

# Better health for people with learning disabilities

What social care staff need to know about GP learning disability registers, annual health checks and the Summary Care Record



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*“Many of the health complications that people with learning disabilities experience are entirely preventable. It is totally unacceptable that people with learning disabilities experience poorer health outcomes and die younger than people in the general population. Social care providers have a key role to play in directly addressing these inequalities.*”

*This guide has been developed by VODG members to help social care providers ensure the requirements of people with learning disabilities are identified and communicated to health services. This resource helps to ensure better healthcare, and therefore better lives, for people who use social care services.”*

***Rhidian Hughs – CE VODG***

We would like to thank all VODG members and the people they support who helped us develop the guide and film.

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## Introduction

Did you know that people with learning disabilities have poorer health and die at a younger age than people without learning disabilities?

Did you know that some of this poor health is avoidable?

This means that people with learning disabilities experience health inequalities that we can all do something about. For example, people with learning disabilities are:

- More likely to be obese or underweight than the general population
- Less likely to do exercise
- More likely to have constipation
- More likely to have diabetes
- More likely to be on psychotropic medicine<sup>1</sup> when they don't need to be
- More likely to have dental problems
- More likely to have sight and hearing problems that may be undetected and so untreated<sup>2</sup>

**Much can be done by social care providers**, working together with people with learning disabilities, family carers and their health colleagues to improve the situation, and this guide suggests some important steps that social care providers and support workers can take to address health inequalities. Specifically, it is about the important role they can play to ensure that people with learning disabilities:

- are on the GP learning disability Quality and Outcomes Framework (QOF) register
- get annual health checks
- have additional information on their Summary Care Record that says what reasonable adjustments they need

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<sup>1</sup> Psychotropic medication affects mood, perception or consciousness and is used to treat mental health problems. However it is also prescribed for people with learning disabilities who challenge services, often inappropriately, and can have harmful side effects.

<sup>2</sup> Emerson et al (2012) *Health Inequalities and People with Learning Disabilities in the UK: 2012* : Public Health England Learning Disabilities Observatory  
[http://webarchive.nationalarchives.gov.uk/20161101020842/http://improvinghealthandlives.org.uk/publications/1165/Health\\_Inequalities\\_&\\_People\\_with\\_Learning\\_Disabilities\\_in\\_the\\_UK:\\_2012](http://webarchive.nationalarchives.gov.uk/20161101020842/http://improvinghealthandlives.org.uk/publications/1165/Health_Inequalities_&_People_with_Learning_Disabilities_in_the_UK:_2012)

## Supporting Resources:

The guide is supported by a film that can be used during induction or training sessions.

It is one of a number of resources commissioned by NHS England to increase the uptake and quality of health checks for people with learning disabilities.

### See Also:

#### **Don't miss out: Better healthcare for people with a learning disability**

- Main guide
- Supporters guide
- GP Template letter

All available at: [www.mencap.org.uk/dontmissout](http://www.mencap.org.uk/dontmissout)



### The Health Charter for Social Care Providers which includes:

- Guidance
- A self-assessment-tool
- The health charter in practice report
- Sign up page

All available at: [www.vodg.org.uk/campaigns/learning-disability-providers-challenged-to-tackle-health-inequalities/](http://www.vodg.org.uk/campaigns/learning-disability-providers-challenged-to-tackle-health-inequalities/)

## Key messages

People with learning disabilities have poorer health and die at a younger age than people without learning disabilities. Some of this poor health is avoidable

We can all do something to improve the health and wellbeing of people with learning disabilities – it is everyone's responsibility



## What is the health check register and why is it important?

There are actually two registers. The first register is the learning disabilities quality and outcomes framework (QOF) register. The second register is the health check register.

### The learning disability (QOF) register

All GPs have a learning disability QOF register. The register is part of the General Medical Services (GMS) contract for general practices. The QOF requires GPs to establish and maintain a register of all patients with a learning disability whatever their age. Being on the QOF learning disability register is important as it means that any additional needs people have can be identified and reasonable adjustments made.

### Things you can do

- If you are not sure, it is important to check with the receptionist at the GP practice that the person you support is on the register so that they get the support they need.
- If the person is not on the register you will need to support them to make an appointment to see the GP.
- The GP will check whether the person has a learning disability, and may ask for more help, perhaps from specialist learning disability services.
- Once the GP has agreed that the person has a learning disability, a code will be added to the record so that the person is included on the register.
- It is not necessary to get consent to be added to the register as the code is a diagnostic code, and is used in the same way as codes for other conditions such as epilepsy.
- When you support the person to see the GP, you can also talk about the reasonable adjustments they need. You can use the template letter created by Mencap to help with this discussion: [www.mencap.org.uk/dontmissout](http://www.mencap.org.uk/dontmissout)

## The health check register

GPs who are signed up to the Enhanced Service Health Check Scheme will also have a health check register. People with learning disabilities who are eligible for an annual health check will be identified from the QOF register and put on the health check register. To be eligible for a health check, the person with learning disabilities will need to be aged 14 and over.

