

Learning Disability Annual Health Check Toolkit for Southwest England



Healthier Together

Improving health and care in Bristol,
North Somerset and South Gloucestershire

NHS

Bristol, North Somerset
and South Gloucestershire
Integrated Care Board

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Cornwall Partnership
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Introduction

This toolkit has been designed to support good quality Learning Disability Annual Health Checks (AHC) within General Practice. It is aimed to be used by all staff within primary care who are involved in organising, managing or delivering annual health checks to people with a learning disability. It contains guidance to support the completion of high-quality health checks to improve lives and enable earlier identification of health problems, with the aim of improving physical and mental health outcomes for this population.

This guide is designed to complement and not replace national guidance, local guidance and professional judgement. It will be updated to align with other national and regional guidance once published.

Why complete a Learning Disability Annual Health Check?

- Patients with learning disability are less likely to present with health problems to a GP
- They are more likely to answer specific questions
- More likely to present late and as emergency
- There is a high risk of diagnostic overshadowing: This means that a symptoms from physical or mental ill health is misattributed to a person's learning disability or autism leading to delayed diagnosis or treatment
- Have a higher risk of co-morbidities- epilepsy, poor mental health, obesity, constipation, dysphagia, diabetes, respiratory disease
- 44% of death certificates list potentially reversible

Have all colleagues in your practice accessed the Mandatory Learning Disability and Autism Awareness Training? [The Oliver McGowan Mandatory Training on Learning Disability and Autism | Health Education England \(hee.nhs.uk\)](https://www.hee.nhs.uk/learning-disability-and-autism-mandatory-training)

Watch this [video](#) to learning more about Harshi, her mum Khilna and their GP explain why it is important for people with a learning disability to have an Annual Health Check and a Health Action Plan (HAP).

A further video here explains the challenges people with a learning disability face when accessing primary care: [Animation around the challenges of people with learning disabilities in primary care - YouTube](#)



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Learning Disability definition and GP register guidance

A learning disability is a significantly reduced ability to understand complex information or learn new skills; a reduced ability to cope independently; and a condition which started before adulthood with a lasting effect on development (Valuing People, 2001).

All 3 criteria below are needed to meet the definition of a **learning disability**:

1. Significantly **reduced ability to understand** new or complex information, to learn new skills (significantly impaired intelligence)
2. **AND** a reduced ability **to cope independently** (impaired social/adaptive functioning)
3. **AND** the above started **before adulthood** (before 18) with a lasting effect on development.

Not learning disability:

Learning disability is often confused with learning difficulties such as dyslexia, ADHD or Dyspraxia. <https://www.mencap.org.uk/learning-disability-explained/learning-difficulties>.

A learning disability also cannot be due to a brain injury acquired after the age of 18.



NHS guidance on how to identify and code a person on the LD register:

<https://www.england.nhs.uk/wp-content/uploads/2019/10/improving-identification-of-people-with-a-learning-disability-guidance-for-general-practice.pdf>

Inclusion tool for LD register:

[Inclusion-tool-Jan-2019-3.pdf](https://www.learningdisabilityservice-leeds.nhs.uk/inclusion-tool-jan-2019-3.pdf) ([learningdisabilityservice-leeds.nhs.uk](https://www.learningdisabilityservice-leeds.nhs.uk))

CKS Nice <https://cks.nice.org.uk/topics/learning-disabilities/>

Covers diagnosis, management including AHC and behaviour that challenges.

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Flu and Vaccinations

Useful resources for vaccinations:

- Easy read **invite letter**: [Flu vaccination: easy read invitation letter template \(gov.uk\)](#)
- Easy read information (**Flu**): [Flu easy read leaflet- Winter 2022 \(gov.uk\)](#)
- Easy read information (**COVID-19**): [COVID-19 vaccination: easy-read leaflets - GOV.UK \(www.gov.uk\)](#)
- Easy read information (**Pneumococcal**): [Easy read guide to the pneumococcal vaccine \(learningdisabilityservice-leeds.nhs.uk\)](#)
- Easy read information (**MMR**): [Easy-read-MMRleaflet-Final-1.pdf \(wchc.nhs.uk\)](#)



