



Improving Health and Lives
Learning Disabilities Observatory

Health checks for people with learning disabilities: including young people aged 14 and over, and producing health action plans

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

About Improving Health and Lives

Improving Health and Lives (IHaL) was set up in April 2010 to provide high quality data and information about the health and healthcare of people with learning disabilities. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare.

IHaL is a collaboration between Public Health England (PHE), the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. Since April 2013, IHaL has been operated by PHE.

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This report is one of a series of reports written by the Learning Disabilities Public Health Observatory (www.improvinghealthandlives.org.uk) focusing on implementation of health checks for people with learning disabilities. The aim of these reports is to make it easier for people to find, apply and share good practice.

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

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Easy-read summary



Having a health check every year can help find health problems, so people can be given the right help.



Health checks are for people with learning disabilities who are known to family doctors and social services.



Now young people can have health checks when they are 14 years old or more.



You can ask for a health check.

Your school or your family doctor might suggest a health check.



Having a health check is a good time to talk about things that change as you grow up.



After your health check you can have a health action plan.

The plan will say what has been agreed to help you with your health.

Introduction

From 2008/09, the directed enhanced service (DES) offered health checks to people with learning disabilities aged 18 and over who were on the learning disability registers of participating practices. These practices were required to attend specified training and to use a health check format complying with certain requirements. The DES was based on evidence about the effectiveness and value of health checks in mitigating the health inequalities faced by people with learning disabilities.¹ Practical guidance for commissioners and practitioners on implementing the DES can be found on the Public Health England website² and a step-by-step guide for primary care is available from the Royal College of General Practitioners.³

A new enhanced service (ES) was introduced from April 2014: its provisions built on the DES to extend eligibility to young people with learning disabilities aged 14 and over, and to require participating practices to produce a health action plan linked to each person's health check. Full details are available at: www.nhsemployers.org/payandcontracts/generalmedicalservicescontract/directedenhancedservices/pages/enhancedservices201415.aspx

Implementing the new enhanced service

Identifying young people with learning disabilities aged 14 and over

Young people with learning disabilities will generally be known to the local child development team/child health team and through medical reviews at school or college. Some will be known to child and adolescent mental health services (CAMHS). Many will be eligible for the new Education, Health and Care Plans (EHCPs) – see below.

Local authorities are responsible for ensuring that young people with special educational needs have an annual review from age 14 onwards that helps them to prepare for adult life. This includes a review of factors relating to their health. These 'transition' reviews offer an opportunity to identify young people with

¹ www.ihal.org.uk/publications/937/Health_Checks_for_People_with_Learning_Disabilities:_A_Systematic_Review_of_Evidence

² www.ihal.org.uk/publications/1168/Improving_the_Uptake_of_Health_Checks_for_Adults_with_Learning_Disabilities:_Evidence_into_practice_report_no.6
www.ihal.org.uk/publications/1224/Making_reasonable_adjustments_to_primary_care_services:_supporting_the_implementation_of_annual_health_checks_for_people_with_learning_disabilities

³ www.rcgp.org.uk/learningdisabilities/~media/Files/CIRC/CIRC-76-80/CIRCA%20StepbyStepGuideforPracticesOctober%2010.ashx

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learning disabilities who would be eligible for a health check. The results of the health check, and the health action plan, should in turn feed into these reviews and preparation for adulthood.

More reliable identification and clinical coding of children and young people with learning disabilities, and their health needs, will support the development of both the Quality and Outcomes Framework (QOF) registers and the local Joint Strategic Needs Assessment (JSNA).

Suggestion: Primary care commissioners, practitioners and service providers will want to agree how consultation takes place with local child development/child health teams, child and adolescent mental health services, schools and colleges, and the designated medical officers (see below) to identify the initial cohort of young people aged 14 and over who should be offered health checks. They should also agree a process whereby 14-year-olds with learning disabilities are notified to the practice in future years. (See Sunderland example on p. 11). It might help to have a clear description of the young people to be included, and of the clinical coding to be used, so that everyone locally shares the same understanding.

Linking with the Children and Families Act 2014

Each clinical commissioning group (CCG) will have a designated medical officer (DMO) or designated clinical officer responsible for supporting it to meet its statutory responsibilities for children and young people with special educational needs or disabilities. The DMO acts as a point of contact for all the partner agencies in relation to the health of this group of young people.

