



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)

HEALTH
CHARTER

V O D G

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

The PHE Learning Disabilities Observatory

The Public Health England Learning Disabilities Observatory (PHELDO) provides high-quality data and information about the health and healthcare of people with learning disabilities. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare. PHELDO is a collaboration between PHE, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. The observatory is operated by PHE and is also known as Improving Health and Lives (IHaL).

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000

www.gov.uk/phe

Twitter: [@PHE_uk](https://twitter.com/PHE_uk) Facebook: www.facebook.com/PublicHealthEngland

© Crown copyright 2017

You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit [OGL](https://www.ogil.io) or email psi@nationalarchives.gsi.gov.uk. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Published October 2017
PHE publications
gateway number: 2017453

PHE supports the UN
Sustainable Development Goals



Contents

Easy read summary	4
Introduction	8
Implementing the charter	10
The charter statements and guidance	11
References	32

Easy read summary

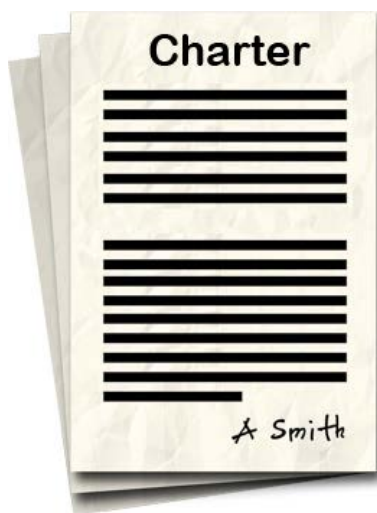


People with learning disabilities often have poor health



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



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

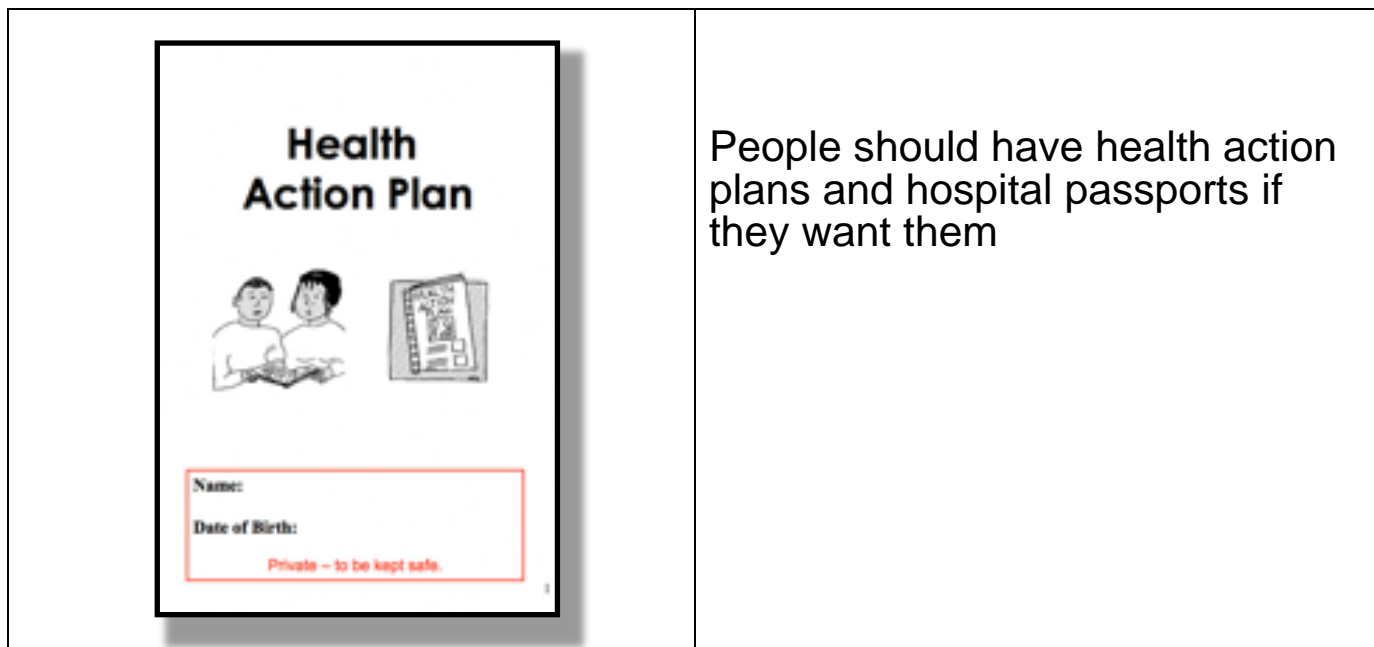


If you go to a health appointment, you should have someone with you who knows you and can support you well



People should be helped to go to health screening appointments

	<p>Staff should know that sometimes people with learning disabilities can be given too many drugs to manage their behaviour</p> <p>There is a health campaign called STOMP to stop the overuse of these drugs</p> <p>The campaign has actions staff can take to stop this happening</p>
	<p>Staff should be able to give medicines safely</p>
	<p>People should be supported to go for health checks</p>



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

The pictures in this report are from Photosymbols: www.photosymbols.co.uk

Acknowledgements

We would like to thank everyone who contributed to the development and revision of this document including those who responded to the survey in the summer of 2015.

