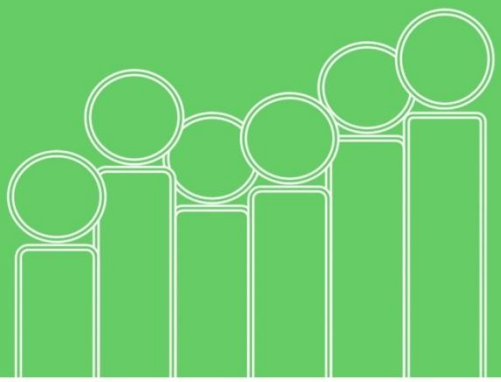
Improving Health and Lives:
Learning Disabilities Observatory

Health Checks for People with Learning Disabilities: Implications and actions for commissioners

Evidence into practice report no.2

Sue Turner and Carol Robinson



Supported by the Department of Health

DH Department of Health

Health Inequalities and People with Learning Disabilities in the UK: 2010

Sue Turner
Carol Robinson

Contents **Page**

National Development Team
for Inclusion

Montreux House
18A James Street West
Bath BA1 2BT
T: 01225 789135
F: 01225 338017
www.ndti.org.uk

Improving Health and Lives:
Learning Disabilities Observatory

Introduction

Improving Health and Lives (IHaL) is the Learning Disabilities Public Health Observatory - www.improvinghealthandlives.org.uk – one of two three year projects funded by the Department of Health in response to Sir Jonathan Michael's 2008 inquiry into access to healthcare for people with learning disabilities[1]. The other project is the Confidential Inquiry into the premature deaths of people with learning disabilities. IHaL aims to provide better, easier to understand information on the health and wellbeing of people with learning disabilities and to help commissioners to make use of existing information whilst working towards improving the quality and relevance of data in the future. This paper is the second in a series, which aims to translate the key messages from research into advice for commissioners. It focuses on the importance of regular high quality health checks for people with learning disabilities and draws on two main research papers: 'Health Checks for People with Learning Disabilities' by Emerson and Glover (2010)[2] and 'Health Checks for People with Learning Disabilities: a Systematic Review of the Evidence by Robertson, Roberts and Emerson[3]. It is also consistent with, and builds on the Royal College of General Practitioners guidance[4.] All papers from the IHAL project can be downloaded from: http://www.improvinghealthandlives.org.uk/uploads/

People with learning disabilities face serious health inequalities that health services have a duty to reduce. They are also less likely to proactively seek help to address health issues. One practical step that GPs can take is to offer good quality health checks on an annual basis. Where these are in place, research indicates that they can lead to the detection of potentially treatable conditions and targeted actions to deal with them.

This document provides guidance for those people with responsibility for commissioning services about ways to increase access to health checks and maximise the benefits of them. The information presented may also be of interest to family carers and professionals concerned with the health and welfare of people with learning disabilities. Effective commissioning to address these inequalities will comprise several key actions including:

1. Updating and validating GP learning disability registers.
2. Ensuring that as many people with learning disabilities as possible get health checks.
3. Increasing uptake of the Directed Enhanced Service (DES) and putting alternative arrangements in place for those not covered by the DES.
4. Putting in place reasonable adjustments, including easy read information, to ensure that health checks are accessible.
5. Providing strategic leadership to ensure a consistent message to all relevant partner agencies about the importance of health checks, year on year.
6. Benchmarking progress and being transparent about local/regional progress.
7. Ensuring that health checks are comprehensive, and actions following the health check are identified and followed up.
8. Ensuring that there is a system for offering Health Action Plans.

Background

In 2006, the Disability Rights Commission recommended the introduction of annual health checks for people with learning disabilities in England following its investigation into the physical health of people with mental health needs and people with learning disabilities[5]. The study, which examined eight million primary care records, included four area based in- depth studies and extensive consultation exercises, showed that people with learning disabilities are much more likely than other citizens to have significant health risks and major health problems.