Young people with special educational needs are eligible for a single assessment and planning process, which may lead to an EHCP. This will set out all the co-ordinated support they need. Health action plans resulting from health checks should form part of the EHCP. If the practice identifies a young person who may be eligible for an EHCP but does not yet have one, the practice should (with the young person's consent) bring them to the attention of the local authority. The practice may also refer parent carers for assessment by the local authority "if it appears they may have needs for support".

The Code of Practice for the Act sets out all the details of these and other provisions.⁴

⁴ www.gov.uk/government/publications/send-code-of-practice-0-to-25
www.gov.uk/government/publications/send-guide-for-health-professionals

Suggestion: Primary care commissioners, practitioners and service providers will want to talk to the local teams responsible for implementing the Children and Families Act 2014 about how health checks and health action plans can best link to EHCPs.

Extra considerations for young people with learning disabilities

Many primary care teams will know young people with learning disabilities as part of a family registered with the practice. Practitioners will be accustomed to working with the family, perhaps particularly in communicating with the young person and in making decisions. Undertaking health checks from age 14 offers an opportunity to begin establishing a more direct, adult relationship. This helps lay the groundwork for changes in legal status from age 16 (Mental Capacity Act and Children and Families Act) and it is important for young people and their families to understand how these will affect decision making about health matters.

This is also an age when young people may wish to explore some health or health-related issues in confidence, without their parents. This can be particularly challenging for the families of young people with learning disabilities, who may not have had support to think about the implications of their child becoming more independent, or about issues such as sexual health and relationships. They may simply fear what they perceive as additional vulnerabilities and feel ill-equipped to deal with all the changes occurring in their son or daughter during puberty and beyond.

Suggestion: Practices could find out about local sources of information and advice for young people and their families (for example, via schools, health services and voluntary organisations) on the Mental Capacity Act 2005, relationships and sexual health.

The enhanced service guidance sets out what a health check should cover. This is likely to overlap with the assessments used by local child health teams, but may cover some additional questions.

A young person with learning disabilities is likely to have had comprehensive, co-ordinated healthcare via their child health team. As they move into adulthood it can be confusing and a shock to find that they need to see different specialists for different conditions. These challenges are explored in more detail in the report of a

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local audit of healthcare for young people⁵ and the Care Quality Commission's recent report on transition.⁶

Suggestion: Practitioners and service providers can assist with planning a smooth transition to adult healthcare, based on a young person's health action plan. For example, the first transition review meeting for a young person (age 14) could:

- identify the lead health professional
- identify the main paediatric and adult health services relevant to the young person
- decide on the optimal time for transition (this might vary from one specialty to another, as well as varying for the young person)
- identify the team who, with the lead professional, will develop three transition documents:
 - a comprehensive summary of the young person's medical history and health needs
 - a clear management plan for current health issues
 - contact details and referral criteria for specialists from whom the GP might need advice
- plan health transition meetings for the young person and their family and/or support staff to meet paediatric and adult health service providers

(Suggestion taken from the recommendations of the Northumberland audit cited in the footnote.)

Health action plans

Updated guidance on health action planning and health facilitation was issued by the Department of Health in 2009.⁷ This restated that a health action plan is:

“ ... the actions needed to maintain and improve the health of an individual and any help needed to accomplish these. It is a mechanism to link the individual and the range of services and supports they need if they are to have better health... the plan is primarily for the person with learning disabilities and is usually co-produced with them.”

The purpose of a health action plan is thus to translate the results of a health check into agreed actions. It can then serve as a prompt throughout the year to all

⁵ Milner, C. (2008) Experiences of health transition for young people with learning difficulties and complex health needs in Northumberland. Northumberland: Northumberland NHS Care Trust

⁶ Care Quality Commission (2014) From the pond into the sea. Children's transition to adult health services. Newcastle: CQC

⁷

[webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096505](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096505)



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those responsible for action (including the person themselves and their family or other supporters). Health action plans should be formulated with regard to the individual's person centred plan and should link strongly with this (or with the EHCP for a young person – see above). With the individual's consent, or on the basis of a best interests decision, the health action plan should be shared with those who need to take action or be aware of important issues. For example, it could help the individual's family or paid support staff to understand the importance of the person sticking to a particular diet or treatment.

