Have you and/or colleagues had access to and/or made use of local training to help you provide a better service for the people with learning disabilities who use your service?
- What kind of support and advice can you offer Health Facilitators by contributing to HAPs and healthcare in general from your own specialist knowledge and experience?
- What advice do you have on building good working relationships with a person's family and other carers as well as the person him or herself? How can this help ensure high quality healthcare, reducing inequality and combating discrimination?
- How can Health Action Plans provide a basis for improving teamwork?
- What examples of good practice do you have that might be useful to colleagues from other disciplines?
- What kind of support and advice can local Health Facilitators provide to support your work with people with learning disabilities?

Part 2: Health Facilitation

The information below is based on guidance from the Department of Health:

Action for Health – Health Action Plans and Health Facilitation: Detailed Good Practice Guidance on Implementation for Learning Disability Partnership Boards. In his foreword to this book, David Colin-Thorne, National Director fro Primary Care says:

> 'I know that many people working in primary care teams and other parts of the NHS are eager to take up this challenge (of delivering the vision set out in 'Valuing People') It is essential that both children and adults with learning disabilities are helped to be full citizens using NHS services like everyone else. This may not always be easy but the good practice guidance contained in this booklet will help this to happen.'

Health Facilitation… … evolved from roles developed by family carers, practitioners and others wishing to improve the health of people with learning disabilities, also from the wishes of people themselves, relatives and support workers who wanted help to access the best possible healthcare.

The role of Health Facilitation is at two levels:

Level 1 – Service development work and informing planning and commissioning
Level 2 – Person to person work with people with learning disabilities

Level 1 – Service development work and informing planning and commissioning

- Supporting the achievements of targets in Valuing People: all people with learning disabilities registered with GP by June 2004; all GPs know the people with learning disabilities on their list.
- Developing, monitoring and auditing initiatives designed to reduce health inequalities, liaising with Patient Advice and Liaison Services (PALS) in the NHS trust; with colleagues, monitoring the health status of people with learning disabilities relative to the general population; helping services meet the needs of people with learning disabilities from black and minority ethnic communities; auditing discriminatory practice in access to healthcare; auditing health information for ease of use by people with learning disabilities; liaising with Workforce Development Confederations to develop training plans for mainstream healthcare and direct suppot staff. A range of health professionals, managers and commissioners could fulfil these responsibilities.

Level 2 – Person to person work with people with learning disabilities

The focus is on individual health outcomes. A health professional, support worker, advocate, friend or family carer could fulfil this role. The responsibilities are:

- Helping to identify and record health targets for the Health Action Plan (HAP)
- Supporting access to all health services

- Making sure the HAP is an integral part of care pans, transition plans and person centred planning
- Helping to identify and meet health education needs
- Regular review, monitoring individual health outcomes and adapting and developing the HAP

Additional responsibilities might include:

- Ensuring health checks for people in residential care in line with National Minimum Standards
- Ensuring Single Assessment Process for older people as specified in National Minimum Standards
- Training family carers to ensure optimum health outcomes
- Supporting people with learning disabilities and family carers to raise concerns with, complain to or complement health service providers; liaise with PALs about complaints or concerns
- Reporting discriminatory practice to Learning Disability Partnership Boards
- Reporting any service deficits which affect individual health improvement. People with profound and multiple learning disabilities, severe mental illness or complex health needs are likely to need a specialist health professional to assist with HAPs.

Health Action Plans

A Health Action Plan:

- details the actions required to maintain and improve the health of an individual person with learning disabilities and the support required to achieve this.
- links the individual and the range of services required to ensure better health
- needs to be supported by wider change
- is for the person with a learning disability and is co-produced with them

Secondary functions might include:

- Educating the person and supporters about health
- Improving the coordination of services for the person
- Influencing services and other structures that affect the person's life HAPs improve the health of people with learning disabilities by:
- Focusing on healthcare issues
- Identifying health concerns and how to address them
- Ensuring an adequate response from a range of services
- Supporting changes in the wider context and dealing
- with health issues that prevent social exclusion

The Principles of Health Action Planning

Health Action Planning:

- should support the White Paper's values of rights, independence, choice and inclusion.
- is about more than individual plans. It should include strategic actions to support and sustain their implementation.
- should address both individual and societal influences on the health of people with learning disabilities.
- is a shared responsibility with each person and agency playing a role appropriate to their skills and experience.
- should support the mainstream health agenda and the drive to reduce health inequalities.

Stages in Health Action Planning

1. Initiation of a HAP:
   - can be initiated by the Primary Healthcare Team or other health professionals;
   - people with learning disabilities or family carers may initiate it, possibly with the support of staff in day or housing services.

2. Assessment of the actions needed to maintain and improve the person's health:
   - developed locally with full involvement from Primary Care staff and appropriate others;
   - should be evidence based and accessible and reflect current health policy;
   - should consider health issues of relevance to the person concerned
   - should pay particular attention to issues that are known to be particularly relevant to people with learning disabilities
   - should be holistic and consider all areas of person's life which might affect health.

