



Public Health  
England

# **Making reasonable adjustments to primary care services – supporting the implementation of annual health checks for people with learning disabilities**

# About Public Health England

Public Health England's mission is to protect and improve the nation's health and to address inequalities through working with national and local government, the NHS, industry and the voluntary and community sector. PHE is an operationally autonomous executive agency of the Department of Health.

The LDPHO is one of a small number of specialist public health observatories that cover England. It was set up in April 2010, following a recommendation in the Report of the Independent Inquiry into Access to Healthcare for Learning Disabilities (the Michael Report).<sup>28</sup> It is a collaboration between three organisations: Public Health England, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. The LDPHO became part of Public Health England in 2013.

This report is part of a series of reports written by the Learning Disabilities Public Health Observatory (LDPHO: [www.improvinghealthandlives.org.uk](http://www.improvinghealthandlives.org.uk)) focusing on reasonable adjustments in specific service areas. The aim of these reports is to make it easier for people to find and use reasonable adjustments, and to share good practice regarding implementation of reasonable adjustments.

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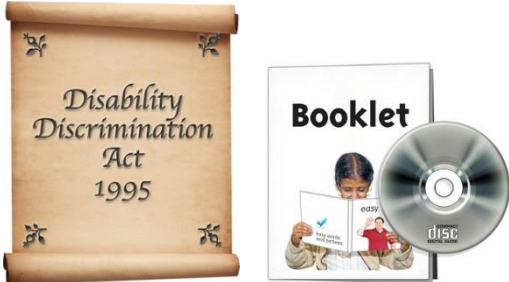




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## Easy read summary

 A man in a dark hoodie and jeans stands looking at a blue hospital sign. The sign lists various departments: T.S.S.U., Day Surgery Unit (Ward 1), Pain Relief Clinics, Clinic 4, Clinic 5, Dietetics, Diabetes Specialist Nurse, and Podiatry. A large red question mark is overlaid on the left side of the image.	<p>People with learning disabilities have poorer health than other people.</p> <p>They may find it hard to use health services.</p>
 A healthcare professional in a white coat is sitting and talking to a woman wearing a black jacket and a white t-shirt with 'POLO' on it. They are looking at some papers together.	<p>People with learning disabilities may not know they have a health problem.</p>
 A healthcare professional in a white uniform is sitting and taking the blood pressure of a woman wearing a white t-shirt with 'POLO' on it. The woman is sitting in a chair, and the professional is using a blood pressure cuff on her arm.	<p>Having a health check every year can help find health problems, so people can be given the right help.</p>

	<p>Health checks are for people with learning disabilities who are known to family doctors and social services.</p>
	<p>The law says public services should put “reasonable adjustments” in place to help people with learning disabilities to use them. This means services need to change so they are easier to use.</p>
	<p>This report has lots of information about reasonable adjustments to help people have annual health checks. Professionals and carers can use them to get better health services for people with learning disabilities.</p>
	<p>The report also has some examples of how local services have put reasonable adjustments in place so that people with learning disabilities have better annual health checks.</p>

## Introduction

Reasonable adjustments are alterations made to the way services are delivered to help ensure that people with disabilities or other Protected Characteristics (in the terms of the Equalities Act)<sup>41</sup> are able to use them as effectively as other people. They can apply to any sort of service, offered to the public. Services provided by public sector organisations like the NHS have particular responsibilities. This report is about general practice.

A key reasonable adjustment in providing general practice (GP) care for people with learning disabilities is inviting them for an annual health check. The English Department of Health has had a programme for this since 2008 but asking people with learning disabilities to come for a health check needs a number of reasonable adjustments to the way many GP surgeries operate.

This document begins with a background description of the health check programme, why it was set up and the evidence about its effectiveness. It goes on to provide examples of special arrangements which have been developed in different parts of the country to help make the health check programme easier to use. Some of these are in the form of links to websites and some are examples we have been told about.

## How we worked

We used the Janet Cobb Network, a major email network for people working with, or interested in people with learning disabilities to collect information about work around the England. We asked people working in this area to send us examples of reasonable adjustments they had made to general practice arrangements to make it easy for people with learning disabilities to access Learning Disability Health Checks. We also looked at a number of websites (see resources section for details).

## Reasonable adjustments

Under English Equalities law<sup>40-41</sup>, public sector organisations are required to tailor the way they provide care so that people with disabilities are not disadvantaged. Law governing the regulation of healthcare services is more explicit about the requirement for healthcare providers to 'avoid unlawful discrimination including, where applicable, by providing for the making of reasonable adjustments in service provision to meet the service user's individual needs', and to have systems in place to enable them to regularly assess and monitor the quality of the services provided against this and other requirements.

For people with physical disabilities, required reasonable adjustments can mean alterations to buildings provide lifts, wide doors, ramps and tactile signage.

For people with learning disabilities it more commonly involves clear, simple and possibly repeated explanations of what is happening, and of treatments to be followed, helping with

appointments, managing issues of consent in line with the Mental Capacity Act. These requirements are likely to need to be reflected in operational policies, procedures and staff training to ensure that services work equally well for people with learning disabilities. Public sector organisations are not allowed simply to wait and respond to difficulties as they emerge – the duty on them is “anticipatory” – they have to think out what is likely to be needed in advance.

## People with learning disabilities and healthcare

Learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development<sup>3</sup>. It does not include conditions like dyslexia where people have a specific difficulty with one type of skill but do not have wider intellectual impairment.