What GP surgeries can do to support vaccinations

1. GP surgeries should give a **clear message** that people with a learning disability, their family carers and paid supporters are **entitled certain vaccinations , for free.**
2. People on the Learning Disability Register should have it **recorded in their notes that they “need a flu immunisation”**
3. **Talk** to people at their annual health check about **why it is important that they have vaccinations.**
4. Put [reasonable adjustments](#) in place to help people with a learning disability have a **vaccinations.**
5. The person seeing the patient may need to **assess the patient’s capacity to decide to have the vaccination.** If they **do not have capacity for this decision,** then this should **not be a barrier** to the vaccination being given; there would need to be a **decision taken by the health professional that this is in their best interests.**
6. Consider use of **the nasal spray flu vaccine as a reasonable adjustment.** (further guidance [here](#))

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Preparing for an Annual Health Check

- Organise health checks from April and complete them before mid-December to avoid January to March, when there may be additional pressures on the practice.
- Consider aligning health checks to patients' birthdays to spread them across the year to ease pressure.
- To keep people well for winter, consider prioritising health checks for people who are frequent attenders to hospital, have recurrent chest infections or have long term conditions.
- Send out easy read invitation letters: [Annual Health Check Invitation template](#)
- Share easy read information about AHC from Mencap (also has a checklist): [Annual health checks Easy Read 1.pdf \(mencap.org.uk\)](#)
- Sending a pre- health check questionnaire can help prepare the patient and their carer/ supporter for the health check appointment. This may reduce anxiety and improve effectiveness of appointments:
 - [Healthwatch SG LD AHC Checklist Cover Letter](#)
 - [Healthwatch SG LD AHC Checklist](#) to send or give to patients prior to health check
 - [EMIS Preparation checklist for AHC](#)
- NHS England teamed up with Mencap to produce a [video and a series of guides in different languages](#) which highlight the benefits of being on the learning disability register- including getting a free health check each year.

We recommend the use of the EMIS AHC template “*Learning disabilities annual health check*” or the Ardens® template “*learning disability*” to help with a structured assessment.



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Reasonable Adjustments – It is a legal duty to provide patients with reasonable adjustments so they can access health care the same as the general population.

Before an appointment – Preparation is key!

Appointment invites should be accessible. Explain what the appointment is about. Find out how best to contact the patient- letter, phone, video call. For annual health check use [pre-checklist and send easy read information](#).

Ask the person what reasonable adjustments they need, what works for them. If people are unable to express their preferences speak to someone who knows them well. Keep a note in the records for next time.

Is the person able to wait for the appointment? Consider first and last appointments. Where is the best place to wait? Can they wait in the car and be called in last minute?

Is extra time required for the appointment? How long can the person engage for? It may be useful to split the health check/appointment. Consider if the person needs time to process information so the consultation might be much slower!

Is the person is comfortable in the environment? Consider if it is too noisy, overstimulating, lighting? Can something to be adjusted or a different room found?

Continuity of care. Seeing a single clinician helps building a trusting relationship. It is difficult for people with a learning disability to see a lot of different people. It also aids the clinician to understand the persons individual needs, how to communicate with them and aid clinical decision making.

During an appointment

Speak to the person and ensure that they are included in their own health. If you want to speak to a supporter, ask the person if they are happy for you to.

Suggest booking a further appointment with someone who knows them well if you feel that their supporter doesn't know the person well enough to aid.

Speak clearly and slowly, facing the person, to demonstrate your undivided attention.

Use short sentences and easy language. Use words the person is used to, like heart and poo instead of cardiac and faeces/stool.

Pictures and diagrams (body maps) may help the person to explain their symptoms. Do they need easy read information?

Identify an interest that will keep the person engaged – this builds trust and may help to continue the discussion.

Don't focus on just the spoken language. Observations from body language is important and can be questioned.

Listen to what the person is saying. Even if you feel that what they are describing isn't accurate or difficult to understand, this may be the only way that they can express what is happening.

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Undertaking an Annual Health Check

1. Holistic Assessment

Look at the annual health check as a holistic assessment that gives you the chance to get to know the patient better.

Ask about:

- Daily living skills and support needs including with eating/drinking, selfcare, dressing, mobility
- Is support in place. Are carers paid carers or family carers
- Do they go to work, school, college
- Finances
- Housing and accommodation

Outcomes:

- Offer social prescribing and carers support if appropriate.
- Referrals to social care where required.

2. Lifestyle factors

Only 9% people with learning disability achieve recommended level of activity per week In the UK inactivity contributes to 1 in 6 deaths, similar to smoking.