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 inequalities¹:

- greater risk of exposure to the social determinants of poorer health such as poverty, poor housing, unemployment, discrimination and isolation
- increased risk of health problems associated with specific genetic, biological and environmental causes of learning disabilities
- communication difficulties and reduced understanding of health issues
- personal health risks and behaviours such as poor diet and lack of exercise
- 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 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 (where they exist) 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 is 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

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 is 'anticipatory', meaning that public sector organisations must consider in advance the adjustments people with learning disabilities will require, rather than waiting until people with learning disabilities experience problems using public services.

Charter statements and guidance

Charter Statement 1: Make sure that all staff understand and apply the principles of the Mental Capacity Act 2005

Why is this important?

The Mental Capacity Act 2005⁴ 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:

- 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 as 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

The Act 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.

Using the Mental Capacity Act: case study 1

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.

Using the Mental Capacity Act: case study 2

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/

This resource is helpful for social care staff:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/348440/OPG603-Health-care-workers-MCA-decisions.pdf

This brief information sheet on the Mental Capacity Act is helpful for social care staff:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655376/Social_care_staff_briefing_sheet_on_Mental_Capacity_Act_in_learning_disabilities.pdf

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. 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.

The importance of listening to families: case study

Justin was a young man with Down's syndrome who died as a result of a pulmonary thromboembolus following 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/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf

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.ndti.org.uk/uploads/files/Working_Together_2.pdf

This brief information sheet on hospital admissions is helpful for social care staff:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655384/Social_care_staff_supporting_hospital_admissions_in_learning_disabilities.pdf

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 understood¹. 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, which can lead to challenging behaviour and of course significantly affects quality of life. The following case study from the Confidential Inquiry demonstrates the importance of knowing about the implications of specific syndromes and health conditions.

Case study: knowing about specific health risks

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 or 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.

Improving the health and wellbeing of people with learning disabilities: guidance for social care commissioners and providers (to support implementation of the health charter).

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/toolkits/health-check-toolkit.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/

Tip: 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.

This brief information sheet on common health problems is helpful for social care staff:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655378/Common_health_problems_in_learning_disabilities_guidance_for_social_care_staff.pdf

This brief information on recognising and managing pain is helpful for social care staff:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655386/Social_care_staff_supporting_pain_management_in_learning_disabilities.pdf

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 diabetes¹. People with learning disabilities are also more likely to be underweight than the general population, and this can make them vulnerable to a premature death⁵.

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.

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 to be more healthy.

Case study: Malcolm, a self-advocate

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)
- encouraging 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.

Case study: working together to help Tom lose weight

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 1lb (1 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.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. CIPOLD⁵ 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.

Good support: case study 1

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.

Good support: case study 2

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,

Improving the health and wellbeing of people with learning disabilities: guidance for social care commissioners and providers (to support implementation of the health charter).

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/2016-06/2012.340%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

Promoting 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.

Ensuring access to health screening: case study

Saul was from a loving family of Asian origin, and attended 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. This 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 a Health Action Checklist 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))

Improving the health and wellbeing of people with learning disabilities: guidance for social care commissioners and providers (to support implementation of the health charter).

SeeAbility has lots of information and easy read fact sheets about eye care and sight problems: 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:

http://webarchive.nationalarchives.gov.uk/20160704171243/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:

http://webarchive.nationalarchives.gov.uk/20160704171312/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:

http://webarchive.nationalarchives.gov.uk/20160704150138/http://www.improvinghealthandlives.org.uk/publications/313910/_Making_reasonable_adjustments_to_cancer_screening_An_update_of_the_2012_report

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:

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

This brief information sheet on screening programmes is useful for social care staff:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655383/Social_care_staff_supporting_screening_in_learning_disabilities.pdf

Charter Statement 7: Tackle over-mediation by following the actions set out in the Stopping Over-Medication of People with a learning disability, autism or both (STOMP) pledge for social care

Actions include:

- helping staff know about psychotropic medication¹, its main uses and side effects
- monitoring the use of psychotropic medication and ensuring there are regular reviews
- working with people with learning disabilities, their families and others to stop over-medication

Why is this important?

A lot of people with learning disabilities, autism or both are prescribed psychotropic medication² as a way of controlling behaviour that challenges. This can happen even though there are other evidence based approaches available. NICE guidance³ says that psychotropic medication should be used as the last resort for managing behaviour which challenges. It should only be prescribed for managing behaviour which challenges when it is used in combination with psychology or other therapies. Long-term use of psychotropic medication puts people at unnecessary risk of a wide range of side effects including weight gain, organ failure and even premature death.