In England, approximately 1.2 million people have learning disabilities (290,000 children, 900,000 adults).<sup>3</sup> On average they have poorer health and die younger than others.<sup>3-7</sup> In part this is because they are more exposed to causes of ill health through greater levels of material deprivation, poorer health-related behaviours and physical conditions often associated with causes of learning disabilities. But it is also partly a result of poorer understanding of physical changes and problems that indicate illnesses or conditions that could be treated and of how to get help from health services. This means that many people with learning disabilities have health problems for which they do not themselves seek medical help<sup>10</sup>.

## Annual learning disability health checks

Currently NHS GPs in England are paid undertake annual health checks for people with learning disabilities who meet eligibility criteria. These criteria are that they are aged 18 or older and that they are known as having a learning disability by both their local authority social services department and their GP. This scheme was developed following recommendations from a formal investigation by the Disability Rights Commission (2006). They considered this was a reasonable adjustment for primary health care services which would help to address health inequalities<sup>9</sup>. Two years later, the Independent Inquiry into Access to Healthcare for People with Learning Disabilities also recommended that a national scheme for health checks should be set up<sup>28</sup>. In several parts of the country, local schemes emerged following this guidance. In September 2008 the NHS and the British Medical Association announced plans for an England-wide Directed Enhanced Service (DES) to provide annual health checks.

Full details of the scheme are published annually in the General Medical Services contract: Guidance and audit requirements for new and amended services. In addition to the eligibility criteria for patients, the scheme also requires practices to undertake relevant training and to use a health check protocol agreed with their local commissioning organisation. From April 2014 Health Checks will be available also to people with learning disabilities aged 14 to 17.



## What learning disability health checks achieve

There is clear evidence to suggest that the provision of health checks for people with learning disabilities in primary care is effective in identifying previously unrecognised health needs, including those associated with life-threatening illnesses.

In 2010, IHaL published a systematic review of evidence concerning the impact of health checks on the health and well-being of people with learning disabilities. IHaL also produced a briefing for GP Commissioning Consortia and PCTs on practical commissioning actions to address the issues identified in the review. Much of the research contained in the review was conducted prior to the introduction of the DES scheme of Health Checks for People with Learning Disabilities.

In 2013 the 2010 review was updated to include new evidence. There will be a number of outputs from the 2013 review which will be made available during 2014 the first of these outputs are included in appendices 1, 2 and 3, namely:-

- appendix 1 - are health checks for people with learning disabilities helpful? The effectiveness of health checks for people with learning disabilities
- summary findings – health checks show up previously unidentified health conditions. Some of these are common and distressing, others are serious and life threatening. They prompt action to address these health needs. So far there is no good evidence about how much this improves health status in the short, medium or long term
- appendix 2 - can health checks help people with learning disabilities who display behaviour that challenges? Health checks: identifying health issues in people who display behaviour that challenges
- summary findings – challenging behaviour may result from physical health problems and/or pain. The small amount of available evidence shows that: 1) health checks identify health problems in a significant proportion of people who display behaviour that challenges; 2) treating these health problems can reduce or stop the display of challenging behaviour by people
- appendix 3 - what makes health checks for people with learning disabilities work better? Implementing health checks for people with learning disabilities
- summary findings – health checks are highly valued by people with learning disabilities and family carers if the process does not impose barriers to access. GP views of the value of health checks vary, although directly involved GPs report greater professional knowledge and confidence about addressing the health needs of people with learning disabilities



## The NHS health check and learning disability health checks

It is important not to confuse learning disability annual health checks with the wider NHS health check scheme.

The NHS health check programme is intended to help individuals reduce their risk of heart disease, stroke, diabetes and kidney disease. It is for adults in England aged between 40 and 74 who haven't already been diagnosed with these diseases. Eligible people are invited for a check once every five years. Their risk of heart disease, stroke, kidney disease and diabetes will be assessed, and they will be offered personalised advice and support to help lower the risk. For more information see [www.healthcheck.nhs.uk](http://www.healthcheck.nhs.uk). This programme is essentially mechanical. It does not matter where individuals get their check as long as they get it.

By contrast, learning disabilities health checks are designed to pick up a wider range of unmet health needs – essentially all the things that people who do not have a learning disability would normally go to their doctor for unprompted. But when properly organised it can also serve the wider purpose of familiarising people with learning disability with what their local GP service provides for them, and helping them learn how to use it. In addition to the key aims of identifying and treating otherwise unrecognised problems, this should also serve help people with learning disabilities to use health services better, and in some cases more appropriately.

The underlying rationale for the use of Learning Disabilities DES health check is that:

- (1) primary care services tend to be reactive, responding to problems raised by patients;
- (2) people with learning disabilities may be unaware of the medical implications of symptoms they experience, have difficulty communicating their symptoms or may be less likely to report them to medical staff;<sup>33-35</sup>
- (3) carers may not always attribute the manifestations of clinical symptoms to physical or mental illness;<sup>47</sup>
- (4) health checks provide a way to detect, treat and prevent new and/or unmet health conditions in this population.<sup>39</sup>

Health checks may help provide baseline information against which changes in health status can be monitored, a particular issue given the frequency of changes in paid carers supporting people with learning disabilities and the difficulties that people with learning disabilities may have in detecting and reporting longer term changes in health status.