3. Assessment of the help needed to implement identified actions

4. Response delivery
   - will identify the appropriate person to address each area of health action listed
   - will identify who will provide any help needed to implement the required actions

5. Review of the HAP:
   - Checking that actions have happened and necessary help provided
   - Evaluating their effectiveness; assessing the need for any new actions.

Some other 'good practice' ideas that might help

- Having 'resource boxes' relating to different health issues which contain accessible materials for explaining the issues and consulting people with learning disabilities
- Purchasing easy–read books relating to health issues (see information below)
- Asking dedicated learning disability staff to supply you with, and provide training about, practical tools for good practice, e.g., communication passports, accessible leaflets etc
- Simplifying forms and having information on audiotape

FACTSHEET 3A: Healthcare for People with Additional or Complex Needs

People with profound and multiple learning disabilities

People are described as having profound and multiple learning disabilities (PMLD) if they have:

- profound intellectual impairment
- additional disabilities which might include impaired sight and hearing, physical disabilities and/or autism or mental illness.

Some also have challenging or self-injurious behaviour. Many have complex health needs and some are technology dependent, require tube feeding or suction equipment. Someone with profound and multiple learning disabilities will need considerable support with all aspects of life. Most people with profound and multiple learning disabilities have difficulty with verbal communication. Many people use and/or understand non-verbal ways of communicating such as gestures, body movements, eye contact and vocalisation but some have difficulties with this also. Most people depend on a family carer, support worker or advocate to make their voice heard.

Common health problems

People with profound and multiple learning disabilities are more likely than others to have:

- Epilepsy
- Cerebral palsy
- Some reflexes which are more common in infancy, such as the startle reflex
- Problems with sucking, chewing and swallowing which can cause malnutrition, dehydration or pneumonia
- Respiratory problems
- Limitations in reflexes such as chewing and gagging
- Frequent infections
- Difficulties with wound healing
- Impaired sight and/or hearing

- Nutrition and feeding problems
- Problems with muscle tone
- General posture difficulties, including sitting
- Oral/dental problems
- Incontinence of bowel and bladder
- Gastrointestinal problems such as oesophageal reflux
- Physical problems relating to limited mobility, e.g., muscle atrophy, contractures,
- loss of limb flexibility, podiatry problems, fractures and pressure sores
- Health problems related to cerebral palsy and epilepsy such as involuntary muscle spasms, post seizure pain and limb and lower back pains

People with profound and multiple learning disabilities are capable of being involved in their own Health Action Plans to a greater or lesser extent, depending on their capacity and their life experience. Much of this involvement will be done in partnership with those who know the person best – a family carer, advocate or other carer.

What you can do

- Make sure the person is present at all consultations and discussions even if you think they don't understand. Use inclusive body language, gesture and facial expression, such as making eye contact. It can help to exaggerate movements and facial expressions and take extra time over them. Use touch if the carer advises it's useful and note how the person responds.
- Your involvement in the person's Health Action Plan will be governed by your role, but should give you insight into different aspects of that individual's life.
- The carer(s) and those closest to the person are usually the central people developing the plan but the aim is holistic assessment and planning, so your role is likely to be crucial, especially if the plan is not being led by a health professional. The fuller the plan the more holistic it is likely to be.

Communication

Undoubtedly one of the greatest challenges we face in providing support of any sort for people with PMLD is that of communication. You might start by establishing a baseline based on the following questions:

- How many different ways does s/he communicate?
- Where does s/he communicate best?
- What techniques and tools help to involve her/him?
- Does s/he use any communication aids?

The following approaches are often used with people with PMLD:

- 'Total communication' -used to refer to a system of communication in which we use all means at our disposal to communicate – words, touch, signs or symbols, tactile experiences such as feeling different textures etc.

- Communication passports. The passport is a book in which details of the person's background (home, family, school, day centre etc), daily life activities, likes and dislikes, prefer ways of communicating etc are written. Photograph and pictures are incorporated. The person carries the book around with her and uses it to communicate with other people. Many people with PMLD relate well to their communication passport, especially the photographs, and become very animated and involved when others are using it to communicate with them.
- Objects of reference, i.e., objects which the person learns to associate with particular experiences or events, e.g., a toothbrush when going to the dentist, a pair of glasses which signifies a visit to the optician, a jar of foot cream to indicate a visit to the podiatrist etc.
- The person is taught to associate the object with the event or experience. Objects which offer the fullest tactile experiences are best as they lend themselves to touch, smell, sight, sound and taste. The person is encouraged to 'experience' the object before, during and after the event.
- Hand held health logs which are in some ways similar to communication passports but focus on health. They may be superseded by HAPs or may continue to have a role. They contain information about the person's conditions, medication, preferred ways of communicating, family and friends, likes and dislikes Assessing pain and distress in people with PMLD

The assessment of pain and distress is also very difficult.

