



Public Health
England

Improving the health and wellbeing of people with learning disabilities

Guidance for social care providers and
commissioners (to support
implementation of the health charter)

Revised September 2015

The logo consists of a teal square containing the words "HEALTH" and "CHARTER" in white, bold, sans-serif capital letters. "HEALTH" is on the top line and "CHARTER" is on the bottom line.

HEALTH
CHARTER

The logo consists of a dark blue square containing the text "Voluntary Organisations Disability Group" in white, sans-serif capital letters.

Voluntary
Organisations
Disability Group

V O D G

About Public Health England

We work with national and local government, industry and the NHS to protect and improve the nation's health and support healthier choices. We address inequalities by focusing on removing barriers to good health.

We were established on 1 April 2013 to bring together public health specialists more than 70 organisations into a single public health service.

Public Health England
133-155 Waterloo Road
Wellington House
London SE1 8UG
Tel: 020 7654 8000
<http://www.gov.uk/phe>
[@PHE_uk](#)

www.improvinghealthandlives.org.uk

Twitter - [@ihal_talk](#)

Prepared by: Sue Turner & Carol Robinson
For queries relating to this document, please contact: sue.turner@ndti.org.uk
© Crown Copyright 2014
Published February 2014
PHE gateway number: GN 2013482

This document is available in other formats on request. Please call 020 8327 7018 or email publications@phe.gov.uk



Improving Health and Lives
Learning Disabilities Observatory

Contents

About Public Health England	2
Easy Read Summary	4
Introduction	11
The Charter Statements and guidance	13
References	29

Easy read summary

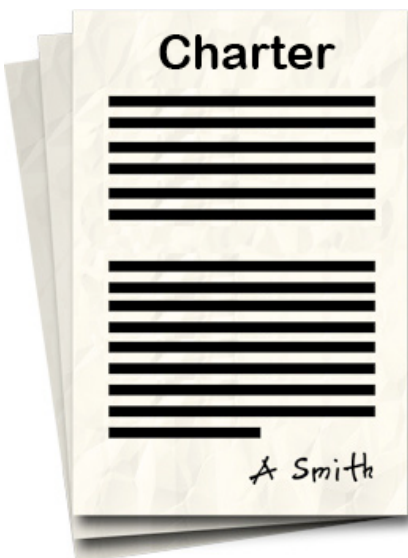


People with learning disabilities often have poor health



Social care staff can help people with learning disabilities use health services

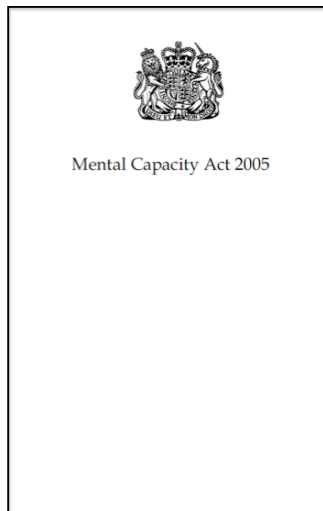
They can help people live healthier lives



Social care staff can sign a charter to say what they will do to help people with learning disabilities be more healthy



This is what the charter says



All staff should understand and use the Mental Capacity Act



Listen to and involve family carers



There should be training for staff on –

Healthy lifestyles

Knowing if someone is in pain

Health problems people might have





People should be helped to understand about their health, using accessible information



If you go to a health appointment, you should have someone with you who knows you and can support you well.



People should be helped to go to health screening appointments





Staff should be able to give medicines safely



People should be supported to go for health checks

A sample Health Action Plan form. It includes the title 'Health Action Plan', an illustration of two people looking at a document, and a section for 'Name:' and 'Date of Birth:'. A red box at the bottom says 'Private - to be kept safe.'

People should have health action plans and hospital passports if they want them





If people have lots of health problems we will ask for a health co-ordinator

Improving the health and wellbeing of people with learning disabilities. Guidance for social care providers and commissioners

We would like to thank everyone who contributed to this document including:

Self Advocates from the Changing our Lives group - Wolverhampton

All the family carers who met in Leeds specifically to discuss health issues affecting their sons and daughters

Anna Marriott, Research Fellow on the Confidential Inquiry into Premature Deaths of People with Learning Disabilities, the Norah Fry Research Centre, University of Bristol

John Adams , General secretary, VODG

Jean Jay, Director of Quality, and all her colleagues at Vibrance

Julie Harding, Director of Business Development, Choices Housing Association

Lisa Greg–Herrett , Assistant Director Quality and Learning and Development, ChoiceSupport

Jill Roberts , Policy and Practice Advisor, Action on Hearing Loss

Margaret Sharpe, Assistant Director, Workforce Development, the Westminster Society for People with Learning Disabilities

Cally Ward, self employed consultant and trainer and NDTi Associate

Liz Wilson, Dimensions family carers' lead

Members of the Voluntary Organisations Disability Group (VODG)

.We would also like to thank everyone who responded to the Health Charter for Social Care Provider survey 2015 for additions to the revised guidance.