The subsequent independent inquiry into access to healthcare for people with learning disabilities[1] also recommended the introduction of health checks for people with learning disabilities and in September of the same year, the NHS and British Medical Association announced plans for a Directed Enhanced Service (DES) to deliver them.

In 2009, the Department of Health issued directions that required Primary Care Trusts (PCTs) to offer GP surgeries the opportunity to carry out health checks as part of the DES[6]. This arrangement is currently in place and extends into the 2010-11 financial year. In terms of the future, ministers are committed to ensuring health checks continue.

Recent data[7] on the number of health checks taking place indicates that whilst there has been a rapid increase in the number of health checks between 2008-09 and 2009-10, only 41% of people who are eligible to receive them, did so. In addition, there is enormous variability between PCTs and Strategic Health Authorities in the percentage of people with learning disabilities, known to adult social care, who are having health checks. This suggests that some areas have managed to develop good strategies for informing people about health checks and encouraging high levels of uptake whilst others have yet to address the issue in an effective way.

Throughout this paper, we will include examples of good practice both in relation to the number and quality of health checks.

We would like to thank all people who provided examples of good practice, and to those who commented on and contributed to this paper.

What can commissioners do to improve access and uptake of health checks?

GP Registers

Issue

Currently the number and percentage of people who are identified as having a learning disability on GP registers is highly variable across the country. Some of this variability results from inaccurate and inadequate identification of people with learning disabilities in GP registers. There are two registers, the Quality Outcomes Framework (QOF) register, which should include all people identified as having a learning disability registered with the practice, and the DES register which only includes people known to local authorities. Without being easily identifiable, people will not be offered health checks[2].

Commissioning action

- In order to check that all people on GP registers who have a learning disability are clearly identified within the medical record system, Commissioners should ensure there is a process by which **GP practices compare their lists with those known to adult social care** to ensure no one is omitted who is eligible for a health check. Specialist learning disability teams and primary care liaison nurses are well placed to support practice managers in this task.

For example

The East Midlands good practice guidance which can be used as an Accreditation scheme for Annual Health Checks includes a requirement for the QOF register to be updated on a yearly basis as a minimum, and as things change during the year. The DES registers are updated from the QOF.

- Not all people with learning disabilities are known to social care so there are likely to be people with learning disabilities on the Quality Outcomes Framework (QOF) register who are not eligible under the DES**. In order to reduce health inequalities, some areas have prioritised health checks for all people with learning disabilities**.

- As the QOF Indicator for Learning Disabilities asks practices to produce a register of patients aged 18 or over. **GPs need to be made aware of any children with learning disabilities registered with their practice** so that they can be added to the register when they become 18, **and any adults with learning disabilities newly registered** with any practice. Commissioners should request, and ensure, that pathways are in place so that this information is made available to GPs.

- IHaL will soon be publishing estimates of how many people with learning difficulties we would expect to be living in each PCT and Local Authority in England. **Use these estimates to benchmark current local rates of identification.**

In summary

- Regularly update and validate GP learning disability registers.
- Increase the uptake of health checks to reduce health inequalities for all people with learning disabilities.
- Ensure there is a pathway in place to inform GPs of children with learning disabilities and newly arrived adults registered with the practice.
- Use IHaL estimates to benchmark current local rates of identification.

Issue

Currently, 59% of people who are eligible for health checks are not receiving them.

Commissioning action

- There is sometimes a lack of clarity between specialist learning disability and primary care commissioners as to who is responsible for commissioning elements of the health check pathway. **Commissioners should agree respective responsibilities** and write these into their contracts with the learning disability provider and GP practice, so that there is a clear and agreed pathway.

- There are still a number of GP practices that are not signed up to the Directed Enhanced Service (DES). This may be because GPs lack experience of working with people with learning disabilities and are reluctant to take on the extra responsibility. Commissioners should **encourage GP practices to sign up to the DES** and provide support to them via the specialist learning disability team and/or primary care liaison nurse.