It has also been argued that health checks may be cost effective as the detection of new or underlying medical conditions, may reduce the consumption of resources in other areas of healthcare, such as services for challenging behaviour and mental health problems, and reduce the need for future and potentially more expensive treatment.

## Resources

The following sub-sections include some examples from practice, resources and links to other easy read resources, which can be found on:

- the Easyhealth site: [www.easyhealth.org.uk](http://www.easyhealth.org.uk)
- the picture of health site: [www.apictureofhealth.southwest.nhs.uk](http://www.apictureofhealth.southwest.nhs.uk)
- the Alzheimer's Society site [www.alzheimers.org.uk](http://www.alzheimers.org.uk)
- the Down's Syndrome site: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)
- the British Institute for Learning Disabilities site: [www.bild.org.uk](http://www.bild.org.uk)
- the Royal College of Psychiatrists site: [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)
- the LDPHO reasonable adjustments database:  
[www.improvinghealthandlives.org.uk/projects/reasonableadjustments](http://www.improvinghealthandlives.org.uk/projects/reasonableadjustments)

The resources are in three sections:-

1. Information and evidence
2. Guidance
3. Information for people with learning disabilities

Please note that some resources may be available from more than one site but we have only included one link per resource, and we have only included resources that are free to download, although the Easyhealth site includes resources you can buy.

Theme	Description	Provider	Link
<b>Information and Evidence</b>			
JSNA	Joint Strategic Needs Assessments: how well do they address the needs of people with learning disabilities?	IHaL	<a href="http://bit.ly/1fmcB73">http://bit.ly/1fmcB73</a>
Systematic Review	Health checks and people with LD: A systematic review of evidence 2010	IHaL	<a href="http://bit.ly/1dN90h8">http://bit.ly/1dN90h8</a>
Systematic Review 2013 Update	The effectiveness of health checks for people with learning disabilities	IHaL	Appendix 1 of this report

Systematic Review 2013 Update	Health checks: identifying health issues in people who display behaviour that challenges	IHaL	Appendix 2 of this report
Systematic Review 2013 Update	Implementing health checks for people with learning disabilities	IHaL	Appendix 3 of this report
<b>Guidance</b>			
Reasonable Adjustments	Reasonable adjustments for people with LD - implications for commissioners and providers of healthcare	IHaL	<a href="http://bit.ly/1kgSrPs">http://bit.ly/1kgSrPs</a>
Health Check Audit Tool	Health check audit tool – easy read version also available	IHaL	<a href="http://bit.ly/1enYfqi">http://bit.ly/1enYfqi</a>
Information for Commissioners	Health checks for people with learning disabilities - implications and actions. Evidence into practice report no 6	IHaL	<a href="http://bit.ly/1dOfgp5">http://bit.ly/1dOfgp5</a>
Health Checks Report	Health checks and people with learning disabilities in England 2012/13	IHaL	<a href="http://bit.ly/1bPKSda">http://bit.ly/1bPKSda</a>
DES Guidance	Clinical Directed Enhanced Services (DES) for GMS contracts – guidance and audit requirements 2013/14	NHS Employers/NHS England	<a href="http://bit.ly/1bPCzvz">http://bit.ly/1bPCzvz</a>
Staff Guide	Learning disability annual health check flow chart for eye check outcomes.	South Devon Healthcare NHS Foundation Trust	<a href="http://bit.ly/1bQnXPQ">http://bit.ly/1bQnXPQ</a>

Campaign Pack	Annual health checks local campaign pack to increase annual health checks	Mencap	<a href="http://www.mencap.org.uk">www.mencap.org.uk</a>
Health Check Screening Template	DES health check screening template for people with learning disabilities	Solent NHS Trust	<a href="http://bit.ly/1bQmvNi">http://bit.ly/1bQmvNi</a>
<b>Information for people with learning disabilities</b>			
Health action plan	Easy read health action plan	Redbridge and Waltham Forest LD Partnership	<a href="http://bit.ly/1cQwR0N">http://bit.ly/1cQwR0N</a>
Health check poster	Easy read annual health check poster	NHS Bradford and Airedale	<a href="http://bit.ly/19Sarld">http://bit.ly/19Sarld</a>
Health check leaflet	Easy read health check leaflet	NHS Bradford and Airedale	<a href="http://bit.ly/19Sarld">http://bit.ly/19Sarld</a>
Rights	Having a health check – the rights of your relative. Easy read	Mencap	<a href="http://www.mencap.org.uk">www.mencap.org.uk</a>
About having a health check	Information about having a health check – Easy read	Mencap	<a href="http://www.mencap.org.uk">www.mencap.org.uk</a>
Pre health check questionnaire	Easy read pre health check questionnaire	Devon Partnership NHS Trust	<a href="http://bit.ly/1bPMnsM">http://bit.ly/1bPMnsM</a>
Health Checks and People with LD	Health checks and people with LD easy read guidance	IHaL	<a href="http://bit.ly/1jhoXDc">http://bit.ly/1jhoXDc</a>
Annual health check results form	Easy read annual health check results form for patients	Devon Partnership NHS Trust	<a href="http://bit.ly/18QJ9BQ">http://bit.ly/18QJ9BQ</a>
Reasonable Adjustments	Guidance on reasonable adjustments for people with LD – Easy read	IHaL	<a href="http://bit.ly/19ccn47">http://bit.ly/19ccn47</a>