Introduction

People with learning disabilities have poorer health than the general population, much of which is avoidable. This means that people with learning disabilities experience health inequalities, often starting early in life. The impact is serious. As well as having a poorer quality of life, people with learning disabilities die at a younger age than their non-disabled peers. There are five determinants of health inequalities ¹:

1. Greater risk of exposure to the social determinants of poorer health such as poverty, poor housing, unemployment, discrimination and isolation.
2. Increased risk of health problems associated with specific genetic, biological and environmental causes of learning disabilities.
3. Communication difficulties and reduced understanding of health issues.
4. Personal health risks and behaviours such as poor diet and lack of exercise.
5. Problems with access to healthcare provision.

Although health services have an important role to play, and need to do more to make their services accessible, many of the health issues that people with learning disabilities face are to do with social determinants of poorer health, and the support they receive regarding general health and wellbeing. Social care providers and support staff have an important role to play in promoting general health and wellbeing, and enabling access to primary health services.

In order to support social care staff in this role the Learning Disabilities Public Health Observatory (LDPHO: www.ihal.org.uk) has been working with the Voluntary Organisations Disability Group (VODG: www.vodg.org.uk/), the leading umbrella group of voluntary sector providers of social care services for adults, to develop guidance and a self-assessment exercise based on a charter.

Who should sign up to the charter?

Social care provision is complex, with large and small organisations providing a range of support and services. We suggest that where possible, the social care provider organisation should sign up to the charter, and support their staff regarding implementation. However, staff teams within organisations may also want to sign up to the charter to enable those they support to improve their health and wellbeing.

What support do providers need to implement the charter?

Social care providers should talk to their commissioners and healthcare colleagues about the charter. Many community learning disability healthcare teams have expressed their support for this initiative, and will be willing to work with providers on implementation. Learning Disability Partnership Boards should be included in the discussion, and may want to play a role in overseeing progress. The Health Equality Framework (HEF), an outcomes tool based on the determinants of health inequalities complements the Charter. It designed to help commissioners, providers, people with learning disabilities and their families understand the impact and effectiveness of services. For further information see:

www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1 The charter also supports the implementation of the Joint Self-Assessment Framework. For further information see:

www.improvinghealthandlives.org.uk/projects/jhscsaf2014results

Implementing the charter

The charter statements are set out below, along with some information about why each one is important, some practical tips and links to further resources.

It is important to remember that public sector agencies are required under the Equality Act 2010² and the NHS and Social Care Act 2008 (Regulated Activities) Regulations³ to make 'reasonable adjustments' to their practice that will make them as accessible and effective as they would be for people without disabilities. Reasonable adjustments include removing physical barriers to accessing health services, but importantly also include making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities. This legal duty for health services is 'anticipatory', meaning that public sector organisations are required to consider in advance the adjustments people with learning disabilities will require, rather than waiting until people with learning disabilities experience problems using health services.

The Charter statements and guidance

Charter Statement 1: Make sure that all staff understand and apply the principles of mental capacity laws

Why is this important?

The Mental Capacity Act 2005 ⁴ is designed to make a real difference to the lives of people who lack the capacity to consent. It supports people to make decisions for themselves wherever possible, and puts the person at the heart of the decision making process. The legislation sets out five key principles to determine whether a person has the capacity to consent to treatment:

- a person must be assumed to have capacity unless it has been clearly established that they lack capacity regarding the specific decision under consideration at that point in time
- a person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success
- a person is not to be treated as unable to make a decision merely because he/she makes what is considered to be an unwise decision
- an act done, or decision made, under the Mental Capacity Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests
- before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action

It also sets out how to make decisions in a person's 'best interests' if they are unable to consent. However the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) ⁵ found problems with assessment of capacity, Best Interest decision making, and failure to follow national guidance regarding decisions to attempt cardiopulmonary resuscitation. The following two case studies from the Confidential Inquiry highlight some of the issues they found.