For example
In Calderdale, all GP practices signed up to the DES have been given the opportunity to offer health checks to people with learning disabilities registered with practices not signed up to the DES. GPs will use the Cardiff Health check and refer any health issues that need following up back to the individual's own GP. A directory of available practices is being sent to the individuals concerned.

- Despite support, some GP practices will not sign up to the DES. Commissioners should **ensure that people with learning disabilities in practices not signed up to the DES, receive health checks from an alternative provider**.

For example
Cornwall PCT have spent time developing good relationships with their GP practices and have achieved 97% sign up to the DES by providing support to practices via their primary care liaison nurses.

- Some people on the DES register are not being called up for health checks. Commissioners need to **check that eligible people are receiving health checks**, and follow up with GP practices as necessary. Some commissioners are also encouraging providers to follow up with GPs if the people for whom they are providing services do not get offered a health check.

- Even when health checks are offered, some people with learning disabilities do not attend their appointments. People with learning disabilities may not understand the information they have been sent, or the reason for having a health check. They may not use a diary. Commissioners should ensure that GP practices **provide easy read information** about the benefits of a health check, as well as easy read appointment letters and a **telephone call the day before the appointment,** as this can increase uptake. There are examples of easy read appointment letters and pre-check information in A Step by Step Guide for GP Practices[7].Easy read health information can also be found at www.easyhealth.org.uk and www.apictureofhealth.southwest.nhs.uk

For example
A study in Devon found that people with learning disabilities were more positive about their health check when they had received a letter, knew what the check was about, had received easy read information and knew what the doctor/nurse was saying to them. For more information, please contact katy.welsh@devon.gov.uk

- Although accessing generic services such as GP surgeries should always be the preferred option, some people with learning disabilities may find this difficult. Therefore commissioners should ensure that there is potential within each locality, for example via the DES specification, to **offer reasonable adjustments in the form of flexibility around health checks,** for example in the patient's home or at their normal day setting.

For example
In Gloucestershire a man with learning disabilities and complex physical impairments requested an examination to determine the cause of abdominal pain. The surgery did not have a suitable hoist and therefore offered a telephone consultation with the carer. The specialist learning disability service and PCT argued for a home visit on the grounds of reasonable adjustments. As a result of the home visit, a number of health issues were resolved, greatly improving the man's health and wellbeing.

In summary

- Agree respective responsibilities regarding the health check pathway between learning disability and primary care commissioners.
- Encourage and support GP practices to sign up to the DES.
- Engage alternative providers to provide health checks to people in practices not signed up to the DES.
- Ensure that people who are eligible for a health check are being offered them.
- Ensure GP practices provide easy read information and appointment letters.
- Ensure that reasonable adjustments are utilised to maximise the accessibility of health checks.

Issue

There is wide variation between PCTs and SHAs in terms of the number of health checks conducted.

Commissioning action

- Reducing health inequalities through health checks should be a priority for all. Therefore **strategic leadership** at a senior level within regional and/or local services is crucial. There should be a named lead in every commissioning organisation who is part of the generic commissioning team, as reducing health inequalities is a mainstream NHS responsibility and should be embedded in strategy documents. The lead should report to the Partnership Board and can ensure that tackling health inequalities becomes everyone's business by giving clear and consistent messages about the importance of health checks.

For example
In the South West, the SHA embedded the reduction of health inequalities in its strategic ambitions. They gave clear and frequent messages about reducing health inequalities by increasing health checks and required every PCT to have a named lead who reported to the Learning Disability Partnership Board. They are also asking PCT Chief Executives for monthly progress reports on numbers of health checks completed. Compared to other regions, the South West has the highest reported percentage of health checks in 2009/10.