## Examples of reasonable adjustments and case studies

This section of the report demonstrates that making a variety of reasonable adjustments throughout all points of the health check pathway are likely to be the most effective in improving outcomes for individuals. However, the key examples of reasonable adjustments which have been identified from these case studies provided include:-

- GP resource packs or toolkits which are also available electronically. The packs include, for example, information about the Mental Capacity Act, protocols for delivering health checks and tips on communicating with people with learning disabilities
- a health check template which produces local data and health action checklists
- GPs carrying out home visits for people with learning disabilities, and complex needs, in order to carry out annual health checks
- health facilitators supporting individuals with learning disabilities, community learning disabilities teams and GP practices

### **GP Resource Pack**

#### **Coventry and Warwickshire Partnership NHS Trust**

Coventry and Warwickshire Partnership NHS Trust has developed a resource pack for all their GP practices. The pack is given to GPs at events and is designed to raise awareness of health issues for people with learning disabilities. The nominated learning disability lead in the practice also receives electronic copies of the documents and the folder can be updated as necessary.

The folder contains information on what a learning disability is and a screening tool to help determine if someone has a learning disability. There is advice about read codes (all GP practices in the area now use standardised read codes) and a practice protocol for delivering health checks, including an easy read invitation letter. There is information on the Mental Capacity Act and consent, tips on communication and signs and symbols, information on the associated health needs of people with learning disabilities, epilepsy management plans and other useful information. The folder includes information on referring to the Community Adult Learning Disability Service. All referrals to the team go through a central booking service, making it easier for GPs and others to refer.

The Trust has been encouraging GPs to use the Health Check template developed in the North East of England. All practices in Solihull are using the template, and some GP practices in other areas are beginning to pilot the template. The template enables better local data collection, and produces a health action check list following the health check.

### **Home Annual Health Checks Oxford City Learning Disability Team**

A number of people who have a learning disability living in the same house in Oxfordshire have been offered annual health checks by their local GP. The surgery wrote easy read letters to each of them inviting them to come in for an appointment. Due to the complex physical health needs of several individuals, a GP from the surgery visits them at home to do the health checks.

### **The world's best brother**

My brother has profound and multiple learning disabilities and we experienced generally poor services at a previous local surgery. It was as if he was 'too much trouble'.

Since moving practices we have nothing but praise for the whole team. He is invited for a regular health check and medication review. Whilst he usually won't co-operate with having blood pressure taken he will, with distraction allow his heart to be listened to, be weighed and have a general physical check. Blood tests and vaccinations are problematic as he has very little understanding of waiting so the practice sends a nurse to take blood at home and to give him his flu jab. Our practice has one GP in particular who greets us with a big, welcoming, smile and seems genuinely interested in my brother's well-being, both physical and mental.

I recommend not putting up with shoddy, unacceptable, practice and move surgeries if you are unhappy. If you need extra support, time, or special arrangements (we are allowed to park in GP's car park as crossing four lanes of traffic from the public car park is extremely challenging), then arrange to meet with the practice manager to explain why you need such adjustments.

### **Partnership Working Barking and Dagenham Community Learning Disability Team**

Barking and Dagenham Community Learning Disability Team link Health Action Plans and reviews to annual health checks.

Each GP practice has been allocated a health facilitator, nurse or assistant practitioner. GP practices book people in for health checks and contact the Community Learning Disability Team. The allocated Health Facilitator contacts the person with learning disabilities to inform them of the appointment. This approach increases uptake as most people with learning disabilities are known to the team. Individual team members encourage people with learning disabilities to attend their annual health checks and inform them that they will be at the practice to provide support if the person wants this support.

While the health check is being done, the team member gathers information for the health action plan. Being present can also help the team member to follow up any referrals made during the health check.

The team only work with practices which invite them to provide support and most practices in the area welcome this. This approach means that health action plans are completed more efficiently, learning disabilities registers are validated regularly and practices have a team member which they can contact for support if there are any patient issues outside of the annual health check.

### **Five Top Tips Oxleas NHS Foundation Trust**

**1. Quality checking and linking this to the GP Contracting team payment process.** In Oxleas the Health Facilitation Co-ordinator visited practices when they claimed for completed health checks, this:

- a) Increased the interaction between specialist learning disability services and primary care
- b) Developed the learning disability nurses experience of primary care
- c) Increased the primary health care professionals' understanding of the DES requirements for annual health checks
- d) Improved the quality of the health check
- e) Ensured the NHS is getting what it is paying for - If the health checks are not of the required standard there was no payment and this encouraged GPs to ask for support.

GP contracting teams are much smaller now, and are not as well-resourced as they previously were, so can find it difficult to check whether GPs are doing what they're contracted to do. Consequently, GP contracting and primary care performance managers tend to welcome the assurance that what they are commissioning is of a sufficient standard. This is an important part of a Health Facilitator's role.

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## Five Top Tips Oxleas NHS Foundation Trust

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**2. Training delivered in-house, practice by practice** - this helps develop personal relationships between professionals from learning disability services and primary care. They should know the sound of your voice on the phone - if the practice doesn't know who you are, you're not doing your job properly in relation to: Health Facilitation / Health Access.

**3. Learning disability social care provision training** - All training for paid carers regarding health checks and health action planning support should finish with a phone call to the surgery to:

- a) Introduce the residential/supported living home manager to the practice manager and
- b) Secure some dates for health checks.

