

# Learning Disability Register Inclusion Tool

Striving to ensure better life chances for  
people with Learning Disabilities



## Dear Carer,

NHS Dorset recognise the crucial role carers play in providing people with a learning disability support, company, and a safe way to interact with society.

Establishing or maintaining a good relationship with primary care – the GP practice is a crucial way to ensure everyone with a learning disability has access to the learning disability register and a good quality annual health check to keep them happy, healthy, and safe.

GP practices also hold a carers register which can support you in your vital role as well.

This Guide is designed to support you understand why the Learning disability register, annual health checks and health action plans are so important for people with learning disabilities. It also shows how you can help ensure that the people you look after have access to the services they are entitled to.

Without the support of the carer network, our health services cannot reach those who need preventative care the most. Our vision with this work is to tackle health inequalities for people with learning disabilities. Helping people to form positive relationships with primary care GP services makes a huge difference to the lifelong support people with learning disabilities need.






# Learning Disability Register Inclusion Tool

People with learning disabilities experience significant health inequalities and are more than three times as likely to die of preventable causes than those without them. GP practices tackle this by helping people onto the learning disability register and accessing annual health checks, which are a critical enabler for preventative health.

## We know that:

- Not enough people know about the registers and checks
  - Some people on the register may not access their check each year
  - Some people may be on the register but not understand why they are and what the check is
  - Not enough people with learning disabilities are accessing health checks
  - Many young people do not access their GP practice as they are seen by paediatricians in secondary (hospital) care. This ends when they transition into adult care. Forming early relationships with their GP is a vital part of transition.
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## Why is it important?

- 6 out of 10 people with a learning disability die before they are 65. This compares to around 1 in 10 of the general population.



- 62 years is the median age of death for people with a learning disability (2021 data). The median age of death in the general population in 2018 - 2020 was 82.7 years.
- Over 50% of people with a learning disability died in areas rated as some of the most deprived.
- 49% of deaths were classified as “avoidable” for people with a learning disability. This compares to 22% for the general population.



“ Avoidable deaths appear to increase towards middle age so early interventions may be necessary ”

# What is a Learning Disability?

This definition from Mencap can inform your decision in helping someone onto the learning disability register.

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.



[www.mencap.org.uk/learning-disability-explained/what-learning-disability](http://www.mencap.org.uk/learning-disability-explained/what-learning-disability)

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.

A lot of people with a learning disability have more than one diagnosis and have a set of conditions that are unique to them.

Learning disability is often confused with learning difficulties such as dyslexia or ADHD. Mencap describes dyslexia as a “learning difficulty” because, unlike learning disability, it does not affect intellect.






## How do GPs add someone onto the Learning Disability Register?

- People can be added to the register at any age, enabling patients to share reasonable adjustments they need to access the practice and appointments.
- Those aged 14 and over on the register need to be invited to an annual health check.
- Deciding if someone should be on the register **does not involve a formal diagnosis** of a learning disability but is about need.

## What are Learning Disability Annual Health Checks?

- They enable health practitioners and patients to regularly review their physical and mental health.
  - They help patients take ownership of their own health needs putting them in a good position to live their lives in the same way as the general population.
  - They improve relationships between patients and primary care (GP) professionals.
  - Each check should result in a patient receiving an inclusive and accessible health action plan, which can be referred back to at the next health check.
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# What are Learning Disability Action Plans?

- Every patient who receives a check needs an action plan to take away with them
- They provide recommendations on how to improve and maintain health and wellbeing
- Plans needs to be written in a way the patient can understand
- There are people who can help 'action' the plan, this may be parents/carers, teachers and school staff, care, and support providers and many more professionals who are in the network around each individual.
- The plan should be shared with these people.
- The plan can be reviewed at the next annual health check but may also be updated if other appointments are needed to help someone address specific health and wellbeing issues over the year.



# Common misconceptions

Misconception	Facts
All learning disabilities are diagnosed	<ul style="list-style-type: none"> <li>• Some young people will have a 'Global Development Delay' diagnosis from a Paediatrician.</li> <li>• Some people may be waiting for a diagnosis</li> <li>• Some people's learning disability maybe an undiagnosed secondary impairment.</li> <li>• Patients can still be added to the register and removed at any time.</li> </ul>
Not all people will receive an exact diagnosis of 'learning disability'	<ul style="list-style-type: none"> <li>• Many people's 'learning disability' may be a secondary or a significant other impairment.</li> <li>• Some young people will have a 'Global Development Delay' diagnosis from a Paediatrician.</li> <li>• Who to add to the register is a clinical judgement, based on a conversation with the patient and their parent/carer (if suitable).</li> </ul>
You need a diagnosis to be added to the register	<ul style="list-style-type: none"> <li>• Deciding if someone should be on the register does not involve a formal diagnosis of a learning disability but is about need.</li> <li>• It is down to clinical judgement and informed by a conversation with the patient and their parent/carer (if suitable).</li> <li>• Being on the register does not automatically mean you have a diagnosis or that you may be put forward for one. This is a different process.</li> </ul>
Having educational support is a clear indication of a 'learning disability'	<ul style="list-style-type: none"> <li>• Educational support is a good indicator of a 'learning disability' but it is not the only indicator.</li> <li>• Educational support is offered to young people with many needs, many of which will not be related to a learning disability.</li> <li>• It is important to recognise the difference between a 'learning disability' and a 'learning difficulty' as outlined within this tool.</li> </ul>
All people with Autism/ ADHD should be included on the register	<ul style="list-style-type: none"> <li>• Some autistic people may have a learning disability but many autistic people won't (previously referred to as asperger's syndrome). Autism is a very large spectrum of need. Refer to the learning disability definition and use clinical judgement to work with the patient and their parent/carer (if suitable) to understand if they are autistic and have a learning disability.</li> </ul>



# What can carers/care agencies do?

## Helping a person with a learning disability access the register, health check and action plan.

**Step 1:** At a time that's right have a conversation about health. Is the person you work with aware of the health checks and on the learning disability register? If not, can you start to plan to support them do this (remember a diagnosis of learning disability is not needed)

### **Step 2: (if the person you care for is aged between 14 – 25)**

Use our resources to help signpost people and towards their GP so that they can be added to the register and receive their annual check. The resources include:

- GP finder by postcode
- Letter a young person can send to their GP informing that they wish to be added to the register
- A guide (available in easy read format) to explain to pupils and parents/carers what the register and check is
- Films created by young people for pupils to show the importance of staying healthy
- A what to expect guide (also available in easy read format)

[www.dorsetyouth.com/health-checks](http://www.dorsetyouth.com/health-checks)

**Step 3: (if the person you care for is aged over 25)** You can still access, and use resources as above however decide if this is appropriate. You can also visit [dorsetyouth.com/health-checks](http://dorsetyouth.com/health-checks) to access adult materials designed to support improving the knowledge and understanding of the checks.

**Step 4:** Encourage the people you care for to share their action plans with you. There may be things you can help them with which such as accessing a more physically active lifestyle, choosing a different diet, or encouraging them to be more socially confident. Help them celebrate any success they have had no matter how small a step it is.

**Step 5:** Keep a diary in care plans when the check was completed and what actions are being worked on. This will help other carers understand what is important and ensure that dates for health checks are not missed in the future.

## Things you can share

We have a short film and promotional assets that we have co-created with young people with learning disabilities across Dorset, to promote health checks, along with short films with teachers, a parent and a carer from adult services, all of which are available as a toolkit you can use with the people you look after.