Doctors are responsible for prescribing medicine, but following the actions set out in the STOMP pledge can help providers think about their role in supporting people to reduce the amount of inappropriate psychotropic medication they take, and reduce long term health risks. The actions that one provider has taken are detailed below.

Reducing over-medication: case study

Following their sign-up to the STOMP pledge, Dimensions developed a self-assessment and planning tool that mirrors the Health Charter for Social Care Providers self-assessment tool. It is designed to help services develop an action plan regarding reduction of medication, and measure improvement. This is complemented by an individual psychotropic medication reduction plan, and a leaflet and form for staff who

¹ The term “psychotropic” refers to medication which results in changes to perception, mood or consciousness

² The term “psychotropic” refers to medication which results in changes to perception, mood or consciousness

³ National Institute for Health and Care Excellence (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Retrieved from: <https://www.nice.org.uk/guidance/ng11>

Improving the health and wellbeing of people with learning disabilities: guidance for social care commissioners and providers (to support implementation of the health charter).

who are accompanying a person with a learning disability to a GP or consultant appointment to talk about psychotropic medication. The leaflet aims to help staff work with the person to prepare for and get the best out of the appointment.

Resources and practical tips

The STOMP pledge for social care was developed by VODG, NHS England and sector stakeholders. The pledge aims to improve the quality of life of people with a learning disability, autism or both by supporting providers to ensure they only receive psychotropic medication for the right reasons and in the right amount. The pledge, guidance and self-assessment template can be downloaded here:

<https://www.vodg.org.uk/campaigns/stompcampaign/>

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

http://webarchive.nationalarchives.gov.uk/20160704152031/https://www.improvinghealthlives.org.uk/publications/1248/Prescribing_of_psychotropic_medication_for_people_with_learning_disabilities_and_autism

A report by the Challenging Behaviour Foundation on the views and experiences of families when medication is suggested or prescribed for their relative:

www.challengingbehaviour.org.uk/learning-disability-assets/stompfamilycarerperspective210517.pdf

Charter Statement 8: 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 generally, 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.

Medication: case study

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

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))

A report about making reasonable adjustments to pharmacy services can be found here: <https://www.ndti.org.uk/useful-tools/pharmacy-reasonable-adjustments-report>

Charter Statement 9: 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.

Having a health check: case study

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. 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

Guidance and an accompanying film about what social care staff need to know about GP learning disability registers, annual health checks and the Summary Care Record: www.ndti.org.uk/resources/publications/better-health-for-people-with-learning-disabilities

Don't Miss Out – guidance and video for people with learning disabilities and support staff on the importance of being on the GP register and how this can help people get a health check: www.mencap.org.uk/advice-and-support/health/dont-miss-out?q=dontmissout

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/toolkits/health-check-toolkit.aspx

Improving the health and wellbeing of people with learning disabilities: guidance for social care commissioners and providers (to support implementation of the health charter).

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

www.easyhealth.org.uk

Tip: 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.

Tip: 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.

Charter Statement 10: 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

People with learning disabilities who have a health check should get a Health Check Action Plan from their GP following their health check. Work may need to be done to make this accessible for the person with learning disabilities.

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.

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.

Having a health action plan: case study 1

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. 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.

Having a health action plan: case study 2

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

Improving the health and wellbeing of people with learning disabilities: guidance for social care commissioners and providers (to support implementation of the health charter).

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))

This brief information on reasonable adjustments is helpful for social care staff:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655373/Social_care_staff_supporting_reasonable_adjustments_in_learning_disabilities.pdf

This brief information on end of life care is helpful for social care staff:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655388/Social_care_staff_supporting_palliative_and_end_of_life_care_in_learning_disabilities.pdf

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

Lots of resources about end of life care for people with learning disabilities can be found here:
<http://www.pcpld.org/>

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

Charter Statement 11: 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.

Importance of care co-ordination: case study

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 range 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 learning disability Consultants. The overview panel felt the lack of someone with a coordinating role had contributed to his premature death.

Resources and practical tips

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

www.bris.ac.uk/cipold

Charter Statement 12: 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.

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 http://webarchive.nationalarchives.gov.uk/20160704170934/http://www.improvinghealthandlives.org.uk/publications/978/Health_Inequalities_&_People_with_Learning_Disabilities_in_the_UK:_2011
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 http://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/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>
- 6, Robertson et al (2010). Health checks for people with learning disabilities. A systematic review of the evidence. Retrieved from: http://webarchive.nationalarchives.gov.uk/20160704171248/https://www.improvinghealthandlives.org.uk/publications/937/Health_Checks_for_People_with_Learning_Disabilities:_A_Systematic_Review_of_Evidence