These registers are not the same as the register that is held by the local authority. This register includes all the people supported by the local authority, whereas the QOF register will include all people with learning disabilities known to the GP practice. The GP practice should liaise with the local authority to make sure that people with learning disabilities on the local authority register are also on the learning disabilities QOF register.

Although this should happen on a yearly basis this is not always the case. Therefore, even if a person with learning disabilities gets social care support they may not be on the register, so it is important to check.

### Key messages

Sharing information is necessary and appropriate. Being 'known' to have additional needs that require reasonable adjustments is important, so that the right changes to services can be made

Being on the GP learning disability QOF register is a way of making sure that reasonable adjustments are known about. It is the first step to getting an annual health check

## Case Study:

### Certitude Treat Me Right Project

The project is about better health and people with learning disabilities, and has been developed in partnership with people with learning disabilities and service providers.

For example, to increase the uptake of health checks, **Certitude worked with GP surgeries to ensure people with learning disabilities were identified and flagged so that health checks were offered.** They also worked with people with learning disabilities and their supporters to ensure that they understood their rights to health checks.

**As a result, over 70% of people in Ealing with a learning disability had a health check in 2015-2016.**

One example of a practical reasonable adjustment that has worked well is asking the GP and nurse to come to the service for nervous patients or those who found the surgery difficult, so they were able to have their annual health checks at home.

For further information about Treat Me Right! see:

[www.certitude.org.uk/find-support/learning-disability/services-we-offer/support-with-healthcare/more-about-tmr-health/](http://www.certitude.org.uk/find-support/learning-disability/services-we-offer/support-with-healthcare/more-about-tmr-health/)





## What are health checks and why are they important?

### People with learning disabilities:

- Do not always know when they are ill or need to see a doctor.
- May not be able to tell people that they feel unwell or different.

Support staff and families often notice things like changes in behaviour that may indicate someone is feeling unwell, and make an appointment with the doctor. This is important, and there are some resources below that can help support staff know when things are wrong.

### Resources

The resource	Where you can find it
Pain profile and assessment of pain	<a href="http://www.dyingmatters.org/sites/default/files/user/images/pain%20assessment%20tool%20Notts%20final%20doc.pdf">www.dyingmatters.org/sites/default/files/user/images/pain assessment tool Notts final doc.pdf</a>
The Disability Distress Assessment Tool	<a href="http://www.disdat.co.uk/">www.disdat.co.uk/</a>

However, it is not always easy to do this, and there is evidence to show that poor health in people with learning disabilities is in part due to unidentified health needs and lack of timely access to health services<sup>3</sup>.

**Annual health checks** were introduced to address these problems. There is good evidence that health checks identify unmet health needs, including life threatening conditions<sup>4</sup>. The health check is a chance for the GP, the person with learning disabilities and support staff or family carer if appropriate to review the individuals' physical and mental health. It is also a chance for the person with a learning disability to get to know the doctor, and become familiar with the surroundings. The sort of things that should be covered in an annual health check are included in appendix 1. Health checks are an important reasonable adjustment that primary care services can put in place for people with learning disabilities.

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<sup>3</sup> Public Health England (2014). *The Uptake of Learning Disability Health Checks 2013 to 2014*: [http://webarchive.nationalarchives.gov.uk/20161101020842/http://improvinghealthandlives.org.uk/publications/1239/The\\_Uptake\\_of\\_Learning\\_Disabilities\\_Health\\_Checks\\_2013\\_to\\_2014](http://webarchive.nationalarchives.gov.uk/20161101020842/http://improvinghealthandlives.org.uk/publications/1239/The_Uptake_of_Learning_Disabilities_Health_Checks_2013_to_2014)

<sup>4</sup> Robertson et al (2010). Health Checks for People with Learning Disabilities. A Systematic Review of Evidence. Public Health England Learning Disability Observatory: [http://webarchive.nationalarchives.gov.uk/20161101020842/http://improvinghealthandlives.org.uk/publications/937/Health\\_Checks\\_for\\_People\\_with\\_Learning\\_Disabilities:\\_A\\_Systematic\\_Review\\_of\\_Evidence](http://webarchive.nationalarchives.gov.uk/20161101020842/http://improvinghealthandlives.org.uk/publications/937/Health_Checks_for_People_with_Learning_Disabilities:_A_Systematic_Review_of_Evidence)

## Top Tips for Social Care Providers

Social care providers can do a lot to help people with learning disabilities get a health check that works well for them. They can:



- Support the person to understand the importance of a health check
- Support the person to ask the GP for a health check
- Support the person to fill out a pre-check questionnaire and think about any questions they need to ask
- Work with community teams and GP practice staff to put in place reasonable adjustments needed for a successful health check
- make sure that someone the person knows and trusts goes to the health check with them – if this is something the person wants
- support the person to ask the doctor to explain anything they don't understand
- support the person to ask for a Health Check Action Plan from the GP and then provide support for these actions to be actively followed up and reviewed

For more information see the Health Charter for Social Care Providers and guidance:  
[www.vodg.org.uk/campaigns/learning-disability-providers-challenged-to-tackle-health-inequalities/](http://www.vodg.org.uk/campaigns/learning-disability-providers-challenged-to-tackle-health-inequalities/)

For more information on Health Checks and Health Action Plans see:  
[http://webarchive.nationalarchives.gov.uk/20161101020842/http://improvinghealthandlives.org.uk/publications/1243/Health\\_checks\\_for\\_people\\_with\\_learning\\_disabilities\\_including\\_young\\_people\\_aged\\_14\\_and\\_over\\_and\\_producing\\_health\\_action\\_plans](http://webarchive.nationalarchives.gov.uk/20161101020842/http://improvinghealthandlives.org.uk/publications/1243/Health_checks_for_people_with_learning_disabilities_including_young_people_aged_14_and_over_and_producing_health_action_plans)

## Example Checklist:

### Making sure people with learning disabilities get all the right health checks

As part of the 2015 SAF Action Plan, Derbyshire County Council asked Derbyshire Healthcare Foundation Trust to develop some information for providers setting out all the different health checks and screening appointments people with learning disabilities should have including Annual Health Checks. The aim was to make it easier for providers to ensure that they supported people appropriately to attend these appointments.

A checklist was produced. See:

[www.ndti.org.uk/uploads/files/Schedule of expected health appointments for Adults with Learning Disabilities 1docx.pdf](http://www.ndti.org.uk/uploads/files/Schedule_of_expected_health_appointments_for_Adults_with_Learning_Disabilities_1docx.pdf)

The checklist was circulated to all the learning disability providers commissioned by Derbyshire County Council, and was shared across the East Midlands.

People with learning disabilities can get a health check from the age of 14 onwards. They also need to be eligible. This means they need to have been assessed as having a moderate or severe learning disability, or profound learning disabilities. People with mild learning disabilities who may have other health needs are also eligible. The eligibility criteria are currently being reviewed. Please talk to the GP to find out more.

In order to get a health check, people with learning disabilities need to be registered with a GP who provides health checks through a scheme called an Enhanced Service (ES). GPs who are part of this scheme will add those who are eligible to the health check register. The GP practice should invite all people with learning disabilities on the health check register for an annual health check.

Most GP practices are signed up to the ES, but about 12% of people with learning disabilities entitled to a health check are registered with practices that do not provide health checks. If the person you support does not get invited for a health check you should check with the GP practice to make sure that:

- The person is identified as having a learning disability and is on the register
- The practice provides health checks

If the practice does not provide health checks, you should talk to the person with learning disabilities about changing their practice. In some areas there are also arrangements with another GP practice to provide health checks.

### Key message

Health checks can help identify health needs. There are lots of things social care providers can do to support people to get good health checks

## Practical Example: Supporting people with learning disabilities to understand the importance of health checks



Share provides training and employment support to disabled adults including adults with learning disabilities. The Healthy Living Co-ordinator at Share has been raising awareness of the importance of health checks, including annual health checks,

with the students Share supports. She talks the students through the different health checks, why they happen, how regularly, how appointments are made, and asks when their last check-ups were. She also supports people to get their health passports completed as she has found this is a great resource that can be used at health appointments. She has found that not all health check-ups are being done as regularly as they should and hopes that raising awareness amongst the students and where appropriate, their support workers, should increase the number of health checks being done.

Jenny Bourlet, Healthy Living Co-ordinator at Share says:

*‘Health affects so many aspects of a person’s life. Simple things like eye tests can mean that people are more confident to get out and about, and being as healthy as possible helps with wellbeing and motivation too’.*



## What happens after the health check?

After the health check the GP should give the person with a learning disability or their supporter a health check action plan.

This may include actions that health services need to take such as a referral for further tests, and actions the individual can take such as doing more exercise. It is important to work with the person with a learning disability to understand these actions and agree the best way to take any individual actions forward.

For example, if the need to do more exercise has been identified, are there things the person likes doing where exercise can be added in, or are there preferred ways of doing exercise such as swimming rather than going to the gym. It is important that any actions are followed up and reviewed regularly to ensure ongoing support for the person's well-being.