The guidance on the Enhanced Service supports the use of an electronic template in the GP clinical system and many practices would welcome this. Some areas have devised templates that are available in their local systems (see Derbyshire example on p12).

Suggestion: Primary care commissioners, CCGs, service providers and practices could agree on a local template if they are not already using one.

The guidance also notes that the health action plan may need to be provided in a different format to enable the person (and/or their family or paid supporters) to understand it. There may well be local systems already in place for adults with learning disabilities to have health action plans and/or health passports; the plan generated by the practice should link into this.

Suggestion: Practices could talk to the local learning disability primary care liaison nurse or the community learning disability team about existing local approaches to health action plans and how these can be linked with practice systems.

Practice examples and case studies

Sunderland: Identifying young people and preparing for health checks

The consultant paediatrician (disability) sends a letter to the GP, copied to the learning disability acute liaison nurse and the learning disability transition nursing team, whenever a child or young person is confirmed as having a learning disability, asking for electronic medical records to be flagged so that reasonable adjustments can be made in the event of a need for access to healthcare.

For example, this would be done whenever an educational psychology report or statement of special educational needs that confirms a learning disability is received. This takes very little time. The template was disseminated across the North East to all paediatric departments, all clinical governance departments and all learning disability liaison nurses. This can be downloaded at

www.ihal.org.uk/adjustments/?adjustment=323

The senior specialist school for young people with learning disabilities prepares young people for their annual health check with their GP, including sharing a DVD

showing what a health check may consist of and how it can be helpful.

The paediatrician also developed a 'traffic light' tool, with children and young people and their families, which families complete in the clinic waiting room and bring in to inform their review consultation. The tool gives them a chance to raise issues of concern to them, including barriers to participation and quality of life, and to highlight what is going well. The form is very simple, though not yet easy-read, and there has been positive feedback from those using it. It may be useful in primary care to inform appointments for health checks. This can be downloaded at www.ihal.org.uk/adjustments/?adjustment=324

Derby, Derbyshire, Nottingham City, Nottinghamshire:

Supporting practices to implement the enhanced service

A joint letter from the NHS England Area Team and the relevant CCG is sent to each practice:

- highlighting the NHS commitment to improving quality and reducing health inequalities
- offering guidance on the enhanced service, including links to useful resources, information about local templates and training requirements

Each practice has access to support from a named learning disability nurse contact from the strategic health facilitation team. Electronic templates are available for TPP SystmOne and EMIS (available to download at www.ihal.org.uk/adjustments/?adjustment=328) including a health action plan for the practice to complete and to send to the individual with an easy read letter (available to download at www.ihal.org.uk/adjustments/?adjustment=329).

Initially, the learning disability strategic health facilitation team helped practices to identify young people, using Read codes and practice knowledge. In the future, commissioners and the lead GPs for children and for learning disability will work with paediatricians and school nurses to agree systems to inform practices about young people to invite.

Bexley and Bromley: Training and support for health checks

The clinical lead for transition is training community learning disability nurses to offer training to practices on the enhanced service. Each nurse links to a number of practices. In addition, a CQUIN⁸ has been agreed for the learning disability service to offer health checks to people who are known to the service and whose GPs do not sign up to the enhanced service.

A strategic health forum for transition has been set up in each borough, to include representatives from public health, commissioning, families, clinicians and managers. Each forum is using a self-assessment framework to agree local priorities and develop plans with measurable outcomes. (This can be downloaded at www.ihal.org.uk/adjustments/?adjustment=326).

⁸ 'Commissioning for Quality and Innovation' payment for agreed activity

Gloucestershire: Training and templates to support implementation

In Gloucestershire, 82 out of 84 practices have signed up to deliver the enhanced service. In the past, each practice has used its own preferred approach to health checks; the CCG's Learning Disability Programme Board is now planning to pilot a standardised health check and health action plan template.

Refresher training for primary care on the enhanced service is planned. This will consist of a 'protected learning' event linked to a Health Check Open Day, to encourage links between practices and the range of local people and organisations attending the open day. Training will also cover concerns raised by GPs about working with people with profound and multiple learning disabilities (for example, swallowing and dysphagia, postural management and behavioural management). An easy-read 'My Health Book' and follow-up monitoring tool were developed for support workers to use with individuals to help identify person-centred health outcomes and actions. (These can be downloaded at www.ihal.org.uk/adjustments/?adjustment=325). Indicators from the Health Equalities Framework will be added into 'My Health Book' ready for the primary care refresher training in 2015.