When Brenda was admitted to hospital her medical notes on admission described her as 'mute, aphasic and having learning difficulties.' A plan was made to stop any treatment for her and to transfer her back to the nursing home for 'TLC' (tender, loving care). The nursing home manager disagreed with this treatment plan as did Brenda's GP. The nursing home manager reported to the CIPOLD review that she had to insist on the Mental Capacity Act being followed and a Best Interest meeting being held, and had explained to the doctors that 'just asking the relatives would have been illegal'.

A Best Interest meeting was held that afternoon, attended by the hospital doctors involved, the nursing home manager, hospital Learning Disability Liaison Nurse, and four members of Brenda's family. Active treatment was resumed as a result of the decisions made. Brenda improved within 48 hours, was discharged 2-3 weeks later and lived for more than another year before dying peacefully at home.

The agencies attending Frances when she became acutely unwell apparently thought that 'capacity' was a once and for all concept, and did not appreciate that it should be reassessed for each new decision and in each new set of circumstances. When she became increasingly unwell Frances refused to go to hospital. She said that she had been to the hospital once and did not want to go back again. The paramedics established that she had been assessed as having the capacity to make this decision and decided that they were powerless to act. Early the following morning it was apparent that Frances needed urgent life-saving medical attention, but she was still refusing to go to hospital. The attending GP did not reassess her capacity regarding this decision, but relied on her previous mental capacity assessment when she was less critically ill. It was not until she collapsed several hours later that she was taken to hospital and received surgical treatment, but she did not recover and died two weeks later.

Resources and practical tips

The Mental Capacity Act Code of Practice can be downloaded from:

www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

A helpful guide to the Mental Capacity Act can be found at: www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/

A Mental Capacity Act Best Interest Pathway can be downloaded from:

www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=176

Charter Statement 2: Listen to, respect and involve family carers to achieve the best possible outcomes for the individual

Why is this important?

Families usually know the person best, and have a wealth of knowledge about the individual, their likes and dislikes, how they communicate and what to look out for if the person is unwell or in pain. There are numerous examples of families acting as advocates for their relative.

However there is plenty of evidence to show that families are not always listened to, and the consequences for the individual can be serious, leading to poor care, lack of pain relief and premature death as the following example from the Confidential Inquiry demonstrates.

Justin was a young man with Down's syndrome who died as a result of a pulmonary thromboembolus as a consequence of a deep vein thrombosis. He had complained of pain in his left leg after sitting cross-legged for a prolonged period of time (playing computer games). On visiting a Locum GP at the surgery, left knee pain was documented with the history as described. The GP thought that this might be a tendonitis having examined him and found no calf swelling and no temperature, and prescribed ibuprofen, asking him to return after the bank holiday. The pain did not get better over the Christmas period. Whilst mum described Justin as sometimes "dragging things out a bit", she also recognised that he had a very high pain threshold. She reports that over this period, Justin made attempts to be 'himself' but that he wasn't able to. Justin returned to the surgery six days after his initial visit. He saw a different doctor who hardly looked at him and was very dismissive. Records document that Justin was limping and complaining of pain in his left ankle. On examination, the area inferior to the medial malleolus had a slight rash and was tender to the touch and the GP queried whether or not this was a sprain, despite his mum telling her he had been sedentary for the last three days. She prescribed ibuprofen and asked him to return in a week. Justin did not return to the surgery. His left leg remained swollen and painful and just over 10 days later Justin collapsed on the floor, struggling to breathe. Paramedics worked really hard to resuscitate Justin and he was transferred via helicopter to the local Accident and Emergency Department. Blood gases revealed readings that were not compatible with life and following a discussion of all present, cardiopulmonary resuscitation was terminated.

Resources and practical tips

The Mencap report *Death by Indifference. 74 deaths and counting* has a number of case studies illustrating the problems families face in getting their good health care for their relative. The document can be downloaded from: www.mencap.org.uk/74deaths

Improving the health and wellbeing of people with learning disabilities. Guidance for social care providers and commissioners

There is a video clip on the IHaL website of Tony (a man with learning disabilities) and his sister, talking about Tony's experience in hospital:

www.improvinghealthandlives.org.uk/videos/nhsexperience

HFT, a provider organisation, worked with family carers, health and social care staff to develop a guide for hospitals, families and paid staff called Working Together: easy steps to improving how people with learning disability are supported when in hospital.