Over recent years a considerable amount of work has focused on indicators which will enable us to move forward in this area. Common indicators include:

- Irritability
- Changes in sleep patterns
- Mood changes
- Changes in the sounds the person makes, e.g., when a happy sound becomes a wail
- Different energy patterns, e.g., lethargy and lack of interest in anything
- Changes in facial expression, e.g., grimacing
- Changes in body posture
- Unusual sensitivity to touch & light
- Changes in appetite

Some work has been done on the adaptation of behavioural pain assessment tools for this group of people. Pain management strategies found to work include distraction, relaxation through touch and massage, aromatherapy, acupuncture and TENS

Mental Health Needs and People with PMLD

Research findings indicate that people with PMLD are as prone to mental health difficulties as other people. They exhibit signs of stress, anxiety and depression which may be as a result of their inability to control their environment or a reaction to what they perceive as a threatening

situation, for example. This might be shown in unusual ways such as self-harm. A link between epilepsy and mental health has also been suggested.

The publication The Wellbeing Workshop is a training resource to help family carers and support staff acknowledge, identify and react to changes in the emotional and mental well-being of people with profound and multiple learning disabilities. The pack is produced by the Foundation for People with Learning Disabilities – details below.

People with challenging behaviour

Challenging behaviour is know to be more common in:

- boys & men;
- people with an autistic spectrum disorder
- people with more severe disabilities
- people with additional impairment, e.g., hearing problems

Reasons for challenging behaviour

Challenging behaviour always has a reason and does not arise as a result of someone's impairment, although the impairment might exacerbate the problem, e.g., if the person has communication difficulties. We know that people who have severe communication difficulties and people who have spent long periods of their lives in institutions are more likely to experience challenging behaviour. The shift to the term 'challenging' instead of problem behaviour or behaviour difficulties is a reasoned one which signifies a shift in thinking. The former locates the behaviour within a 'blaming the person' framework, whereas the latter is about requires us to ask ourselves why they person is challenging the system or situation. Thus we recognise that the behaviour is not just a part of the person's learning disability, but a response to a situation the person finds intolerable. In effect, challenging behaviour is 'normal' behaviour that is at, or near, the extreme of the spectrum.

Reasons for challenging behaviour can include:

- The person's state of health – head banging or hitting self because of pain
- Difficulty with communication – expressive and receptive
- Life events such as moving house, bereavement etc
- The physical environment – too hot or cold, noisy, light, colour etc
- Social isolation -having no meaningful relationships in everyday life
- Change -being taken out of everyday routine and being in an unfamiliar surroundings
- Inability to predict what is going to happen
- Previous experiences of health care or of unpleasant experiences often evoked by smell, the sight of a white coat etc
- Seeing an opportunity to get some attention in an otherwise socially deprived life
- Sight and hearing difficulties
- Mental health problems, e.g., depression
- Pain and undiagnosed conditions

There are often multiple reasons which can make it more difficult to assess. People with an Autistic Spectrum Disorder often present challenging behaviour, so the suggestions below apply equally to them. What you can do to prevent challenging behaviour:

- Get as much information about the person before an appointment – HAPs can help here
- Give a first appointment so that the person is not kept waiting, which tends to exacerbate anxiety
- Give a double appointment
- Making simple changes like seeing him when there is no-one else around might help
- If you think the surroundings are causing the problem, is it possible to provide treatment elsewhere?

Managing challenging behaviour

If in spite of precautions, the person exhibits challenging behaviour, you can try the following:

- Stay calm and relaxed and show this by your body posture and facial expression. It may help to speak in a soothing tone but be alert to the possibility of this escalating the situation
- Avoid any sudden movement towards the person
- Respect personal space
- Observe the person carefully
- Try to identify the trigger (what caused the behaviour) and avoid it in future
- It may help to calm the person down or encourage the carer to do this
- It might be possible to distract the person
- If the person is extremely agitated and the behaviour seems out of control, you may have to remove yourself and anyone else involved from the situation after making sure the person is safe and in no immediate danger. If possible, stay where you can observe the person concerned.
- Once the person has calmed down, reassure him or her
- If the person can communicate verbally, it might help to talk over the event afterwards or to encourage the carer to do so in order to avoid recurrence of the situation
- Do not insist on an apology or treat an adult like a child.
- In extreme situations you might have to work with challenging behaviour specialists to try to resolve the situation.
- Keep records so that you can see any patterns.

People with autistic spectrum disorder

The National Autistic Society (NAS) defines Autistic spectrum disorder (ASD) as ‘a term used to describe a lifelong developmental disorder that is characterised by impairments in social interaction, communication and imagination.’ And add ‘There is a spectrum or range of disorders with these features, including autism and Asperger syndrome. Some people with an autistic spectrum disorder have severe learning disabilities and some may never speak. People with Asperger syndrome, on the other hand, usually have an average or above average IQ and acquire spoken language at the same time as typically-developing children’.

People with an ASD have three main areas of difficulty, usually referred to as the 'triad if impairments'. These comprise:

- Social interaction – difficulty with social relationships and with understanding other people's perspectives and intentions
- Social communication
- Imagination -difficulty with interpersonal and symbolic play.