Ask about:

- Smoking/vaping
- Alcohol
- Drugs
- Mobility
- Physical activity
- Weight/height /BMI
- (MUST score)

Outcomes:

- Refer to local smoking cessation services
- Refer to local drug and alcohol services
- Refer to social prescribers
- Refer to local weight management services

3. System review

Instead of asking for symptoms in general go through a structured list of questions asking for specific symptoms.

Ask for signs and symptoms of:

- Respiratory & Cardiovascular problems
- Gastrointestinal problems – **Constipation, Reflux, Dysphagia.**
- Skin problems
- Bladder problems
- Problems with hearing- *low threshold for referral*
- Eye problems- *eye check every 2 years*
- Dental/oral problems-annual dental reviews

Ask about:

- Sexual health- contraception-period problems- menopause
- Pain, and how pain is expressed
- Sleep
- Mental health and behaviour
- Cognition and abilities, any changes?

4. Examination

A physical examination should include:

- Heart sounds, pulse, blood pressure
- Chest examination, Respiratory rate, Sats
- Skin
- Abdominal examination
- Ears- check for wax.
- Breast/testicles- how to self check.

Any other relevant examination that is guided by the patient and their presentation.

Have a flexible approach and explain to the patient what you are doing. Involve family and carers.

Having a baseline set of observations is helpful if the patient presents unwell.

You might not be able to complete a full set of examinations, sometimes a second appointment is required

5. Screening

Discuss participation in screening and purpose at every annual health check

- Cancer Screening:
 - Bowel cancer
 - Breast cancer
 - Cervical cancer
- Abdominal aortic aneurysm - AAA
- Other screening as indicated

Consider:

- Offer reasonable adjustments
- Offer easy read material
- Try desensitisation
- Discuss with local Learning Disability Screening Practitioner for advice and guidance

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Syndrome specific checks - additional examinations and tests for patients with the following genetic conditions

Down's syndrome:

Website for health care professionals: <https://www.dsmig.org.uk/>

With guidance for surveillance: <https://www.dsmig.org.uk/informationresources/guidance-for-essential-medical-surveillance/>

Fragile x-syndrome:

Website mainly aimed at families/carers : <https://www.fragilex.org.uk/>

Rett Syndrome

Website: <https://www.rettuk.org/>

PDF Rett best practice guidance:

<https://www.rettuk.org/wpcontent/uploads/2015/03/Rett-UK-Management-Care-Guidelines.pdf>

Others include: Dyscerne <https://dyscerne.org/dysc/Guidelines> has detailed clinical management guidelines for four dysmorphic conditions:

- Angelman syndrome
- Kabuki syndrome
- Noonan syndrome
- Williams syndrome

Epilepsy

Check list to consider - *This summary was developed by local primary care colleagues in BNSSG, it has not been checked and should be used in accordance with local and national guidance*

- Last fit, seizure frequency, any changes
- Effects on daily life
- Triggers and lifestyle including drugs/alcohol
- School/work aware
- Seizure plans in place including emergency plan & stand by mediation
- Medication review, compliance, side effects
- Drug monitoring or blood tests required?
- Screen for depression/ anxiety
- Discuss contraception, pregnancy
- Discuss driving
- Provide SUDEP and seizure safety information
- Carer support?

Referral to neurology:

- poor seizure control
- Problems with drug treatment
- Planning pregnancy
- Consideration for emergency medication
- Withdrawing treatment (if seizure free > 2y)

Support and information:

<https://www.epilepsy.org.uk/>
<https://epilepsysociety.org.uk/>

DVLA:

<https://www.gov.uk/epilepsy-and-driving>

EpSMon app to self monitor epilepsy

<https://sudep.org/epilepsy-self-monitor>

safety checklist

<https://sudep.org/5udep-and-5eizure-5afety-ch3cklist-2020>

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People with a learning disability are often taking several different drugs, both those prescribed and over-the-counter.

People with a learning disability often want more help to understand their medicines, what they are for, how they help, how to take them, and any side-effects.

People with a learning disability often rely on others to administer or prompt them to take their medication, therefore it is important to ensure that carers are also clear on medication instructions and the monitoring of side-effects.

People with a learning disability are sometimes prescribed treatments from different sources that may not be well coordinated. Ensure new medicines are promptly to summary care records and remove old ones.