The guide sets out the actions that family carers, paid support staff and hospital staff can take to achieve the best outcomes for people with learning disabilities at different stages of the admission and discharge process: before admission, at or during admission, during a stay in hospital and on discharge. At the back of the booklet, there is a Checklist for an admission meeting, plus links to other sources of useful information, such as the Traffic Light Hospital Assessment and the Risk, Dependency and Support Assessment forms.

The guide has been updated by the LDPHO and can be found at:

www.ihal.org.uk/publications/1247/Working_together_2:_Easy_steps_to_improve_support_for_people_with_learning_disabilities_in_hospital

Charter Statement 3: Provide on-going training to staff on basic health and wellbeing issues including pain recognition, and the implications of specific syndromes and health conditions

Why is this important?

There are a number of syndromes associated with learning disabilities that are also associated with specific health risks. For example, people with Down's syndrome are more likely to have dementia, and people with autistic spectrum disorders are more likely to have mental health problems.

People with learning disabilities may find particular environments more difficult to cope with. For example, people with autistic spectrum disorders may find busy environments difficult to cope with, leading to behaviours that challenge if this is not understood ¹.

People with learning disabilities may also find it difficult to tell people they are in pain. Lack of recognition of pain can mean that health problems are not diagnosed, can lead to challenging behaviour and of course significantly affects quality of life, as the following case study from the Confidential Inquiry demonstrates.

Phil had congenital rubella which affected his eyesight, hearing and to a limited extent, his cognitive abilities. He communicated with BSL and his support staff were trained in this. He was fairly independent and lived in supported living with two others where he had 11 hours of support per week to provide assistance with shopping, healthy eating, maintaining a safe environment at home, dealing with letters, bills and maintaining social contact with his friends and family.

Phil developed diabetes and this proved very difficult to manage because he would not take his medication reliably nor tolerate blood tests. Both professionals and support staff made little progress in trying to get Phil to take his medication, agree to blood tests and no alternative approaches to managing his diabetes were tried. e.g. using urine sticks instead of blood tests to monitor his condition. Phil died unexpectedly in his forties and staff were shocked and upset by his death. No one had talked to them about the health risks associated with congenital rubella syndrome such as thyroid conditions and diabetes and the importance of regular medical check-ups.

Resources and practical tips

Information on syndromes and health risks is available at:

www.easyhealth.org.uk/categories/health-leaflets

Encouraging people to have regular health checks is important (see below). A number of syndrome specific checks are available. See: www.rcgp.org.uk/clinical-and-research/clinical-resources/learning-disabilities.aspx

Good knowledge of the person, and a record of how they present when they are well/not well is important for identifying possible health problems/pain. A pain identification tool is available.

See: www.disdat.co.uk/

Community learning disability teams can often provide support and training to help understand individual's specific needs, and the best way of working with them.

Charter Statement 4: Provide information on health and wellbeing that is accessible to people with a learning disability

Why is this important?

Many people with learning disabilities have a poor diet, and do not take much exercise. People with learning disabilities are more likely to be overweight than the general population, and are at an increased risk of diabetes.¹ People with learning disabilities are also more likely to be underweight than the general population, and this can make them vulnerable to a premature death.⁵

Supporting people to understand more about their bodies and health issues in general, can enable people to take more responsibility for their health, and can improve health and wellbeing generally.

It will also be important to ensure support staff understand about healthy diets and the importance of exercise, so that they can support people with learning disabilities. Malcolm, a self-advocate told us his story.

Malcolm has several health problems including epilepsy, diabetes, high blood pressure and raised cholesterol levels. He lives in supported living and has a few hours of support several days a week but his support hours have been reduced recently. He is very positive about the staff who support him and says they help him to manage his health conditions by:

- supporting him to choose healthy foods in line with his GP's advice. They do this by checking food packets for sugar, fat and calorie content
- encourage him to cut down the amount he has at each meal
- only taking him to cafes and restaurants that serve healthy options
- helping him limit the number of treats he has, like chocolate and alcohol
- helping him to get to health appointments and acting as both interpreters and advocates to ensure he gets the treatments he needs. Malcolm says he often does not understand what the doctors or receptionists are saying
- encouraging him to walk and take other exercise although he no longer has enough hours of support to have staff accompany him to his favourite exercise class

By doing all this, Malcolm has been able to lose 8 inches off his waistline.

Tom's family told us about how they worked with staff to improve his health.