Many also have repetitive behaviour patterns and strongly resist any change in routine. Some people with ASD are hyper or hypo-sensitive to pain, sound, light and other visual and auditory stimuli. They might:

- Find the world very confusing
- Be highly sensitive to lights, noise and other things around them
- Be over or under sensitive to pain
- React unusually to pain e.g., laugh

Some strategies for supporting people with ASD

- Negotiate appointments – where and when
- Make sure you have a full history – the HAP is relevant here
- Limit the number of staff involved with the person to allay anxiety and avoid confusion • Say the person's name first to get their attention
- Use clear, simple & literal language – people with ASD take things very literally
- Use pictures, photos and gestures
- Make direct requests to the person
- Check back to make sure the person understands
- Leave enough time for a response
- Stay calm and relaxed
- Make choices simple
- Explain when something is about to change, stop or happen
- Avoid using body language and gesturers without verbal instructions
- Give direct and literal requests, e.g., 'Please sit down' rather than 'Can you sit down' or 'Take a seat'
- Behaviours such as hand flapping, rocking, putting fingers in ears etc are used by people to deal with situations and calm themselves so don't try to stop them unless essential
- Be aware of the effects of surroundings, e.g., sensory overload, busy waiting rooms
- Depending on the severity of the impairment, it may not be possible for you to communicate directly with the person, so you may have to work with and through those who know the person best.

Some other 'good practice' ideas that might help

- Ensuring that the HAP of people with complex health needs is led by someone with the required health expertise
- Minimising intrusion into people's lives and saving time by coordinating the collection of information for HAPs and limiting the number of people involved
- Using 'tactile stories' for people with profound learning disabilities, i.e., a box with a objects which can be used to help people understand and relate to what is happening to them
- Joint clinics between health specialists – audiologists, neurologists – and specialist learning disability staff
- Sight and hearing assessments in a venue familiar to the person

FACTSHEET 3B: Partnership in Healthcare

Health Action Planning: a vehicle for partnership

We know that partnership in health and social care is one of the most potent means of improving quality. Because a number of different agencies are likely to be involved with people with learning disabilities, teamwork across professional boundaries and with the individual and the family or other carers is crucial. Health Facilitators and the Community Learning Disability Team have a range of specialist skills which can be of use to professionals from other disciplines – and vice versa. Similarly, we have a lot to learn from those with firsthand experience of learning disability and those closest to them.

Health Action Planning improves partnership working

Health Action Planning is a particularly powerful vehicle for improving partnership and coordinating healthcare for the following reasons:

- Like other current NHS developments and initiatives, HAP has its basis in partnership – it's impossible without it.
- HAP is closely linked to all other NHS developments, such as National Service Frameworks, Quality and Outcomes Framework, Clinical Governance, Skills for Health, Agenda for Change, Better Metrics and so on. Because of this, it contributes to the achievement of clinical outcomes.

Health Action Planning improves the quality of healthcare for people with learning disabilities

Health Action Planning is probably the most effective approach we've ever had for improving the quality of health for people with learning disability, because:

- It offers a way of speeding up their inclusion in mainstream health services, not least those who have hitherto been isolated in longstay hospitals but who now live in the community
- We have to specify the actions needed to improve people's health and identify who is responsible for these actions. Thus access is addressed directly.
- HAP is built on the principles of person centred healthcare
- There is emphasis on prevention and healthy lifestyles
- The plan is built around the needs, wishes and aspirations of the person concerned so they have a say in their own healthcare plan.

Health Action Planning works for Primary Care Teams

The White Paper Valuing People says that all health initiatives aimed at the general population, and all policies on health inequalities, should make specific reference to people with learning disabilities. Health Action Planning can help Primary Care Teams achieve this because:

- It helps in meeting local targets and requirements
- It reflects PC responsibilities such as reshaping local services, developing and creating local networks, prevention as well as treatment and improving clinical outcomes
- It meets national priorities to include people with learning disabilities in mainstream healthcare
- There may be funding available for particular activities
- It enables people to remain within their own communities
- It supports carers and can help to avoid health problems

Partnership opportunities for people with learning disabilities

People with learning disabilities have much more opportunity for partnership than they have ever had. Here are just a few examples:

Learning Disability Partnership Boards

Learning Disability Partnership Boards were set up after Valuing People was published with a remit to bring people and organisations together to plan better services for people with learning disabilities and help them get better access to the chances and services that everyone else uses. The Board brings together councils, health services and other support services with people with learning disabilities and family carers. This should result in a coordinated approach to provision. For more information log onto

http://www.valuingpeople.gov.uk/dynamic/valuingpeople128.jsp

and

http://www.bild.org.uk/pdfs/05faqs/pb.pdf

Expert Patients Programme

Several places in the country are investigating ways of involving people with learning disabilities in the EPP. For an evaluation of such a programme in Bristol, download 2005 Expert Patients Programme for People with Learning Disabilities

Expert Patients Programme for People with Learning Disabilities

LInks Forums

These forums provide opportunities for the perspectives of people with learning disabilities to contribute to health developments locally. Users and Carers groups Local Authorities have a statutory duty to consult on services so there are more opportunities now for people with learning disabilities and their families to be involved. Their involvement includes planning, monitoring, heading up consultation events, providing advice, assisting with accessibility, amongst other things.