This is about keeping the training relevant and striking while the iron is hot. It works incredibly well and reinforces points 1 and 2 above.

**4. Pitch the training properly** - appeal to a GP's sense of clinical and cost effectiveness. Oxleas use a case study and some statistics on A&E attendance for the learning disabled population (eg, Lincolnshire statistics: those with learning disabilities = 0.5% of general population but 6% of all A&E attendances) - if you don't have any local statistics, what evidence does the GP have to say your area is any different?

**5. Public health & central reporting** - unless CCG's have a robust system in place for gathering accurate local data on the often complex needs of people with learning disabilities, how do they commission services

In addition to the tips above, be sensitive to the needs of primary care services, - consider the pressure on their resources and be supportive by offering to sit in on health checks. This can also be a training opportunity.

Other ideas include developing a step by step guide on line, with all the resources available - when training in house, create a short cut on the local internet explorer, so there is always access to the web page about learning disability health checks. For more information see [www.oxleas.nhs.uk/gps-referrers/learning-disability-services/health-check-resources/](http://www.oxleas.nhs.uk/gps-referrers/learning-disability-services/health-check-resources/)

## **Health Action Planning Toolkit Surrey Learning Disabilities Partnership Board**

The Clear Communications People Ltd have developed a toolkit in Surrey to help people understand what is likely to happen when they go for an annual health check at their GP surgery and to help create good health action plans.

The toolkit has been developed with community learning disability nurses and other health professionals in Surrey. The toolkit includes:

- the “Top to Toe Health Checklist” – an easy read checklist covering 21 health topics from “eyes and eyesight” to “feet” and everything in between.
- my Health Action Plan – An easy read booklet for people to record any health actions they need and other important health information.

The toolkit is being piloted with two GP practices in January 2014, following two years of development work in partnership with people with learning disabilities.

The toolkit will be launched as a “free to use” online resource and printed copies will be available to buy. The Learning Disability Partnership Board in Surrey and the South East Region Quality Forum both contributed to the development of the toolkit.

From March 2014 the toolkit will be available at [www.surreyhealthaction.org](http://www.surreyhealthaction.org)

## **People Stories**

### **Haringey Learning Disability Partnership**

#### **Case study 1**

L had very high levels of anxiety around accessing health services. Her sister had passed away following a period of ill health, during which time L had come across many health professionals in what was a very sad and scary situation for her.

When L was referred to Community Learning Disability Nursing she had not had an annual health check and previous experiences had enhanced her fears. However the GP surgery was very accommodating and open to discussing reasonable adjustments. A series of short appointments with L's GP were arranged. During the initial appointments, no health checks were carried out, and L brought a picture that she had drawn at home to each one. The GP put the picture on his wall for the duration of the appointment, and gave L a pen when the appointment ended.

L saw the same GP for each appointment and, where possible, was seen in the same room. This continued, and eventually, after gradually introducing aspects of a health check into the appointments, a full health check, including blood tests, could be carried out. Although L does experience some anxieties around seeing health professionals now, she finds GP appointments much easier, and even laughs and jokes during some.

#### **Case study 2**

B has a moderate learning disability and autism. When her usual GP left the surgery, her anxiety around accessing the surgery increased, and she did not attend several prearranged appointments. However, with support and encouragement from her paid carers she was able to attend her annual health check. During this appointment, her new GP sat with B, away from his desk, and spoke to her using short and simple sentences that B could understand. He mirrored the language and manner of the paid carer during the appointment and spent time at the beginning of the appointment talking to B about Elvis Presley – a favourite subject of hers. This put B at ease, and her health check was successful.

#### **Case study 3**

M has a severe learning disability and autism. He continues to find it extremely difficult to access his GP surgery for an annual health check. His GP is able to do home visits which makes appointments a little easier for M. However, as M finds close proximity and others talking around him quite difficult, physical examinations such as blood pressure monitoring are very distressing. The Community Learning Disabilities Nurse is currently supporting M and his paid carers with some desensitisation work so that M can have his blood pressure checked. During this work, M's GP regularly communicates with M's allocated nurse and has provided equipment that supports the work, for example a stethoscope and a cuff.

### **Increasing Annual Health Checks Luton Borough Council and Luton CCG**

In 2010/11, only 39% of those eligible for a health check in Luton received one. There were problems with poor data and difficulties with understanding DES requirements. In January 2012, a specialist Health Facilitation Service (HFS) was introduced in Luton. It was agreed that a focus of their early work would be to assist practices with increasing health check performance. A lead GP with an interest in learning disabilities was identified and the GP became part of the working group.

The Health Facilitation Service, PCT and Luton Borough Council worked to improve GP DES take up, health check attendance and patient experience. GPs identified a need for resources to improve communication with patients with learning disabilities. In response, a resource pack on CD-ROM was developed and introduced to each practice at a meeting, during which the resource was explained and demonstrated. Practices were encouraged to copy the disk content to each GP computer system so that all GPs had access to the information at the click of a button to print off and give to the patient, or make a referral to a specialist health team.

A protected learning time session was delivered to GPs to explain the relationship between learning disabilities QOF registers and DES lists. The session included a drama performance by people with learning disabilities on their experiences of GP appointments. Articles in the local paper by the shadow CCG lead encouraging learning disabilities health check attendance was part of the improvement plan.