Tom is a young man in his twenties who lives in supported living. Although Tom was previously both very active and slim, he is currently seriously obese. In order to help him lose weight, the family is working with his support staff to help him manage his food intake and take some exercise.

Food is central to Tom's life; he will devour whatever is put in front of him and has a preference for 'junk food and drink'. Any perceived change to his diet is seen as a threat that causes him anxiety and can lead to aggressive outbursts. Tom has severe autism and has become very rigid about what he will and won't do. Some of the things he used to do but will no longer consider include walking, going to the gym and horse riding. The family have talked to staff about their duty of care and their view that personalisation does not mean allowing Tom to eat anything and everything that he wants as he has limited understanding of the impact this has on his health.

Staff have agreed to support a weight reducing diet and have found creative ways of encouraging him to reduce his food intake and take some exercise. They currently are aiming to help him lose one pound of weight per month and have found some things that help:

- give written or pictorial advice rather than just saying what would help
- shop online to ensure Tom is not putting all unhealthy choices in his trolley
- split large boxes of things like chicken nuggets into smaller packets so that he has only a meal's worth of food not the whole packet in one sitting. Tom is OK with this as long as he can finish the packet
- using smaller plates when serving meals
- replacing sweet fizzy drinks with their diet counterparts
- on new bus routes, getting off the bus one or two stops early
- taking Tom bowling once a fortnight
- taking Tom to the sea-side where he is happy to walk for miles

The new regime is currently working and Tom is slowly losing weight.

Resources and practical tips

There is a new accessible information standard for organisations that provide NHS or publicly funded adult social care. The standard sets out how they should ensure that people who use services and, where appropriate, carers and parents, receive information in formats that they can understand, and that they receive appropriate support to help them to communicate.

For further information see: www.england.nhs.uk/ourwork/patients/accessibleinfo-2/

There are a number of accessible resources available at:

www.easyhealth.org.uk

www.improvinghealthandlives.org.uk/adjustments/

www.apictureofhealth.southwest.nhs.uk



Charter Statement 5: Make sure support is available from someone who can, if necessary, advocate on behalf of the individual so that people can attend and benefit from all types of health appointments

Why is this important?

Some people with learning disabilities are afraid of medical professionals. CIPOLD ⁵ found that one of the factors contributing to the early death of people with learning disabilities was delays in diagnosis and treatment of health problems. They also found that little was done to address people's fear of medical professionals, and this was difficult when an emergency arose. People with learning disabilities are likely to feel less anxious if they have someone with them who they know well. It is also very helpful for mainstream health staff to have someone there who can support the person appropriately, and answer questions if the person can't answer them for themselves. The following examples are from provider organisations.

Alex was petrified of going to the dentist but she was getting problems with her teeth. A dental practice has opened next to her GP surgery and she has recently been attending appointments with the dentist. Alex's support worker understood that she had a real fear of going to the dentist so spoke to the dentist to explain this so the dentist was prepared. At the appointment, Alex attended with her supporter and the dentist took a lot of time to say that she understood dentists can be scary and explain what she needed to do. Because the dentist was so patient and the supporter worker was there to reassure Alex, the necessary check-up took place and led to Alex agreeing that she would have treatment. Alex has really overcome her fear of dentists and has recently agreed to let some dental students work on her teeth.

Maggie has a diagnosis of autism and can present challenging behaviour. She lives in supported living accommodation. Support workers noticed that she was not eating properly and was losing weight. She was more aggressive and would shout and scream at anyone within the home especially after meals. A member of staff made an appointment for Maggie to see her GP and a worker who knew her well accompanied her. The GP insisted her behaviour was due to mental health issues, not physical problems, and made a referral to a psychiatrist. The staff were not convinced, so they talked to her family about their medical history and discovered there was a family history of stomach ulcers. Staff then returned to the GP to insist on more investigations. The GP referred Maggie for an ultrasound and she was diagnosed with gallstones, which were removed. Since then, Maggie has fully regained her appetite and weight and is doing activities again.

Resources and practical tips

The How-to guide 4 (Health) for people with profound and multiple learning disabilities contains some background information on common health issues amongst people who have profound and multiple learning disabilities. It can be downloaded from:

www.mencap.org.uk/sites/default/files/documents/2012.340%20Raising%20our%20sights_Guide%20to%20health_FINAL.pdf

If you require Independent Health Complaints Advocacy, please refer to: www.healthwatch.co.uk/

Charter Statement 6: Promote access to screening tests by:

- helping staff and the people we support understand their importance.
- working in partnership with clinical services to ensure support is available before, during and after screening checks

Why is this important?