NPSA focus groups

The National Patient Safety Agency met with frontline health and social care staff, people with learning disabilities, family carers and academics to investigate patient safety issues for people with learning disabilities. They identified five areas of concern:

1. Control and restraint -people with learning disabilities may be receiving injuries and being harmed when physical restraint is used inappropriately

2. Vulnerability of people with learning disability in general hospitals -people with learning disabilities may be more at risk of things going wrong than the general population
3. Swallowing difficulties (dysphagia) -swallowing difficulties are more common in people with learning disabilities and can lead to respiratory tract infections, a leading cause of early death for people with learning disability
4. Lack of accessible information – where a person with a learning disability is unable to understand information relating to their illness or treatment
5. Illness or diseases being mis or un-diagnosed -access to treatment can be delayed because symptoms are not recognised early enough

The reports can be accessed at http://www.npsa.nhs.uk/nrls/ , use the websites search engine with the term learning disabilities

Some common concerns in meeting the needs of people with learning disabilities.

The following concerns have been identified as amongst the most common in providing health services for people with learning disabilities:

- Consent
- Communication
- Capacity to understand
- Confidentiality
- Consultation
- Balancing risk & duty of care
- Lack of specialist knowledge about learning disability

You can find more information on these and many other topics covered in the fact sheets and other parts of this pack in the following publications and on the websites listed below, further resources are listed at the end of this pack:

Accessibility

Building

DRC (2003) Good Signs: Improving signs for people with learning disabilities A report to the Disability Rights Commission
http://83.137.212.42/sitearchive/drc/library/publications/services_and_transport/good_signs_-_improving_signs_f.html

Information

Mencap (2000) Am I making myself clear? Mencap's guidelines for accessible writing. Copyright free. Access at http://november5th.net/resources/Mencap/Making-Myself-Clear.pdf

Working practices
SCIE (2005) How to make events accessible
http://www.scie.org.uk/publications/misc/accessguidelinesevents.pdf

Consent and capacity to understand

DH (2001) Seeking consent: working with people with learning disabilities
http://www.dh.gov.uk/assetRoot/04/06/70/19/04067019.pdf

Communication and consultation

British Institute of Learning Disabilities (BILD) Factsheet: Communication
http://www.bild.org.uk/pdfs/05faqs/communication.pdf

Confidentiality

Musgrave, S., Kruschwitz, U. and O'Neill, D. Confidentiality Issues from the User Perspective – Lessons from Learning Disability Services
http://www.essex.ac.uk/hhs/research/Projects/LDgrid_files/ncess2005_paper_Musgrave.pdf

Balancing risk and duty of care

Foundation for People with Learning Disabilities (2003) Empowerment and Protection
update_Building Expectations.pdf

Lack of specialist knowledge about learning disability

The best source is the person, family carers and local learning disability staff. Some websites for general information are listed on Factsheet 1

How Health Facilitators and members of the Community Learning Disability Team support your work with people with learning disabilities.

Health Facilitators and members of the Community Learning Disability Team can provide the following kinds of support:

- Providing specialist advice and information, e.g. about challenging behaviour, communication strategies and techniques
- Liaison and coordination between mainstream and specialist people and services
- Training, e.g., alternative approaches to communication, how to get involved in Health Action Planning
- Assistance with monitoring and review
- Supporting the person and carer(s) in accessing mainstream and specialist healthcare services
- Coordinating a holistic approach to healthcare
- Assisting with issues about consent and legal requirements and responsibilities
- Helping to make services and information accessible

- Helping with difficult issues, e.g., challenging behaviour, autism, profound and multiple learning disabilities
- Enabling you to play your part in each individual's Health Action Plan -as well as specific issues which relate to individuals and their family or other carers.

How you can support Health Facilitators and members of the Community Learning Disability Team

- Making a commitment to teamwork in Health Action Planning and improving healthcare for people with learning disabilities
- Providing training to Health Facilitators in your own specialist area
- Ensuring that all aspects of health are covered in the person's HAP and providing the necessary specialist advice and guidance in the part of the plan that reflects your specialism
- Assisting with monitoring, review and evaluation
- Sharing examples of good practice from your own experience
- Becoming actively involved in Health Action Planning for individuals who use your service
- Improving access to services and information

Some other 'good practice' ideas that might help

- Keeping sections of the HAP separate, e.g, issues about mental health, and accessible on need to know basis to ensure confidentiality
- Working with an independent advocate if the person has difficulty representing him or herself for any reason
- Developing examples and accessible information to help people understand risky behaviour, e.g., not taking or using medication as prescribed; unprotected sex.

Similarly with situations requiring consent – showing the different options for example.

- Making agreements or contracts with the person to help them manage risky behaviours
- Enlisting the help of people in the practice with artistic skills to produce illustrations for leaflets etc.
- Having a link person between the PCT and CLDT
- Identifying opportunities for partnership at different levels and for particular purposes - individual, local, regional, specific, strategic.