- It is important that commissioners, practitioners, family carers and people with learning disabilities understand how well their area is doing in relation to others, so that appropriate action plans can be put in place. The Department of Health's statistics (on the IHAL web site as an Excel spread-sheet) should be used **to create a regional average and benchmark.** This is important as it enables people to have their hard work acknowledged and shows areas that are not doing so well, what they need to aim for.

- Being open and transparent about performance in order to promote local accountability is becoming increasingly important[8]. Using the **Performance and Self-Assessment Framework (SAF)** www.improvinghealthandlives.org.uk/self_assessment/ to support the uptake of health checks, enables commissioners to give clear messages to providers about priorities, as well as ensuring that family carers and people with learning disabilities are informed of local performance.

- **Sharing good practice** via local and national health networks can help avoid duplication and thus increase effectiveness. Janet Cobb runs a number of national health networks. Go to www.jan-net.co.uk for further information. Local health networks also provide a forum for commissioners to **celebrate success**, which is particularly important in difficult financial times.

In summary

- Ensure that there is clear strategic leadership within the organisation and the reduction of health inequalities is embedded in strategy documents.
- Use the data to create a benchmark and measure progress.
- Use the SAF to reinforce the importance of implementing health checks.
- Share good practice and celebrate success via health networks.

Quality of health checks

Issue

Research indicates that health checks are variable in what they include, who conducts them and what actions follow from them.

Commissioning Action

- It is not easy to extract data from health checks for analysis unless the type and range of data required has been agreed with GP practices when the DES is set up. Learning disability registers can also be linked to other QOF registers such as diabetes to build a better picture of health issues locally. Therefore **health check outcomes should be built into the commissioning feedback process** from the beginning, in negotiation with GPs, practice managers and public health departments. Extracted information can be used to inform JSNAs and local commissioning priorities. It is also helpful for commissioners to communicate findings to GPs on a regular basis.

- The content of health checks varies and some checks are more comprehensive than others. For example, it appears that it is less common for mental health issues and a review of medication[3] to be included. To counter such variations, commissioners should agree with GP practices **a consistent and comprehensive approach to health checks** across all practices which is compatible with the software in use. Commonly used templates can be found at: www.pcc.nhs.uk/ (commissioning – primary care frameworks –management of health for people with learning disabilities). In addition, there are examples of syndrome specific checks[4] which can be used.

- Although it is common for GPs to carry out the health check, there are examples of other personnel such as community learning disability nurses carrying out the check[3]. Whilst this may seem like a pragmatic solution where practices are not signed up to the DES, commissioners should ensure that **only appropriately trained personal carry out the health checks.** It is important for GPs to be involved in the actual screening in terms of **quality assurance,** and because it is more likely to lead to appropriate referrals and ultimately health gains. For helpful guidance on the respective roles of the GP and practice nurse please see A Step by Step Guide for GP Practices[4].

- In order to maximise the chance of a successful health check, **good preparation** is invaluable. This can include taking a medical history and giving an explanation of the procedures, and why they are needed. It will also be important to provide many people with additional support as some will be frightened of needles and other

invasive tests. Commissioners should ensure that **accessible information is available to health staff** so they can help people understand what will happen (see above for helpful websites). There is also a useful checklist of what should happen prior to a health check in a Step by Step guide for GP Practices[4]. The involvement of a familiar person whom the person likes will often be helpful and this option should always be offered.

- People with learning disabilities may need **reasonable adjustments** such as longer appointment times to successfully use health services. Commissioners should ensure that reasonable adjustments are in place, and practices should ensure that there is an auto-alert on the patient record system that tells practice staff about an individual's particular needs.[4.] Additional training and support to practices may also be necessary.

For example
The Health Facilitator in Oxleas has spent time building up a good relationship with practices and checks for evidence of actions in the electronic notes. If nothing is recorded he will follow up with the practice concerned.