People with learning disabilities are more likely to have sight and hearing problems than other people. They are also more likely to have unhealthy teeth and gums. People with learning disabilities are less likely to make use of screening services, and are therefore at risk of undetected cancer and other health problems.¹ The following example is from a provider organisation.

Saul was from a loving family of Asian origin and he was attending a day service provided by an independent organisation. He and his two siblings have the same inherited condition of Tuberous Sclerosis which can cause tumours to grow on soft internal organs and on the face and body. In Saul's case, his condition was also associated with behaviour that could be extremely challenging so support was needed for him to be able to attend any hospital appointments. Despite this, it was possible for Saul to have regular checks to monitor him for tumours because he and his family were provided with the support they needed by staff from the day service. Sadly, at one of these check-ups, it became clear that Saul had developed cancer of the liver. He was able to receive the treatment he needed with ongoing support that not only helped reduce his challenging behaviour but also helped his mother and him fully understand what was happening with regard to his treatment.



Resources and practical tips

Health Action Plans (HAPs) can help people with learning disabilities to understand their own health needs, and should include information about health appointments, and when they are due. Local learning disability teams may be able to help with Health Action Plans. If the person has an annual health check (see below), they should have an action check list which can form part of the HAP. Examples of HAPs can be downloaded from:

[www.easyhealth.org.uk/listing/health-action-plans-\(leaflets\)](http://www.easyhealth.org.uk/listing/health-action-plans-(leaflets))

SeeAbility has lots of information and easy read fact sheets about eye care and sight problems. See: www.seeability.org/our-specialisms

The *Reasonable adjustments in eye care services* document also includes links to helpful information, and has examples of some of the reasonable adjustments that can be put in place to improve access to eye care services. See:

[www.improvinghealthandlives.org.uk/publications/1167/Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities](http://www.improvinghealthandlives.org.uk/publications/1167/Making_Reasonable_Adjustments_to_Eye_Care_Services_for_People_with_Learning_Disabilities)

Making Reasonable Adjustments to Dentistry Services has links to further information and examples of reasonable adjustments. See:

[www.improvinghealthandlives.org.uk/publications/1141/Making Reasonable Adjustments to Dentistry Services for People with Learning Disabilities](http://www.improvinghealthandlives.org.uk/publications/1141/Making_Reasonable_Adjustments_to_Dentistry_Services_for_People_with_Learning_Disabilities)

Making Reasonable Adjustments to Cancer Screening also has links to further information and examples of reasonable adjustments. See:

[www.improvinghealthandlives.org.uk/publications/1126/Making Reasonable Adjustments to Cancer Screening](http://www.improvinghealthandlives.org.uk/publications/1126/Making_Reasonable_Adjustments_to_Cancer_Screening)

A screening strategy and toolkit designed to support local areas to improve uptake of the five national screening programmes by people with learning disabilities is available at:

www.ndti.org.uk/publications/ndti-publications/screening-services-strategy-and-toolkit

Charter Statement 7: Provide clear guidance to staff relating to each individual that will allow them to administer prescription and non-prescription remedies safely

Why is this important?

People with learning disabilities are often on a large amount of medication, and it is crucial that this is administered correctly. People with learning disabilities should be supported to know about their medication and potential side effects where possible. Staff also need to understand possible side effects and what to look out for.

People with learning disabilities may need non-prescription remedies such as pain relief. It is important that there are robust protocols in place to enable administration, so that people are not left in unnecessary pain or discomfort. The following example is from a family carer.

Max was admitted to hospital for a planned operation, which went well. The ward staff noted that he seemed to have difficulty hearing even though his notes never mentioned any hearing loss. A quick examination revealed that he had a lot of impacted wax in his left ear and on discharge, a nurse recommended to his parents that olive oil spray should be used to soften it prior to his ear being syringed. Although he had several types of medication from the hospital, the olive oil was not listed so that when he returned to his residential home, staff said they could not administer it. His elderly parents therefore had to go to the care home twice a day for a week to make sure the oil was used. They said they preferred to do this than 'battle it out' with the provider or go back to the hospital to get the recommended treatment prescribed.