The end of year DES performance increased to 51%, every health check fully meeting the DES conditions with 26/31 practices (84%) signed up to the DES.

The dissolution of the PCTs and changes to Clinical Commissioning Groups brought new challenges, but the joint working relationships continued to improve with GPs making good use of the HFS and the new CCG supporting the partnership. End of year performance for 2012/13 was 72%, with every health check verified as meeting the conditions of the DES.

## **Annual Health Checks Support Bridgewater Community NHS Trust**

The Primary Care Access Team is part of Bridgewater Community NHS Trust Adult Learning Disability Service and it supports primary care services and GP practices to manage the needs of people with learning disabilities including providing support for the Direct Enhanced Service for Annual Health Checks.

Services and developments include:

- support to identify patients with learning disabilities at the practices
- validating GP learning disability registers
- learning disability awareness training
- training to support the Annual Health Check
- training for Health Action Planning and supporting practices with the Mental Capacity Act
- development of Annual Health Check template for GP practices
- one to one support at the health check for GP/Nurse and patients if required
- one to one casework with patients who require support with health needs identified at the Annual Health Check
- did Not Attend /Non Responder (DNA) pathway
- information resource for GP practices on CCG intranet

The team has developed good information sharing protocols with GP practices, the Clinical Psychology Service and the Local Authority. The team receives notification of anyone who has received a cognitive functioning assessment from the Clinical Psychology service; this information is then added to the database and shared with GP practices so that patients can be added to the practice learning disability register if results indicate they have a learning disability.

A pathway has been developed with colleagues from the Learning Disability Transition Nursing team so that the Primary Care Access Team are informed of any children coming through education who have statements of learning disability. This information is shared with GP practices when the patient turns 18 years of age so that they can be added to the register and invited in for a health check.

### **Training**

The team offers learning disability awareness training to all practice staff (GPs, nurses, health care assistants and administrative teams). The training covers identification of patients with learning disabilities, causes and prevalence of learning disability, health needs, communication, how to improve access, reasonable adjustments, awareness of legislation the support the Learning Disability Service can offer. This training is delivered quarterly at pre-arranged venues and it is delivered within the GP practices if required.

/Continued

## **Annual Health Checks Support Bridgewater Community NHS Trust**

/Continued

The team also offers training, on a quarterly basis, to all practice staff in relation to Health Action Planning and how to support patients with learning disabilities to make decisions regarding their healthcare (Mental Capacity Act).

As well as mandatory e-learning training, learning disability awareness training (“Breaking Down Barriers”) is also offered to patient facing and non-patient facing staff working for the Trust.

### **Primary care resource**

A GP resource pack has been developed which is available via the CCG intranet on practice clinical systems.

The resource includes:

- accessible health check invitation letter templates (also available in words only format)
- accessible health check information leaflets (also available in words only format)
- links to easy read websites
- health Action Plan templates/examples
- information around communication (Jargon Buster)
- onward referral information ( telephone numbers, referral forms)
- Learning Disability Service information
- documents, papers, guidance and legislation

This resource provides support to GP practices that is easy to access and available when required.

### **Did Not Attend (DNA) pathway**

Following repeated reports from GP practices regarding learning disabled patients not attending for Annual Health Checks, or not responding to invitations, the team developed a Did Not Attend (DNA) pathway. This enables practices to refer patients into the team so that a team member can contact them to discuss any difficulties/anxieties that may be preventing them from attending their Annual Health check.

Some patients are either too scared or anxious to attend or do not have enough support to enable them to access the health check. As a result of this pathway, the team has ensured that approximately 40% of patients referred via this pathway have either accessed, or planned to access, the health check following intervention from the team.

## **A parent's experience St Helens CCG**

My son has been living in a supported living environment for 9 years in a single person apartment, one of 10 people. The abilities of these 9 people is diverse from those who need only a few hours support a day to others, like my son, who have complex learning disabilities.

Most of his neighbours are registered with the same surgery and all have been having annual health checks for the past nine years which have proved very successful. Everyone has a hospital admission folder and a hospital passport. All support staff keep a close eye on an individual's general health which ensures that any changes in health needs are picked up and acted upon right away. We live in the north west of England and there is a good connection between parents and the CCG team.

Appointments for the annual health checks are written up annually in the individual's health file by the person's key worker. As the appointment gets nearer the key worker, and other members of the person's team, talk about the health check so they are prepared. Anyone who needs extra appointment time is given it and home visits are made, as and when required. The individual's staff team explain the purpose of the health check to those who have good understanding and even to those who have no ordinary means of communication, such as my son, for whom 'easy read' and other pictorial information is inappropriate or wouldn't make sense.

As this has been on going over a long period there is a good relationship between the surgery and the people who live and work with the 10 individuals, even paramedics from our two local hospitals have developed a good relationship with those for whom hospital admissions, or paramedic call out, is a way of life.

A couple of years ago, my son needed a blood sample taking. A community phlebotomist arrived but refused to take the blood as my son needs someone to steady his arm and the nurse said she couldn't carry out the procedure if restraint was used. She left without telling anyone what other options were available. My son's key worker rang the surgery for advice and one of the doctors came out that week to do the blood test at home. She has been doing it ever since whenever my son needs to give a blood sample.

Another procedure is being carried out at the surgery so that my son doesn't have to spend time in a hospital waiting room which is never a good experience for him.

Myself and another parents are members of our local Healthcare for All steering group which is chaired by the Partnership Commissioning Manager with St Helens CCG.