Themed Alphabetical Resources List

Accessibility

Building

DRC (2003) Good Signs: Improving signs for people with learning disabilities A report to the Disability Rights Commission
http://83.137.212.42/sitearchive/drc/library/publications/services_and_transport/good_signs_-_improving_signs_f.html

Information

Mencap (2000) Am I making myself clear? Mencap's guidelines for accessible writing. Copyright free. Access at http://november5th.net/resources/Mencap/Making-Myself-Clear.pdf

Making assessable information for people with learning disabilities including guide for people with sensory loss (making audio and video materials), communication needs and people from ethnic minorities
http://easyinfo.org.uk/dynamic/easyinfo46.jsp

St. George's Hospital Medical School and Royal College of Psychiatrists Books Beyond Words – a series of books to aid communication about difficult subjects, details on
http://www.rcpsych.ac.uk/publications/booksbeyondwords.aspx

Titles include:

- Keeping Healthy 'Down Below'
- Looking After My Breasts
- Going to the Doctor
- Getting on with Epilepsy
- Feeling Blue
- I Can Get Through It (About abuse)
- Jenny Speaks Out (About abuse)
- Bob Tells All (About abuse)

British Institute of Learning Disabilities -Easy Read books –
http://www.bild.org.uk/03books_health.htm
Your Good Health Series – includes:

- Alcohol and Smoking
- Breathe Easy
- Coping with Stress
- Epilepsy
- Getting Older – Feeling Good
- If you are Ill …

- Looking after your Teeth
- Pregnancy and Childbirth
- Seeing and Hearing
- Using medicine safely

Into the mainstream - Accessible resources for people who have cancer
http://www.intothemainstream.cswebsites.org/default.aspx?page=5846 texts include

- Cancer prevention
- Cancer treatments
- Bladder and bowel cancer
- Cervical screening
- Looking after your balls
- What is cancer
- Testicular checks
- Exercise
- What to look for
- The cancer journey

Accessible health info and videos about health care http://www.lookupinfo.org/index.php?id=12
Titles include

- Alcohol
- Coming for a drink
- Asthma
- Blood pressure
- Back
- Breast examination
- Calling an ambulance
- Colds and flu
- CT scan
- Diabetes
- Epilepsy
- Healthy eating

Accessible information about medications http://www.ld-medication.bham.ac.uk/medical.htm

Working practices
SCIE (2005) How to make events accessible
http://www.scie.org.uk/publications/misc/accessguidelinesevents.pdf

Autistic spectrum disorders

DH (2004) National Service Framework for Children, Young People and Maternity Services: Autism. Change for Children – Every Child Matters
http://publications.everychildmatters.gov.uk/default.aspx?PageFunction=productdetails&PageMode=publications&ProductId=Autism-Exemplar&

National Autistic Society – Factsheets: www.nas.org.uk

- About autistic spectrum disorders
- Communication and interaction
- Diagnostic options: a guide for health professionals
- Patients with autistic spectrum disorders – information for health professionals

Capacity

The Mental Capacity Act: guidance for health professionals
http://www.devonlmc.org/uploads/File/Mental%20Capacity%20Act/mentalcapacityact-2005.pdf

Information booklets on mental capacity http://www.dca.gov.uk/legal-policy/mental-capacity/publications.htm#booklets

Cerebral palsy

Scope, gives lots of information about the health needs of people with cerebral palsy
http://www.scope.org.uk/

Challenging Behaviour Foundation – Factsheets which include the following:

- Basic Information about Challenging Behaviour
- Communication and Challenging Behaviour
- Functional Assessment
- Health and Challenging Behaviour
- Self-injurious behaviour
- The Use of Medication in the Treatment of Challenging Behaviour

Can all be found at http://www.thecbf.org.uk/resources/ipack-chall.htm

Confidentiality

Musgrave, S., Kruschwitz, U. and O'Neill, D. Confidentiality Issues from the User Perspective – Lessons from Learning Disability Services
http://www.essex.ac.uk/hhs/research/Projects/LDgrid_files/ncess2005_paper_Musgrave.pdf

Consent

Best interest guidance http://www.pmldnetwork.org/resources/bps_best_interests_guide.pdf

DH (2001) Seeking consent: working with people with learning disabilities
http://www.dh.gov.uk/assetRoot/04/06/70/19/04067019.pdf

Commissioning

Valuing People Support Team New Ways of Working in Health Services for People with Learning Disabilities: A resource guide for people who commission and deliver health services for people with learning disabilities Commissioning Specialist Adult Learning Disability Health Services Good Practice Guidance including Specialist Adult Learning Disability Health Services good Practice Guidance Easy Read Summary

Communication and consultation

There is a great deal written on communication and learning disabilities. The following will give you a start.