Resources and practical tips

A report on use of psychotropic medication for people with learning disabilities and people with autism is on the LDPHO website:

www.ihal.org.uk/publications/1248/Prescribing_of_psychotropic_medication_for_people_with_learning_disabilities_and_autism

Information about medicines and side effects is available on the Easyhealth website:

[www.easyhealth.org.uk/categories/medicines-\(leaflets\)](http://www.easyhealth.org.uk/categories/medicines-(leaflets))

Information about pain killers is available on the Easyhealth website:

[www.easyhealth.org.uk/listing/painkillers-\(leaflets\)](http://www.easyhealth.org.uk/listing/painkillers-(leaflets))

Charter Statement 8: Facilitate access to an annual health check for every eligible person with a learning disability

Why is this important?

People with learning disabilities may have poor awareness of their bodies and health issues generally. They may not express pain or discomfort in a way that others recognise. Limited communication skills may reduce their ability to let others know that something is wrong. As a result, people with learning disabilities often have unmet health needs.¹ We know from research that health checks identify unmet health needs and lead to actions to address these needs.⁶ They are an important reasonable adjustment that primary care services can put in place to reduce health inequalities. Maurice, a self-advocate, told us about his experiences.

Maurice has been having annual health checks for several years. His support staff have always encouraged him to attend and have, at Maurice's request, accompanied him to make sure he understands what is going on. Through having an annual health check, Maurice has found out that he has several chronic health conditions that he did not know he had and as a result of his diagnoses, his GP has introduced new treatment, offered him a flu jab each year and now monitors his lifestyle to make sure none of his health conditions become more serious.

Resources and practical tips

Supporting the person to understand the importance of a health check

Easy read information about health and keeping healthy can be found at:

www.easyhealth.org.uk

Supporting the person to ask the GP for a health check

Mencap in partnership with the Royal College of General Practitioners and Improving Health and Lives has developed a leaflet for people with learning disabilities, and one for carers, about the rights of people with learning disabilities to a health check, and what they can expect. The leaflets can be downloaded from: www.mencap.org.uk/all-about-learning-disability/information-professionals/health/health-tools-and-resources-useful-links

Improving the health and wellbeing of people with learning disabilities. Guidance for social care providers and commissioners

A database of 'reasonable adjustments' made by health agencies is maintained by the Learning Disabilities Public Health Observatory at <http://www.improvinghealthandlives.org.uk/adjustments/>

Supporting the person to fill out the pre-check questionnaire

Filling out a pre-check questionnaire can help prepare the individual for the health check, and can save time at the doctors. An example of a pre-check questionnaire can be found at: www.oxleas.nhs.uk/gps-referrers/learning-disability-services/health-check-resources/

Working with community teams and GP practice staff to put in place reasonable adjustments needed for a successful health check

Some areas have health facilitators or primary care liaison staff who work with GP practices to help make them more accessible. In other areas the community learning disability team does this work. It is helpful to find out what the arrangements are locally, and contact the learning disability health staff to talk about any reasonable adjustments needed.

Arranging for someone who knows the person well to go with them to the health check

People with learning disabilities are likely to feel less anxious if they have someone with them who they know well. It is also very helpful for health staff, and is likely to lead to a better health check and outcomes.

If the person has health needs, supporting him/her to ask for a Health Action Checklist or plan from the GP

It is important that any health actions and referrals from a health check are followed up. Examples of health action checklists can be found in a Step by Step Guide for GP practices: www.rcgp.org.uk/clinical-and-research/clinical-resources/learning-disabilities.aspx

Charter Statement 9: Ensure each person supported by our organisation who wants one, has a health action plan and hospital passport

Why is this important?

Health Action Plans (HAPs) and health passports can help health staff understand what a person's needs are, what reasonable adjustments need to be in place, and how to communicate with people, but they only work if they are available and shared. The Confidential Inquiry into the deaths of people with learning disabilities found that where these documents were used, they were helpful, but that not many people had them, and HAPs were not used to share information effectively.⁵

Many hospitals have learning disability Acute Liaison Nurses who will help people with learning disabilities, family, carers, support staff and internal staff when someone with a learning disability is admitted to hospital. It is important that everyone knows who the Acute Liaison Nurse is at the local hospital. A map of acute liaison nurses showing where acute liaison nurses work and their contact details is available at: www.improvinghealthandlives.org.uk/aln/

End of life care should also be considered and preferences recorded so that people with learning disabilities and their families are able to ensure that their wishes are taken into consideration when a person with learning disabilities is approaching the end of their life. The following examples are from a provider organisation and a self-advocate.