### Key message

People should get a Health Check Action Plan following the health check, and should be supported to put actions in place

## Practical Example:

### Implementing a Health and Wellbeing Strategy

In 2015, Dimensions conducted an organisation wide survey on health issues for the people they support. Lack of access to a range of health checks was one of their findings.

This led to a number of local action plans to address this issue. They are also developing an overarching Health and Wellbeing Strategy that includes:

- compliance with the Health Charter for Social Care Providers
- supporting people to be on the GP learning disability register with a practice signed up to the learning disability health check enhanced service
- investing in and motivating support staff to gain a better understanding of health issues for themselves as well as those they support
- supporting people with regard to healthy eating and exercise

They are planning to repeat the survey in 2017 to check on progress.

One locality manager at Dimensions has identified a health lead for each of the services she oversees. This role has been crucial to ensuring all the people they support get health checks. The health lead schedules a review of the Health Action Plan (HAP) for each individual in January.

The review helps people set their priorities for the year ahead and prompts staff to make an appointment for the annual health check. The lead oversees the implementation of the HAP including any medication reviews, and bi-annual appointments that could otherwise be overlooked, such as audio and eye tests.

Jane Colenso, the locality manager says:

*“Not enough people with learning disabilities are registered with their GP. Of those that are, many don’t take up their entitlement to an annual health check. And like anyone else, if your health suffers, so does the rest of your life. Together, the structures in place and the lead role promote conversations about health with the individual and their circles of support, helping ensure we identify problems early and take a proactive approach to health improvement.”*



## What are Summary Care Records and why are they important?

The Summary Care Record (SCR) is an electronic record of important information about a person's health, for example medical conditions, allergies and medication.

It is created from GP medical records and can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care. This means that if someone has an accident or becomes ill and is unable to tell staff about themselves, health staff can look at the record so that they can decide on the best way to treat them.

**All people registered with a GP will have a SCR unless they chose not to have one.**

You can find out more about the SCR here:

[www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/overview.aspx](http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/overview.aspx)

People can choose to have additional information added to their SCR so that health staff know about any reasonable adjustments they need and can give them the right treatment.

**The annual health check is a good time to ask about adding information to the SCR.**

Information can include:

- the sort of support the person needs including any reasonable adjustments
- how the person would like to be treated
- who should be contacted for more information about the person

This will show up as Additional Information on the SCR, and can help health staff give people the reasonable adjustments and support they need.

The SCR is different to documents like communication or hospital passports. These documents are still important and should accompany the person to hospital and health appointments. They will contain a lot more information than the SCR, but the SCR is electronic, and can be used by health staff in emergency situations when the individual may not have their hospital passport with them. Because it is electronic it is automatically updated when anything in the patient record changes such as medication.

People with learning disabilities will need to give consent to have information added to the SCR. Support staff should work with the individual to help them understand why sharing this information is important and agree what information they want shared. They can support the person to ask the GP to add this information to the SCR.

If the person is assessed as lacking the capacity to consent to sharing additional information, after all steps have been taken to enable them to consent, then a 'best interests' decision should be made in line with the Mental Capacity Act (MCA). For example the health professional may decide, in discussion with the support staff and family that it is in the person's best interests to add information to the SCR. The individual should still be involved in this decision as much as possible.

For more information about the MCA see: [www.mencap.org.uk/advice-and-support/mental-capacity-act](http://www.mencap.org.uk/advice-and-support/mental-capacity-act)

## Key message

Having a Summary Care Record with additional information makes important information available to other people who can help you

## Summary of key messages

**People with learning disabilities have poorer health and die at a younger age than people without learning disabilities.**

Some of this poor health is avoidable

**We can all do something to improve the health and wellbeing of people with learning disabilities – it is everyone's responsibility**

**Sharing information is necessary and appropriate.** Being 'known' to have additional needs that require reasonable adjustments is important, so that the right changes to services can be made

**Being on the GP learning disability QOF register is a way of making sure that reasonable adjustments are known about.** It is the first step to getting an annual health check

**Health checks can help identify health needs.** There are lots of things social care providers can do to support people to get good health checks

**People should get a Health Check Action Plan following the health check,** and should be supported to put actions in place

**Having a Summary Care Record with additional information** makes important information available to other people who can help you.

## Appendix 1 – what should be covered in a health check?

### The health check should include:

- A discussion about the person's lifestyle: what food they eat, whether they drink or smoke, and what exercise they do.
- A check of weight and height, blood pressure, and a check of the heart and lungs,
- A urine test
- A check of eyes and ears
- A check of any medicines the take
- A check of any other conditions - for example epilepsy
- A check of the person's mental health
- Whether any additional checks are needed – for example a breast check

There may also be a blood test.

For further details about the health check see Annual Health Checks for People with Learning Disabilities Step by Step Toolkit: [www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx](http://www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx)