



GP ANNUAL HEALTH CHECKS FOR CHILDREN WITH LEARNING DISABILITIES

This factsheet is for parents of a child or young person with a learning disability. It has information on GP learning disability registers and annual health checks, why they are important and how you can support your child or young person to access the services they are entitled to.

GP LEARNING DISABILITY REGISTERS

GP learning disability registers are a record of all the people registered with the practice that have a learning disability. This is different to the Register of Disabled Children that all local authorities are required to keep. The GP learning disability register enables practice staff to identify children, young people and their families who may need extra help or support to access healthcare.

Anyone with a learning disability, regardless of whether they have a diagnosis of learning disability, can ask to go on it.

Since 2015, the register should include all ages, not just those over 18.

All those on the register aged 14 and over should be offered an annual health check.

Being on the register will help GPs and practice staff understand the complexities of care for children and young people with learning disabilities. It can also help practice staff identify who they may need to make reasonable adjustments for.

WHAT ARE REASONABLE ADJUSTMENTS?

Reasonable adjustments are the changes that services or people must make so that someone with a disability can use or access something just as easily as everyone else. Some examples of what a 'reasonable adjustment' might be are:

- *making sure there is wheelchair access*
- *having a 'quiet' waiting room*
- *providing easy read appointment letters*
- *giving priority appointments or first appointments of the day if waiting is difficult*



- *longer appointments if more time is needed*
- *home visits if attending the surgery causes distress.*

WHAT ARE THE BENEFITS OF BEING ON THE REGISTER?

The benefits of being on the Learning Disability Register include:

- *having an annual health check, if 14 or over*
- *parent carers and siblings being identified as carers*
- *a better understanding of a child or young person's needs before they attend health or care settings*
- *improved transition to adult services, as your GP will be aware of your young person's needs and can be involved in any planning.*

WHO SHOULD BE ON A GP LEARNING DISABILITY REGISTER?

Anyone with a learning disability, regardless of whether they have a diagnosis, can ask to go on it. If your child is under 16, you can ask for your child to be added. If they are over 16, they may need to ask for themselves, or if they are unable to make this decision for themselves, you can discuss with their GP about making a 'best interests' decision using the Mental Capacity Act (2005).

One of the key principles of the Act is that any act done for, or any decision made on behalf of a person must be done, or made, in that person's best interests. As part of this there is an expectation that their primary carers would be consulted.

 For more information on the Mental Capacity Act search for it at www.nhs.uk. The **Office of the Public Guardian** support and promote decision making for those who lack capacity: **0300 456 0300**. You can also find out more in the SEND code of practice on page 20: 'Participating in decision making', and in Annex 1: 'Mental Capacity'. Find it at: www.gov.uk

HOW DO I GET MY CHILD ON THE REGISTER?

A first step would be to have a conversation with your GP as not all children and young people who have a learning disability will have a specific diagnosis, even though they may have other disabilities.

The official definition of learning disability is someone who has **all** of the following:

- *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with*
- *a reduced ability to cope independently (impaired social functioning)*
- *which started before adulthood (under the age of 18), with a lasting effect on development.*

ANNUAL HEALTH CHECKS

Annual health checks were introduced to try to minimise the health inequalities many people with learning disabilities face.

Having a health inequality means you are more likely to develop a particular condition (for example: diabetes or heart disease) or that your life expectancy may be less than the rest of the population. This can be because:

- *symptoms of physical ill health are attributed to a mental health/behavioural problem or the person's learning disabilities*
- *people with learning disability are not able to express their ill health/pain.*

An annual health check gives children and young people time to talk about anything that is worrying them and means they can get used to going to visit the doctor. It will also give you time to discuss any concerns you have about your child or young person's health or wellbeing and how your GP can support you to spot the early signs of your child or young person being unwell.

BENEFITS OF HAVING AN ANNUAL HEALTH CHECK

- Your young person can build their confidence of going to the surgery, and their familiarity with practice staff.
- Identification of any previously undetected health needs or health conditions.
- Health needs are acted upon, for example, referrals to other health care practitioners.
- GP's and practice staff can get to know the person better when they are not unwell.
- Development of a Health Action Plan – see below.
- Can link to the duty on local authorities to make sure all Education, Health and Care Plan reviews from Year 9 onwards include a focus on preparing for adulthood, this is the health outcome.
- Additional information can be added to the Summary Care Record which can 'flag' your child or young person's needs or reasonable adjustments so that all healthcare professionals that care for them are aware.

SUMMARY CARE RECORDS

Summary care records are a summary of your GP medical records. They usually include basic information that can be accessed by any health practitioner, for example medications and allergies.

Additional information can be added to a summary care record that would be useful for other health practitioners to know. You can ask for this information to be added to your child or young person's summary care record. Information that might be added include:

- **diagnosis or health conditions**
- **any reasonable adjustments needed (quiet room, longer appointment)**
- **how your child or young person communicates.**

Having this extra information readily available means that any health practitioner that sees your child or young person should know the important information about them before the appointment.

 For more information on Summary Care Records search for them at <https://digital.nhs.uk>

WHAT TO EXPECT AT AN ANNUAL HEALTH CHECK

You may be asked to prepare for your child or young person's annual health check by filling in a questionnaire. This will give you the opportunity to highlight anything you or your child or young person would like to discuss, or if there might be any elements of the health check that they may find difficult or distressing.

EXAMPLE QUESTIONNAIRES

You can find examples of questionnaires on the Royal College of GPs' website by searching for 'health checks' at www.rcgp.org.uk

Or you may prefer to fill in your own pre-appointment questionnaire. The Traffic Light Communication Tool has been designed by a paediatrician to help parent carers when attending appointments. Search for it at www.mefirst.org.uk

During the health check, the GP or practice nurse will:

- **do a general physical check which may include weight, heart rate, blood pressure and taking blood and urine samples**
- **ask about things that people with a learning disability often have problems with, such as epilepsy, constipation or problems with swallowing**
- **review medicines**
- **check any existing health problems such as asthma or diabetes**
- **discuss any other health appointments**
- **ask about the support you are getting**
- **discuss transition planning**
- **discuss how to stay healthy and offer general healthy living advice where appropriate**
- **discuss and agree the Health Action Plan.**

If your child or young person's learning disability has a specific cause, the GP or practice nurse may do additional tests if there are any other associated health risks.

HEALTH ACTION PLANS

Health Action Plans (HAPs) are care plans that detail what is needed to keep your child or young person healthy. This should include actions by the GP and other health practitioners, and can also include actions for you and your child or young person. HAPs should as a minimum include goals for health care practitioners involved in your child's care and your child's GP to work on together. It should as a minimum include goals for them and the doctor to work towards together.

EXAMPLE HEALTH ACTION PLANS

You can find examples of Health Action Plan templates by searching for them on the following websites:

Council for Disabled Children:

<https://councilfordisabledchildren.org.uk>

Royal College of GPs: www.rcgp.org.uk

Easy Health: www.easyhealth.org.uk

HAPs can also be used to improve your child or young person's knowledge about health and teach them how to stay healthy. This could link to an Education, Health and Care Plan (EHCP) or SEN support plan and could be used to add health information to EHCP reviews. This is especially important from Year 9 when there should be a focus on preparing for adulthood. The Health Action Plan can become the health outcome in preparing for adulthood reviews.

WHAT TO DO IF YOUR GP DOES NOT OFFER ANNUAL HEALTH CHECKS

Although most GPs now offer annual health checks, they don't have to. If your child or young person has not had an annual health check:

- **check that they are included on the Learning Disability Register**
- **ask their GP if they will do an annual health check**
- **if their GP is unable to offer an annual health check, ask if you can go to a nearby surgery to have it done. Many GP's now work closely with other local GP's so may have an arrangement.**

If you are unable to access an annual health check, contact your local Learning Disability Community Team. They may be an adult service, but should be able to help you find a local GP who offers annual health checks.

If you are still unable to access the annual health check you have the option to move to a GP surgery that does offer them.

LOCAL PARENT CARER FORUMS

If you are concerned about not being able to access an annual health check, or about the quality of the health check that was carried out, you can give your feedback to your local parent carer forum. They may be working with GPs in your local area.

A parent carer forum is an organised group of parents and carers of disabled children from a local area. Their aim is to make sure that services in their area meet the needs of disabled children and their families.

They do this by gathering the views of local families and by working in partnership with local authorities, education settings, health providers and others to highlight where local services, processes and commissioners are working well, or challenge when changes or improvements need to be made.

Contact also wants to understand what actually happens when parent carers ask for annual health checks or to ask for their child to be added to the learning disability register so we can look at how the system can be improved. If your child has had an annual health check, or we have prompted you to go and ask, please let us know what happened.

 Email Lynn Hoppenbrouwers, Strategic Health Lead Lynn.hoppenbrouwers@contact.org.uk
Find your local parent carer forum by searching for them at www.contact.org.uk

FURTHER INFORMATION

NHS website information on annual health checks. Search 'learning disability' at www.nhs.uk

Mencap resources and leaflets on annual health checks. Find them at www.mencap.org.uk

Disability Matters online learning modules, including one on the Mental Capacity Act in their 'Decision making and growing up' section www.disabilitymatters.org.uk



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