### **Getting it right - from the start Mencap and Clinical Commissioning Groups**

Getting It Right – From The Start is a partnership pilot project between Mencap and four CCGs in England. It is focused on promoting and supporting GP Practices to make reasonable adjustments to primary care services for people who have a learning disability. The following example from East Surrey Clinical Commissioning Group, demonstrates how an individual who has complex needs and limited communication has been supported to use GP services in the same way as we would all expect to do.

P had never attended a health appointment in a community setting having moved from NHS campus accommodation into supported living.

The practice worked closely with the provider organisation to support P to build confidence about visiting the location, entering the surgery, and becoming familiar with the waiting room and the staff in the practice.

Once this had been achieved the GP offered an “open appointment” so that when P was ready the GP was informed and they were seen straight away. As a result:

- the health risks to the person have been minimised – because they are now able to engage with the practice;
- the surgery has gained insights into the different approaches that can be used to meet patient need;
- making creative reasonable adjustments has resulted in an overall reduction of costs, by avoiding the need for home visits, and unnecessary use of secondary or emergency services

### **Successful pilot**

#### **NHS North Leeds CCG**

A small scale pilot project started in May 2013, for a six month period, to identify barriers and obstacles to accessing health checks and to increase the uptake and quality of health checks. All GP practices were asked to submit an expression of interest to participate in the pilot. Three practices were selected, one in each of the CCG areas.

The project was a partnership between the CCG with a lead for learning disabilities, a GP with a Special Interest, and the learning disability specialist health provider organisation from which two community learning disability nurses were seconded. The nurses worked with the practices and the outcomes were as follows:-

- education on learning disabilities and health issues provided for staff from all three practices including key areas to consider in undertaking a health check
- identification and implementation of electronic templates for EMIS Web and SystemOne that improved the recording of health checks
- searches of the QOF registers identifying people eligible for a health check that practices had previously not recognised
- liaison with families, described as hard to reach, to improve understanding of health checks and support attendance for a health check
- development of easy read information for appointments and health action plans

The success of the project has resulted in a commissioning intention for there to be learning disability primary care liaison nurses across the CCG areas from April 2014.

### **GP resource pack**

#### **Coventry and Warwickshire Partnership NHS Trust**

Coventry and Warwickshire Partnership NHS Trust has developed a resource pack for all their GP practices. The pack is given to GPs at events and is designed to raise awareness of health issues for people with learning disabilities. The nominated learning disability lead in the practice also receives electronic copies of the documents and the folder can be updated as necessary.

The folder contains information on what a learning disability is and a screening tool to help determine if someone has a learning disability. There is advice about read codes (all GP practices in the area now use standardised read codes) and a practice protocol for delivering health checks, including an easy read invitation letter. There is information on the Mental Capacity Act and consent, tips on communication and signs and symbols, information on the associated health needs of people with learning disabilities, epilepsy management plans and other useful information. The folder includes information on referring to the Community Adult Learning Disability Service. All referrals to the team go through a central booking service, making it easier for GPs and others to refer. The Trust has been encouraging GPs to use the Health Check template developed in the North East of England. All practices in Solihull are using the template, and some GP practices in other areas are beginning to pilot the template. The template enables better local data collection, and produces a health action check list following the health check.

## Conclusion

The Learning Disabilities Annual Health Check is a reasonable adjustment that can be effective in detecting unmet health needs, and leads to the treatment of health conditions which may be serious or life threatening. One of the recommendations of the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD) is “Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans”.

Reducing health inequalities through health checks should be a priority for commissioners and providers as reducing health inequalities is a requirement for all public sector organisations. It is important that commissioners, providers, family carers and people with learning disabilities understand the importance of annual health checks and that support systems are put in place to improve the uptake and quality of annual health checks.

There are a number of examples of reasonable adjustments in this report that can be used to increase the uptake and quality of health checks. These examples, together with the resources section, provide information that will help support the implementation of the 2014 Learning Disabilities Annual Health Check Directed Enhanced Service which includes a requirement for health checks for people with learning disabilities aged 14 years and a requirement for Health Action Plans.

## Acknowledgements

We would like to thank everyone who contributed examples from practice to this report.

## Appendix 1

### Are health checks for people with learning disabilities helpful?



**At the health check, most people with learning disabilities (between 51% and 94%) are found to have an illness or health condition that doctors didn't know about before**



**Health checks also help people to get more help with any health problems found in the health check**



**We don't know yet if health checks help people become healthier in the long run**

## The effectiveness of health checks for people with learning disabilities

### Summary

Health checks show up previously unidentified health conditions. Some of these are common and distressing, others are serious and life threatening. They prompt action to address these health needs. So far there is no good evidence about how much this improves health status in the short, medium or long term.

A Directed Enhanced Service (DES) to deliver annual health checks for people with learning disabilities began in 2008-9 and has been extended to 2014/15. In 2012/13, 92,329 people with learning disabilities received a health check, 52% of those eligible to receive one.<sup>1</sup>

This briefing outlines evidence on the effectiveness of health checks for people with learning disabilities, based on a 2013 update of a 2010 systematic review which reviewed 48 studies<sup>2,3</sup>.

### The effectiveness of health checks for people with learning disabilities

The studies consistently demonstrate that health checks are effective in identifying unmet needs.