British Institute of Learning Disabilities (BILD) Factsheet: Communication
http://www.bild.org.uk/pdfs/05faqs/communication.pdf

Video of 3 people with learning disabilities and how to meet their needs
http://www.intothemainstream.cswebsites.org/default.aspx?page=4498

Wide range of resources on Alternative and Augmentative Communication including information about their very good study days http://www.communicationmatters.org.uk/

Total communication including introduction to basic signs including health related signs
http://www.learningdisabilitydevon.org.uk/symbols.htm

Dental (accessible info in accessibility)

Basic information about dental phobia and people with special needs
http://www.dentalphobia.co.uk/fact-sheets/special-patients.html

Downs Syndrome

Range of resources about people with Downs Syndrome http://www.downs-syndrome.org.uk/
Health information about common illnesses people with Downs Syndrome experience
http://www.downs-syndrome.org.uk/resources/publications/medical-and-health.html

Duty of care and risk

Foundation for People with Learning Disabilities (2003) Empowerment and Protection update_Building Expectations.pdf

Ethnicity

DH (2001) Learning Difficulties and Ethnicity report to the Department of Health
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4002991&chk=eDQIRa

Families

DH (2001) Family Matters, Counting Families In Family Carers' Report to the Government
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4006536&chk=3J7VtJ

Genetic Conditions

General information about genetic conditions from the NHS library
http://www.library.nhs.uk/geneticconditions/Default.aspx

Health (for accessible health resources see 'Accessibility' above)

FPLD, Learning about intellectual disabilities and health
http://www.intellectualdisability.info/home.htm

Hatton, C., Elliott, J. & Emerson, E. 'Key Highlights' of Research Evidence on the Health of People with Learning Disabilities Institute for Health Research, Lancaster University

King's College London (2003) Valuing Health for All: Primary Care Trusts and the Health of People with Learning Disabilities-summary http://www.natpact.nhs.uk/uploads/vhsumm.pdf

Mencap (2004) Treat me right! Better healthcare for people with a learning disability
http://www.mencap.org.uk/document.asp?id=316

Mencap has a series of information leaflets on healthcare topics, including:
all available on http://www.mencap.org.uk/ under resources

- Diagnosing a learning disability
- Diet and people with a learning disability
- Epilepsy and people with learning disability
- Foot care and people with a learning disability
- Hearing, ears and people with a learning disability
- Learning about intellectual disabilities and health
- Mental health problems and learning disability
- Oral health and people with a learning disability

Valuing People Support Team (2004) Healthy Lives reading list
http://www.valuingpeople.gov.uk/echo/filedownload.jsp?action=dFile&key=943

Valuing People Suggested Areas of the PPF Requiring Explicit Consideration of the Health Needs of People with Learning Disabilities
http://www.valuingpeople.gov.uk/dynamic/filedownload.jsp?action=dFile&key=660

Valuing People Support Team The Valuing People Support Team Newsletter June 2004: All about health http://www.valuingpeople.gov.uk/

Health Inequalities

Baxter H, Lowe K, Houston H, Jones G, Felce D, Kerr M. (2006) Previously unidentified morbidity in patients with intellectual disability. **British Journal of General Practice.** 56, 93-98

Cooper SA, Morrison J, Melville C, Finlayson J, Allan L, Martin G, Robinson N. (2006) Improving the health of people with intellectual disabilities: outcomes of a health screening programme after one year. **Journal of Intellectual Disability Research**. 667-677

Hollins et al (1998) Mortality in people with learning disability: risks, causes and death certification in London **Developmental Medicine and Child Neurology** 40: 50-56

Lennox et al. (2007) Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. **International Journal of Epidemiology**. 36, 1, 139-146

Mencap (2007) Death by Indifference http://www.mencap.org.uk/document.asp?id=284

Michael J, (2008) Healthcare of All: Independent Inquiry into Access to Healthcare for People with Learning Disabilities full report

Medication (also see accessibility above)

Association for Real Change (2005) Handling Medication in Learning Disability Social Care Settings -A guide and training framework for social care organisations
http://www.arcuk.org.uk/388/default/managing+medication.html

Learning disabilities and medication free download page from The University of Birmingham
http://www.ld-medication.bham.ac.uk/download.htm

Menopause and women with learning disabilities

Research report and recommendation for good practice
http://www.learningdisabilities.org.uk/publications/?esctl526505_entryid5=22304&char=M

Mental health

Valuing People Support Team (2004) Green Light for mental health: A service improvement toolkit http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=64540

Free resources pack to download
http://www.learningdisabilities.org.uk/publications/?esctl526505_entryid5=22305&char=M

Pain and Distress

DISDAT tool for assessing distress in people with cognitive impairment
http://www.mencap.org.uk/document.asp?id=1476&audGroup=&subjectLevel2=&subjectId=&sorter=1&origin=pageType&pageType=112&pageno=&searchPhrase=

Review
http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=313555&tabID=289

Assessing pain in people with learning disabilities
http://www.library.nhs.uk/learningdisabilities/viewResource.aspx?resID=259948

Partnership boards

British Institute of Learning Disabilities Factsheet – Partnership Boards
http://www.bild.org.uk/pdfs/05faqs/pb.pdf

Patient safety

National Patient Safety Agency (2004) Understanding the patient safety issues for people with learning disabilities This and other reports can be accessed at http://www.npsa.nhs.uk/nrls/ , use the websites search engine with the term learning disabilities

Policy

NHS (2007) Primary Care Service Framework: Management of Health for People with Learning Disabilities in Primary Care http://www.pcc.nhs.uk/204.php

DH (2001) Nothing About Us Without Us, Department of Health Details on http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4006200&chk=4h3g2I

DH (2001) Nothing About Us Without Us The Service Users' Advisory Group Report to the Government http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4006200&chk=4h3g2I

