Dear

**How General Practice can ensure better outcomes for people with a learning disability**

We are writing to share information on annual health checks and the importance of the learning disability register to support patients. The register improves health outcomes by ensuring people with a learning disability have access to additional health support. Evidence from LeDeR ([Learning from lives and deaths](https://www.england.nhs.uk/learning-disabilities/improving-health/learning-from-lives-and-deaths/)) shows the stark health inequalities that people with a learning disability face, which sees them **dying 19.5 years younger than the general population** and more of these deaths being considered avoidable.

It is important that eligible people are on the GP learning disability register to ensure that they can benefit from the learning disability health check scheme. There is good evidence that not everyone who could be on a learning disability register is on one.  They are more likely to be people with a mild learning disability, and people from Black, Asian and minority ethnic backgrounds.

Everyone has a role in being aware of the learning disability register, to proactively identify people who would benefit from being on the register – without the need for a diagnosis – and to ensure good quality annual health checks and health action plans.

This letter is relevant to all staff working within your practice and not just clinical staff. Ismail, who has a learning disability, has also developed this letter in Easy Read to highlight the importance of accessibility and we hope you can cascade this accordingly. In particular, we encourage you to read and share the case studies included. We know there is a lot of good practice happening and want to thank you for your continued efforts in providing this essential support for people with a learning disability.

**Annual health checks**

Providing annual health checks can improve poor health outcomes for people with a learning disability who often live with a range of long-term conditions including diabetes and epilepsy. These checks ensure people with a learning disability have access to additional support (such as vaccinations and immunisations, and cancer screening), accessible information and tailored support to meet their reasonable adjustment needs.

If you think a patient has a learning disability and they are likely to benefit from being on the register, you should discuss this with them and, if appropriate, their families and/or carers. A learning disability may not be immediately obvious or diagnosed. Some people might instead describe having a learning difficulty or autism, which commonly occurs alongside a learning disability, so you will need to exercise your professional judgement.

The following information may help you: [NHS England » Clinical guide for front line staff to support the management of patients with a learning disability and autistic people – relevant to all clinical specialties](https://www.england.nhs.uk/long-read/clinical-guide-for-front-line-staff-to-support-the-management-of-patients-with-a-learning-disability-and-autistic-people-relevant-to-all-clinical-specialties/).

**Good practice**

An annual health check should be done face to face and with a clinician that knows the patient well. This will allow you to carry out any necessary physical examinations as well as have the opportunity for a chat with your patient and/or their families/carers. It is also important to consider the accessibility needs of each individual and reasonable adjustments they may require, to find the most appropriate way of conducting the check whilst still ensuring it is of a good quality.

The check should be supported by a good quality, accessible action plan to support the patient after the consultation. This plan should be implemented and used throughout the year to ensure it is up to date and effectively supporting the individual’s health and wellbeing. It is a good opportunity to consider people’s reasonable adjustment needs to live a healthy life and add information to their reasonable adjustment digital flag to support their access to relevant healthcare.

The GP contract requires that accurate patient records are maintained, including for patients with a learning disability. The Learning Disability Health Check Scheme continues to be offered via the Direct Enhanced Services Directions (with additional detail in the GMS Statement of Financial Entitlements) to encourage the maintenance and updating of learning disability registers and the completion of annual health checks and health action plans for each registered patient aged 14 years and over on the learning disabilities register. The Investment and Impact Fund continues to directly incentivise delivery of annual health checks and health action plans. We welcome your support in these checks, and, critically, in delivery of the resulting individual plans for people with a learning disability, which also help you maximise practice income through the financial incentives outlined above.

The government’s [10 Year Health Plan](https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future) sets out the importance of moving care from hospitals to communities and preventing sickness rather than treating it. Primary care is a critical part of delivering these ambitions and is the first line of defence for preventing illness and premature mortality for people with a learning disability.

**Case studies**

**Anna Hoyle, 47, Wirral**



Anna is autistic and has a learning disability and wants to see better awareness in GP practices of the learning disability register, annual health checks and health passports.

She said: ‘I only found out about the learning disability register a few years ago when there was a leaflet at work on the noticeboard and I asked someone about it, and how to get it.

‘They told me there was a form and so I got my mum and dad to go through it, and then submitted it. But I only found out about by chance – unless you ask about it you wouldn’t know about it.

‘I often speak to healthcare workers who’ve never heard about the learning disability register, health passports or other reasonable adjustments.

‘And I’d never known about getting a health action plan or even seen one. If it was in easy read and it was accessible that way, I’d be interested in one.’

Anna gets an annual health check and finds them helpful but struggled to get an appointment last year due to an oversight of her patient notes by a surgery nurse.

She said: ‘I didn’t get last year’s health check until February this year as it was very difficult to communicate with learning disability nurse – she kept ringing me even though the notes say on my doctor record to text.

‘We really need to make health and social care better and make things easier and more accessible for people like me.’

**Rahima Begum, 28, from Newham in London has a mild learning disability, cerebral palsy, and needs 24-hour care. To communicate, she uses a special computer which tracks the motion of her eyes to form words.**



Rahima said: “One challenge I face often is making others see or hear me, as they think that I can’t speak for myself, or I am completely unable.

“I have a good relationship with my GP as he has known me for many years. This means that I don’t have to repeat myself which gets very tiring. I have routine appointments with him only and it helps because you know that there will be someone that always checks in.

“Having those annual health checks help with also giving me a routine and the space to prepare for the thing I need. My doctor knows me so well those checks help with him understanding me and how my health can go up and down.

“I like when doctors know me because they speak to me directly and involve me in my care. Everyone has a voice including me. We are all different in many ways, but we all want and live for the same thing which is respect for who we are and understanding.”

**Additional information**

The following resources are available to support you to provide appropriate care for people with a learning disability:

* Accessible information standard [NHS England » Accessible Information Standard](https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/)
* Reasonable adjustment digital flag [Reasonable Adjustment Flag - NHS England Digital](https://digital.nhs.uk/services/reasonable-adjustment-flag)
* Oliver McGowan Mandatory Training on Learning Disability and Autism [The Oliver McGowan Mandatory Training on Learning Disability and Autism - elearning for healthcare](https://www.e-lfh.org.uk/programmes/the-oliver-mcgowan-mandatory-training-on-learning-disability-and-autism/)

**Signed by:**

|  |  |
| --- | --- |
|  |  |
| Ismail KajiParliamentary & Government Engagement Officer and Co-Chair of the APPG on Learning Disability, Mencap | Rt Hon Wes Streeting MPSecretary of State for Health and Social Care |
|  |  |