Southampton and West Hampshire: Training support and quality audit

CCGs are using a CQUIN to commission support from Southern Health to offer training and updates on the enhanced service to each practice. A certificate and training pack are sent on completion. The pack provides information and accessible templates for the practice to use. The NHS England area team provided information about when each practice had last had training and this was used to inform invitations.

The lack of health check and health action plan templates embedded in electronic systems is proving a barrier; a simple local health action plan format was devised to try to get practices started. (This can be downloaded at www.ihal.org.uk/adjustments/?adjustment=327). Southampton created a template in the TPP system. It is important for strategic health facilitators and primary care liaison nurses to be thoroughly familiar with coding and primary care information systems.

The CQUIN includes an audit of the quality of a random sample of health checks carried out in 2013/14.

Health facilitators are working to engage with paediatric services to support identification of young people aged 14+.

Liverpool: Training on health checks; identifying young people

MerseyCare NHS Trust produced a DVD about annual health checks. This contains information in separate sections for people with learning disabilities, family carers and support staff, and primary care. The DVD is expected to be available on the trust's website in 2015. People with learning disabilities are involved in training for practices, family carer groups and day centres.

Learning disability primary healthcare liaison nurses are working with practices to

review their registers in order to identify young people aged 14+.

Lancashire: Including eating, drinking and swallowing problems in health checks

The clinical lead for dysphagia (Calderstones Partnership Foundation Trust and Lancashire Care Foundation Trust), working with people with learning disabilities, developed a book to guide and support a conversation between a person with learning disabilities and their supporter about mealtime experience. The book is designed to be used prior to the annual health check, but could be used at any time that concerns are raised about any aspect of health or mealtime skills.

Service users helped to design the book, which will be available in 2015. Details will be posted on Calderstones NHS Foundation trust website

(www.calderstones.nhs.uk).

An extensive staff training programme is helping to raise awareness of eating, drinking and swallowing problems. Staff are encouraged to support individuals to think about how mealtimes are going and to consider various aspects that may be difficult for them and lead to risk of choking or dysphagia. This would inform preparation for a health check (both those in primary care and those carried out by trust staff for inpatients).



Appendix A

Making reasonable adjustments to primary care services: supporting the implementation of annual health checks for people with learning disabilities. March 2014. Learning Disabilities Public Health Observatory.

www.ihal.org.uk/gsf.php5?f=312703

Improving the Uptake of Health Checks for Adults with Learning Disabilities. Evidence into practice report no.6. February 2013. Learning Disabilities Public Health Observatory.

www.ihal.org.uk/gsf.php5?f=16696

Health Checks for People with Learning Disabilities: An Audit Tool - Indicators of Success. August 2011. Learning Disabilities Public Health Observatory.

www.ihal.org.uk/gsf.php5?f=11429

Health Checks for People with Learning Disabilities: An Audit Tool (Easy Read Version). August 2011. Learning Disabilities Public Health Observatory.

www.ihal.org.uk/gsf.php5?f=11430

Health Checks for People with Learning Disabilities: An Audit Tool. August 2011. Learning Disabilities Public Health Observatory.

www.ihal.org.uk/gsf.php5?f=11431

Health Checks for People with Learning Disabilities - Easy Read. June 2011. Learning Disabilities Public Health Observatory. www.ihal.org.uk/gsf.php5?f=8484

Health Checks for People with Learning Disabilities: Implications and Actions for Commissioners. Evidence into practice report no.2. December 2010. Learning Disabilities Public Health Observatory. www.ihal.org.uk/gsf.php5?f=8482

Health Checks for People with Learning Disabilities – Easy Read. December 2010. Learning Disabilities Public Health Observatory. www.ihal.org.uk/gsf.php5?f=8484

Health Checks for People with Learning Disabilities: A Systematic Review of Evidence. September 2010. Learning Disabilities Public Health Observatory.

www.ihal.org.uk/gsf.php5?f=7274

Health Checks for People with Learning Disabilities: Summary of Evidence. September 2010. Learning Disabilities Public Health Observatory.

www.ihal.org.uk/gsf.php5?f=7272