Stopping over medication of people with a learning disability, autism or both- Supporting Treatment and Appropriate Medication in Paediatrics STOMP/STAMP: is a project led by NHS England to stop the inappropriate prescribing of antipsychotic medication in adults, children and young people with a learning disability, autism or both.

Your practice and **PCN pharmacists** may be able to contribute to annual health checks and **lead on medicine optimisation reviews** to support learning disability patients in the practice.

As part of the Medication Review, the following should be discussed with the individual with a learning disability (and carer):

- That they are taking the correct dosage of medication at the appropriate time.
- That they know what the medication is for.
- Any problems taking the medication e.g. Swallowing issues, compliance.
- Any side effects and how they are being monitored.
- That they still require to be on medication.
- Any physical health changes possibly due to side effects of the medication they are taking. (swallowing difficulties, <https://www.swallowingdifficulties.com/>)
- Do they need signposting to appropriate specialist services.

Tests to Consider:

- Blood test
- Weight
- ECG
- Blood pressure
- Urine check
- Consider additional therapeutic drug monitoring e.g. Anti- epileptic drug monitoring.

Useful Resources:

- [Stopping Over-Medication of People with a Learning Disability, Autism or Both: Guide for GPs](#)
- [Accessible medication information leaflets give information on different medicines that are used to manage behaviour problems in adults with a learning disability.](#)

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Transitions – preparing for adulthood

Invite every young person on your learning disability register from the age of 14 for annual health checks. Annual health checks for young people with a learning disability are important to ensure timely identification to coordinate and integrate services for a smooth transition into adult services.

Young people with a learning disability can have complex health needs and be seen by many different health professionals in primary, community, secondary and tertiary settings. When a large number of professionals are seeing a young person, there is increased risk of fragmented care.

Prepare the change from paediatric services to adult services with much more emphasis on patient responsibility. Double check that the young person has had some communication from adult health services at least 1 year prior to the young persons 18th birthday, for example: neurology, dietetics, gastroenterology.

Transition is a process over time and should start early to give the GP surgery and patient and supporters time to get to know each other and build a good relationship and trust

Poor transition and loss of confidence in GP service can lead to missed opportunities to improve health outcomes. getting to know the team and how the surgery works and managing expectations.

Avoid crisis calls that are stressful for patients and health care professionals

NDTi have produced some [resources](#) to support conversations with families and young people with a learning disability about the importance of attending an annual health check.

Consider:

The environment Peak to the young person and their families about how can you make your practice more welcoming. Contact have produced some helpful guidance with simple solutions.

Communication Does the young person use any communication systems, can they bring these to the appointment?

Looked After Children Is the young person a Looked After Child? Request an update on their health and wellbeing and social care needs from the looked after children team.

Sexual health Understanding of issues relating to healthy relationships, including sexuality and sexual activity, contraception, sexually transmitted infection and the particular risks of early sexual activity – do they need a referral to sexual health advice services?

The Mental Capacity Act Inform the young person and their family about the Mental Capacity Act as early as possible so that they can plan what this means for them and plan the young persons adult life. Mencap have produced a Mental Capacity Act Resource Pack for family and carers.

Access to education Ask if the young person has an Education Health and Care Plan – can they bring this to their appointment? SEND statutory guidance

The family carers needs It is important to ensure that families who care for people with a learning disability are offered support to look after their own health. Ensure that you record that the family member has caring responsibilities and ask if they require any support or advice for themselves.

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Health Action Plans

A Health Action Plan (HAP) must be produced as a result of the AHC outlining any actions and outcomes including recommendations on health promotion and wellbeing. The HAC plan is reviewed at the next AHC and progress monitored. Health Action Plans identify the patient's health needs, actions required (including what the person needs to do), who will help and when this will be reviewed.

The focus of the Health Action Plan are the key action points which have been agreed with the person and carer during the health check, it should:

Summarise what was discussed and any other relevant information (e.g. what is important to the person, what their goals or outcomes are that they want to achieve).

Set specific goals to be achieved over the next 12 months at reviewed at the persons next annual health check.

Offer support to the person to manage their own health and make decisions about their health and healthcare, including providing information in a format they can understand.

Is the person happy for you to share their health action plan with their carers? Do the carers understand the information in the health action plan?