- If health checks do not lead to appropriate referrals and further advisable actions such as additional health screening, the reduction in health inequalities is likely to be minimal. Therefore, it will be important for commissioners to **monitor the extent to which health checks lead to appropriate action and to determine where blocks occur.** Developing a robust evaluation framework which demonstrates the outcomes of health checks, including onward referrals, can provide important evidence of their effectiveness. It is also important to check that mechanisms are in place to ensure that useful information about individuals' communication needs, anxieties and preferences are passed onto any departments to which patients are referred as a result of the health check. IHaL will soon be publishing guidance on local approaches to evaluating the impact of health checks.

For example
The East Midlands good practice guidance which can be used as an Accreditation Scheme for Annual Health Checks asks for evidence of the number of health action plans offered, and whether a health support/facilitator is identified on the HAP.

For example
Devon have been informing family carers about HAPs and the role and contact details of their local Primary Care Liaison Nurse. They are currently updating a training pack for family carers which can also be used with support staff.

- To enable people with learning disabilities to be fully involved in their health, commissioners should ensure there is a system in

place to offer **Health Action Plans (HAP)** in a format appropriate to the individual, following the health check. Commissioners should ensure that support staff are appropriately trained to enable people with learning disabilities to improve their health. Family carers also have an important role to play. In one study, 87% of carers reported following up health concerns and they can be essential for helping people adopt any life style changes that are indicated.

For example

For example, in Westminster there is a health facilitation network made up of individuals who have undertaken a four day training course which includes the Royal Society of Public Health level 2 training. As well as developing HAPs the network runs training sessions for staff supporting people with learning disabilities on health issues.

In summary

- Build health check outcomes into the commissioning feedback process.
- Use a comprehensive health check template.
- Ensure that only appropriately trained personnel carry out health checks.
- Ensure that staff have access to accessible information and guidance so that they can support people with learning disabilities appropriately prior to the check.
- Ensure that reasonable adjustments are in place to enable people to use health services.
- Monitor the extent to which health checks lead to appropriate actions.
- Ensure there is a system in place to offer Health Action Plans.

Conclusions

Given the health inequalities faced by people with learning disabilities, the introduction of annual health checks is a reasonable adjustment that appears to be effective in the detection of unmet yet potentially treatable health needs including serious and life threatening conditions.

Although there has been a marked increase in the number of people with learning disabilities who have had a health check in the last two years, over half of those eligible to receive checks are not doing so. Clear disparities between different areas in terms of uptake and practice suggest that much more can be done to help people with learning disabilities receive a health check and thereby reduce the inequalities they face. Commissioners can take a lead in urging practices to adopt best practice and can employ local drivers such as the locally enhanced service, to create incentives for them to do so.

APPENDIX I

Table of summary actions

Actions	Who is responsible?
○ Agree respective responsibilities regarding the health check pathway between learning disability and primary care commissioners	• PCT community commissioners and learning disability commissioners
○ Regularly update and validate GP learning disability registers	• PCT community commissioners/GP consortia and learning disability commissioners
○ Prioritise increasing the uptake of health checks to reduce health inequalities for all people with learning disabilities	• PCT community commissioners/GP consortia
○ Ensure there is a pathway in place to inform GPs of children with learning disabilities and newly arrived adults registered with the practice.	• PCT community commissioners/GP consortia
○ Use IHaL estimates to benchmark current local rates of identification	• PCT community commissioners/GP consortia
○ Encourage and support GP practices to sign up to the DES	• PCT community commissioners/GP consortia and learning disability commissioners
○ Engage alternative providers to provide health checks to people in practices not signed up to the DES	• PCT community commissioners/GP consortia
○ Ensure GP practices provide easy read information and appointment letters	• PCT community commissioners/GP consortia
○ Ensure that reasonable adjustments are utilised to maximise the accessibility of health checks	• PCT community commissioners/GP consortia