- health checks resulted in the identification of previously undetected health conditions in 51%<sup>4</sup> to 94% of patients<sup>9</sup>
- the number of previously undetected or unmanaged health needs identified per patient ranged from 2.2 to 5.2<sup>5-9</sup>
- these conditions included serious and life threatening conditions such as cancer, heart disease and dementia, and more commonly what might be regarded as more minor health conditions, such as impacted ear wax

There was also evidence that health checks are effective in prompting health actions to address identified health needs.

- these include referrals to primary care services such as practice nurses, dentists, opticians, and dieticians for actions such as vaccinations, blood tests, breast and testicular screening, dental review and vision and hearing assessment

There are limitations to the evidence base.

- only three RCTs<sup>10-12,13</sup> and two other robustly designed studies were identified<sup>9,14</sup>.
- there is also a lack of information on changes in health status as a result of health checks
- finally, many of the studies took place prior to the introduction of the DES, and are likely to have conducted with enthusiastic "early adopters"

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## Appendix 2

### Can health checks help people with learning disabilities who display behaviour that challenges?



**Pain or physical health problems can cause challenging behaviour**



**Health checks spot health problems in three out of every four people who have behaviour that challenges**



**Treating health problems can stop or reduce challenging behaviour**



## Health checks: identifying health issues in people who display behaviour that challenges

### Summary

Challenging behaviour may result from physical health problems and/or pain. The small amount of available evidence shows that: 1) health checks identify health problems in a significant proportion of people who display behaviour that challenges; 2) treating these health problems can reduce or stop the display of challenging behaviour by many people.

Behaviours that challenge (aggression, destruction, self-injury and others) are shown by 10%-15% of people with learning disabilities.<sup>1-6</sup> Some challenging behaviours may result from health problems or pain associated with untreated health conditions.<sup>2 7-11</sup>

### Evidence for health checks with people who display behaviour that challenges

In 2013, IHaL updated the results of a systematic review of international published research on the effectiveness of health checks for people with learning disabilities.<sup>12 13</sup> Two studies provided information on the role of health checks in identifying and treating health problems in people with learning disabilities displaying some form of behaviour that challenges:

Of 56 adults with learning disabilities referred to a service for behaviour management, 13 were referred for health screening and for 10 people (18%) health conditions potentially related to challenging behaviour were identified (eg compound leg fracture, urinary tract infection, toxic levels of anticonvulsants). Eight of the 10 stopped or reduced their challenging behaviours once these health problems were addressed.<sup>14</sup>

Medical evaluation of 1,135 people with learning disabilities referred to a clinic for challenging behaviour found that 75% of the sample had one or more undiagnosed or undertreated health problems.<sup>15</sup> These included: epilepsy (46% of the sample); hypothyroidism (13%); gastro-oesophageal reflux (10%); severe closed head trauma (9%) and chronic pain (9%), and more rare but serious conditions such as cancer. In many cases the person's challenging behaviour stopped once their health condition was treated. In 43 people (4%) seizures were identified as the sole cause of their challenging behaviour.

There are serious limitations in the evidence base, and more work is needed to identify the effectiveness of health checks in identifying and treating health issues in people who display behaviour that challenges, and in evaluating their impact upon behaviour.

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## Appendix 3

### What makes health checks for people with learning disabilities work better?



**People with learning disabilities and carers think health checks are really good if they are done right**



**Doing health checks helps GPs and nurses understand better the health needs of people with learning disabilities**



**Some GPs want to do health checks for people with learning disabilities but some GPs don't think they need to**

## The effectiveness of health checks for people with learning disabilities

### Summary

Health checks are highly valued by people with learning disabilities and family carers if the process does not impose barriers to access. GP views of the value of health checks vary, although directly involved GPs report greater professional knowledge and confidence about addressing the health needs of people with learning disabilities.

A Directed Enhanced Service (DES) to deliver annual health checks for people with learning disabilities began in 2008-9 and has been extended to 2014/15. In 2012/13, 92,329 people with learning disabilities received a health check, 52% of those eligible to receive one.<sup>1</sup>

This briefing outlines evidence on the effectiveness of health checks for people with learning disabilities, based on a 2013 update of a 2010 systematic review which reviewed 48 studies<sup>2 3</sup>.

### Implementing health checks for people with learning disabilities

Studies have consistently reported that majorities of people with learning disabilities and family carers think that health checks are a good idea and find their health checks acceptable.<sup>9-11</sup> However, people's concerns about health checks (eg uncertainty and anxiety about the process, fear of needles) may be made worse by processes that put barriers in the way of people accessing health checks (eg invitation letters not in easy read, long waits in the waiting room, doctors not explaining the health check, feeling rushed, not being told test results).<sup>4 5 7 11</sup>

Conducting health checks is associated with increased GP, practice nurse and support worker awareness of the health needs of people with learning disabilities and the range of specialist services available<sup>6 12-15</sup>.

While GPs are becoming more favourable to the idea of health checks,<sup>6 12-15</sup> their views vary from positive to sceptical with some GPs viewing them as unnecessary as they "treat everyone the same".<sup>4 6 8</sup>

Barriers to implementing health checks identified by health professionals included difficulties in aligning registers and determining who was eligible for a health check, missed appointments, the inaccessibility of buildings and equipment, the time needed for the health check, and a lack of professional leadership and direction.<sup>4 6 8 15</sup>

There are limitations to the evidence base in terms of sample sizes and research design.

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