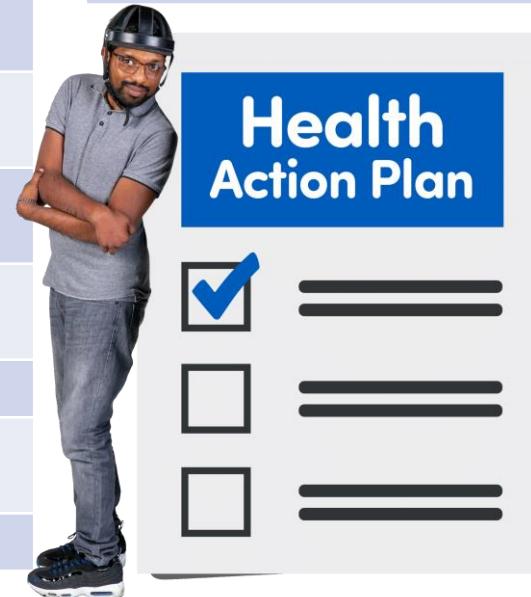
Ensure that you follow up any specific actions/referrals.

As part of each Health Action Plan confirm screening status and attendance at screening appointments.

Ensure that you record any reasonable adjustments that the person may need on referrals.

Summary Care Record (SCR)

Add any information to the Summary Care Record (SCR). This will help improve quality of care for patients when and if they are treated by other services, including emergency and urgent care. Providing additional information to other services may also decrease the number of calls to your surgery, freeing up valuable time and resources. SCR additional information uses existing information already recorded in the GP system and therefore helps to reduce the need for data entry into numerous systems. In addition, all organisations that provide NHS care or adult social care are legally required to follow the Accessible Information Standard and using SCR in your practice will help you meet this.



Recognised Health Action Plans:

- [ICB BNSSG Health Action Plan for Learning Disabilities](#)
- EMIS Learning Disability Annual Health Check Action Plan
- Ardens Learning disability Health Action Plan V15.5 (short and easy to use)
- Ardens Learning Disability Health Action Plan-Long V16.9 (pulls in a lot of information from EMIS)

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How can your local community learning disability team help?

Sirona care & health - **Adult Learning Disability Health Service (ALDHS)**

Advice & Guidance Line



Call or email us between 9-4pm Monday-Friday

0300 124 5888
sirona.bcltdadvice@nhs.net

- General advice and support for someone with a Learning Disability.
- Specific case discussion to support individuals health and wellbeing.
- Information on our current referral criteria & telephone referrals.
- Sign posting to other relevant services.
- Resources to support people to be independent in managing their health, including accessible information.



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Annual Health Check

[AHC step by step guide to AHC for health care professionals](#) (This is a download of the old RCGP Annual Health Check Toolkit)

[Cardiff Health check template](#)

Syndrome Specific

[Syndrome specific checks at the AHC](#)

Reasonable Adjustments

[A for Adjustment](#) - adjusted care resources to support health and care workers

Link to [reasonable adjustment infographic](#)

[Top tips reasonable adjustments for clinicians](#)

Easy read information

Easy health. Easy read leaflets and videos: <https://www.easyhealth.org.uk/> (Access to most resources by membership only, membership is free)

SEPSIS

NHSE easy read information on SEPSIS: <https://www.england.nhs.uk/publication/easy-read-information-sepsis/>

Transitions

[Transition top tips](#)

Link to RCGP transition learning module <https://elearning.rcgp.org.uk/course/view.php?id=485> (requires RCGP log in)

Click [here](#) to access the **letter to send to parents/carers of a young person about the annual health check.**

Click [here](#) to access the **letter a young person can write to their GP surgery to introduce themselves.**

Constipation and Fibre

[EASY READ Constipation resources](#)

[Bristol Stool Chart \(england.nhs.uk\) accessible](#)

[Constipation resources for carers and families](#)

Eyes and Vision

[SeeAbility](#) support people with LD / autism and sight problems. Their website has a function to [look for a local optician](#) with expertise in people with learning disability.

Epilepsy

Epilepsy action has a learning disability friendly section <https://www.epilepsy.org.uk/info/carers/learning-disabilities/easy-read-and-audio>

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Toolkit Information:

This Toolkit has been produced by the SIRONA Adult Learning Disability Health Service and the Cornwall Primary Care Liaison Team.

The tool kit is adapted from the NHS England – London Learning Disability and Autism Programme Team AHC tool kit: <https://www.ndti.org.uk/resources/publication/learning-disability-annual-health-check-toolkit>

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