○ Ensure that there is clear strategic leadership within the organisation and the reduction of health inequalities is embedded in strategy documents.	• PCT community commissioners/GP consortia
○ Use the data to create a benchmark and measure progress	• PCT community commissioners/GP consortia
○ Use the SAF to reinforce the importance of implementing health checks	• PCT community commissioners/GP consortia
○ Share good practice and celebrate success via health networks	• PCT community commissioners/GP consortia
○ Build health check outcomes into the commissioning feedback process	• PCT community commissioners/GP consortia
○ Use a comprehensive health check template.	• PCT community commissioners/GP consortia
○ Ensure that only appropriately trained personnel carry out health checks	• PCT community commissioners/GP consortia
○ Ensure that staff have access to accessible information and guidance so that they can support people with learning disabilities appropriately prior to the check	• PCT community commissioners/GP consortia
○ Ensure that reasonable adjustments are in place to enable people to use health services	• PCT community commissioners/GP consortia
○ Monitor the extent to which health checks lead to appropriate actions	• PCT community commissioners/GP consortia
○ Ensure there is a system in place to offer Health Action Plans	• PCT community commissioners/GP consortia

APPENDIX II

About the Authors

Sue Turner RNLD, Diploma in Nursing, Cert. Ed (FE), BA (Hons), MSc - Primary Health Care Policy Development and Management.

Sue initially trained as a Nurse for people with learning disabilities in Bristol. She has worked within training, as a Nurse Advisor in Gloucestershire, and has managed a variety of services for people with learning disabilities in Gloucestershire and Bristol including community learning disability teams. Sue was the Valuing People Lead for the South West Region for four and a half years, initially job sharing the role with Carol Robinson. During this time, Sue developed the health network in the South west and introduced the health self-assessment to the region. She later worked closely with the Strategic Health Authority on its implementation.

Sue is now leading on the Improving Health and Lives project for the National Development Team for Inclusion.

Carol Robinson, BA, CQSW, Dip Applied Social Studies, PhD.

Carol Robinson began her career as a social worker with Essex County Council. She then undertook a PhD in social psychology at the University of Bristol. Afterwards she went into research and became a Reader in the University's Norah Fry Research Centre where she carried out studies relating to support services for families with disabled children. She also had a period of secondment to the Social Services Inspectorate as an analytic inspector (now CQC) before becoming Director of the South West Learning Disability Network known as SWALD. Carol then went onto work half-time for The Care Services Improvement Partnership's Valuing People Support Team and also for the South West Regional Improvement and Efficiency Partnership. Both roles involved working regionally to improve opportunities for young disabled people, adults and their family carers.

In 2008 she decided to undertake consultancy work and now specialises in transition planning and improving employment outcomes for disabled young people. She is currently involved in the cross government programme called 'Getting a Life' which aims to help young people have the life they want including good careers.

She also has a longstanding interest in support for families who have a disabled member and has published a number of articles and books mainly on the subject of short breaks. She has recently become a trustee of the National Family Carer Network.

Carol is an associate consultant with the National Development Team for Inclusion.

References

1. Michael, J. (2008) *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*
2. Emerson, E. and Glover, G. (2010) *Health Checks for People with Learning Disabilities*
3. Robertson, J. Roberts, H and Emerson, E. *Health Checks for People with Learning Disabilities: a Systematic Review of the Evidence*
4. Hoghton, M. And the RCGP Learning Disabilities Group. (2010) *A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability*. The Royal College of General Practitioners: London.
5. Disability Rights Commission (2006) *Equal Treatment - Closing the Gap*. Disability Rights Commission: London.
6. Department of Health. *The Primary Medical Services (Directed Enhanced Services) (England) Directions 2010*
7. Information Centre for Health and Social Care: *The uptake of health checks by people with learning disabilities* . Downloadable from: http://www.improvinghealthandlives.org.uk/projects/annualhealthchecks/numbers
8. Department of Health (2010) Equity and Excellence: Liberating the NHS