In one residential home where all the residents have significant, chronic health issues, the health records are evaluated and summarised on a monthly basis and cross-referenced to health action plans. This exercise is used as a mechanism to monitor actions and interventions to meet health needs so that all health appointments are put in the diary and a member of staff allocated to ensure people can attend with support. The health action plan also informs the goals that are written into each resident's person-centred plan.

Sean lives in supported living and has a consistent female support worker who visits him to make sure he is well, has everything he needs and is on top of his post and bills. Sean has a health action plan that was written with his support worker. This is where all the things that are important for Sean's health are written and it covers things like exercise, diet, forthcoming medical and dental appointments, his medications, when his injection is due and when his next health check is scheduled. His support worker takes responsibility for keeping Sean's health action plan updated and reminding Sean about his appointments.

Resources and practical tips

Examples of health action plans can be downloaded from:

[www.easyhealth.org.uk/listing/health-action-plans-\(leaflets\)](http://www.easyhealth.org.uk/listing/health-action-plans-(leaflets))

Examples of health passports can be downloaded from: [www.easyhealth.org.uk/listing/hospital-passports-\(leaflets\)](http://www.easyhealth.org.uk/listing/hospital-passports-(leaflets))

A copy of the Confidential Inquiry report can be found at: www.bris.ac.uk/cipold/

Easy-read end of life planning documents can be found at:

www.improvinghealthandlives.org.uk/search.php?q=end+of+life&f=21

Tip - It may be beneficial to visit people with learning disabilities who are in hospital at mealtimes.

Charter Statement 10: If the person has more than one long term health condition including mobility issues, we will request a healthcare coordinator is made available

Why is this important?

The Confidential Inquiry into premature deaths of people with learning disabilities found that many people with learning disabilities had multiple, complex healthcare needs that services struggled to respond to. They recommend that people with learning disabilities with two or more long-term conditions should have a named health care co-ordinator who can enable people to navigate the health care system, ensure proactive support to manage health needs and assist with the development of health action plans, pain assessment tools, access to screening and ensuring reasonable adjustments are provided. This example is from the Confidential Inquiry.

Justin had been seen frequently by the Consultant Paediatrician in the District General Hospital who for many years played a major role in coordinating all of the referrals necessary to a plethora of specialist health care professionals in centres of excellence across the country. However, once he was an adult, there was no one in a position to take on this responsibility i.e. to oversee an adult with complex multiple health needs. Such complex and special needs are rarely seen by General Practitioners (GPs) and because they are not mental health related do not come under the remit of LD Consultants. The overview panel felt the lack of someone with a coordinating role had contributed to his premature death.

Improving the health and wellbeing of people with learning disabilities. Guidance for social care providers and commissioners

Resources and practical tips

A copy of the Confidential Inquiry and its recommendations can be found at:

www.bris.ac.uk/cipold/

Charter Statement 11: Make sure that all staff, people with learning disabilities and their families are made aware of this charter

It will be helpful to display the charter and to tell family carers and people with learning disabilities about its existence. Say what you are doing to promote access to good health by the people you support and explain what this means on a practical level. You can do this by discussing it in review meetings and sending it out with any newsletters or updates you provide.



Improving Health and Lives
Learning Disabilities Observatory

References

1. Emerson, E., Baines, S., Allerton, L., & Welch, V. (2011). Health Inequalities and People with Learning Disabilities in the UK: 2011. Durham: Improving Health and Lives: Learning Disabilities Observatory. Retrieved from www.ihal.org.uk/gsf.php5?f=11441
2. UK Parliament (2010). Equality Act 2010. Retrieved from www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf
3. UK Parliament (2010). The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. SI 2010 No. 781. Retrieved from www.legislation.gov.uk/uksi/2010/781/pdfs/uksi_20100781_en.pdf
4. UK Parliament (2005). The Mental Capacity Act 2005. Retrieved from: www.legislation.gov.uk/ukpga/2005/9/contents
5. Heslop et al (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Final report. Norah Fry Research Centre. Retrieved from: <http://www.bristol.ac.uk/cipold/fullfinalreport.pdf>
- 6, Robertson et al (2010). Health checks for people with learning disabilities. A systematic review of the evidence. Retrieved from: [www.improvinghealthandlives.org.uk/publications/937/Health Checks for People with Learning Disabilities: A Systematic Review of Evidence](http://www.improvinghealthandlives.org.uk/publications/937/Health_Checks_for_People_with_Learning_Disabilities:_A_Systematic_Review_of_Evidence)