DH (2001) Valuing People: A New Strategy for People with Learning Disability for the 21st Century Department of Health DH

DH (2009) Valuing People Now: A three year Strategy for People with Learning Disabilities http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Learningdisabilities/DH_079430

DH (2006) Our health, our care, our say: a new direction for community services. A White Paper from the Government about health and social care. Easy read. Department of Health http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4127453&chk=NXIecj

NHS Executive (1999) Once a day one or more people with learning disabilities are likely to be in contact with your primary healthcare team. How can you help them? http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4006868&chk=tw4Ywq

Prader-Willi Syndrome

General information including health screening http://www.patient.co.uk/showdoc/40001423/

Profound and multiple learning disabilities (pmld)

PMLD Network resources page http://www.pmldnetwork.org/resources/index.htm

DH (2004) National Service Framework for Children, Young People and Maternity Services: Standard 8: Disabled children and young people and those with complex health needs http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089112

DH (2005) Complex disability exemplar. National service framework for children, young people

and maternity services
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4123814

Retts Syndrome

Information about Retts Syndrome including associated health problems
http://www.intothemainstream.cswebsites.org/default.aspx?page=12950

Sensory Loss

Look Up, info on eye care and people with learning disabilities
http://www.lookupinfo.org/index.php?id=14

Look Up, info on hearing loss and people with learning disabilities
http://www.lookupinfo.org/index.php?id=12

College of Optometrists (2005) Examining the patient with learning disabilities (Optometry)
http://www.college-optometrists.org/coo/objects_store/24_10_05.pdf

See ability report on eye health and people with learning disability
www.seeability.org/

Using and get used to hearing aids http://www.easyhealth.org.uk/FileAccess.aspx?id=2212

Statistics

NHS (2005) Adults with Learning Difficulties in England 2003/4
http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/GeneralSurveysArticle/fs/en?CONTENT_ID=4081207&chk=u%2Bd5fv

Syndromes

A comprehensive list of syndromes including specific health screening required can be down loaded from
http://www.intothemainstream.cswebsites.org/default.aspx?page=7393

Charities and organisations

British Institute of Learning Disabilities (BILD) Campion House Green Street Kidderminster Worcestershire DY10 1JL
Tel: 01562 723010
Fax: 01562 723029
Email: enquiries@bild.org.uk
enquiries@bild.org.uk
http://www.bild.org.uk/

Connects: the mental health and learning disabilities portal
http://www.connects.org.uk/

The Foundation for People with Learning Disabilities 9th Floor, Sea Containers House 20 Upper Ground London SE1 9QB
Tel: 020 7803 1100
Fax: 020 7803 1111.
Email: fpld@fpld.org.uk
http://www.learningdisabilities.org.uk/

Health and Learning Disability Network
http://www.learningdisabilities.org.uk/ldhn/

Mencap 123 Golden Lane London EC1Y 0RT
Tel: 020 7454 0454 Fax: 020 7696 5540 Email: information@mencap.org.uk
www.mencap.org.uk

The National Autistic Society 393, City Road London EC1V 1NG
Tel: 020 7833 2299 Fax: 020 7833 9666 Email: nas@nas.org.uk http://www.nas.org.uk/

National Network for Learning Disabilities Nurses http://www.networks.nhs.uk/themes.php

PMLD Network (support of people with profound and multiple learning disabilities)
http://www.pmldnetwork.org/

Scope, 6 Market Road, London N7 9PW,Tel: 020 7619 7100.
http://www.scope.org.uk/

Valuing People Support Team email: valuing.people.info@doh.gsi.gov.uk
http://www.valuingpeople.gov.uk/

Bristol Community Learning Disabilities Teams website
http://www.bristollearningdifficulties.nhs.uk

Databases and libraries

Foundation for people with learning disabilities, library of publications many free to download
http://www.learningdisabilities.org.uk/publications/?char=A

NHS Health information resources http://www.library.nhs.uk/Default.aspx

NHS National Electronic Library: learning disabilities
http://www.library.nhs.uk/LEARNINGDISABILITIES/

Training

BILD offer training

Worcestershire DY10 1JL
Tel: 01562 723010
Fax: 01562 723029
Email: enquiries@bild.org.uk
enquiries@bild.org.uk
http://www.bild.org.uk/

Bristol and South Glos offer training; this is delivered by people with learning disabilities

Unit 35-36 Easton Business Centre,
Felix Rd, Bristol,
BS5
0117 941 5842

Your local CLDT may be able to offer training

Bristol North Community Learning Disability Team
(Brentry) 0117 9085000

Bristol Central Community Learning Disability Team
(Stapleton) 0117 9585666

Bristol South Team Community Learning Disability Team
(Withywood) 0117 9878383

The University of the West of England offer training from workshop, to credited modules

If you wish to commission training contact

Lesley Donovan
UWE Glenside Campus
Bristol
BS16 1DD
Lesley.Donovan@uwe.ac.uk
0117 32 88775

Or visit our website www.uwe.ac.uk and our continuing professional developments pages at http://cpd.hsc.uwe.ac.uk/welcome.aspx