

Adults - Vision, Eye Tests and Glasses

July 2024

Health series



Our Information Team and resources are here to help

Please see our website for up-to-date information: downs-syndrome.org.uk



If you have any questions, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on <u>info@downs-syndrome.org.uk.</u>

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

Adults who have Down's syndrome experience the same eye conditions as everyone else. However, some conditions seem to occur more often and at a younger age.

Loss of, or changes to, vision can be confusing and frightening. Adults may not realise, or be able to tell you about, changes in their vision.

Regular eye tests are therefore absolutely vital.

Always consider a change in vision if a person is showing signs of behaviour/mood changes, anxiety and/or an apparent loss of skills.

You should expect professionals to take your concerns seriously. Changes to vision should not be overlooked as "just part of the syndrome"



Starting point - everyone who has Down's syndrome has poor visual acuity

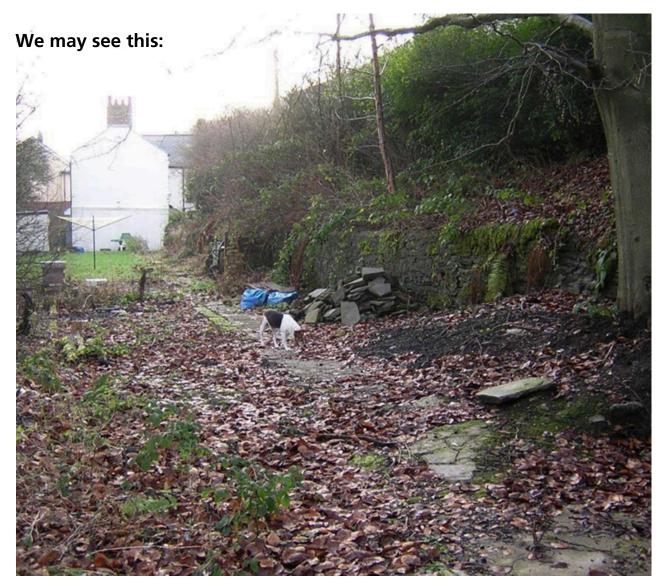
Over half of people who have Down's syndrome will need to wear glasses, but even when glasses are worn, everyone who has Down's syndrome will have poorer visual acuity. Visual Acuity is still poor even when a person who has Down's syndrome is wearing correctly fitted glasses for either long or short sight.

People who have Down's syndrome see the world differently; their world lacks fine details and sharp contrasts.

In order to compensate for the poorer visual acuity, we can make the world around them:

BIG and bold.

BIG and bold printed materials and images will help – people who have Down's syndrome are visual learners so to help them succeed make sure they can see things. It is very important to take their poorer visual acuity into account in all learning environments.



A person who has Down's syndrome will see this:



People who specialise in eye conditions

An Orthoptist

Is specially trained in the assessment of vision in people of all ages and all abilities, the recognition of squints and disorders of eye movements and the treatment of squints and related disorders.

An Ophthalmologist

Is a medical professional specialising in eye conditions.

An Optometrist

Is trained to test for glasses and other aspects of visual function and to recognise eye abnormalities. They are also able to dispense glasses.

An Optician

Is a technician trained to design, verify and fit eyeglass lenses and frames, contact lenses, and other devices to correct eyesight. They use prescriptions supplied by ophthalmologists or optometrists, but do not test vision or write prescriptions for visual correction. Opticians are not permitted to diagnose or treat eye diseases.

Most of us talk about going to the optician for glasses and to have our eyes tested. In everyday language many of us probably use 'optician' and 'optometrist' interchangeably. However, it is the optometrist at the opticians who actually provides primary vision care ranging from sight testing and correction to the diagnosis, treatment, and management of vision changes. For the purposes of this publication we have used 'optometrist' where it is correct to do so.

'Signs and Symptoms of visual loss in people with learning disability

Examples of behaviour associated with sight loss in people with learning disability include:

- Anxiety in unfamiliar situations
- Unwillingness to venture out of their immediate environment or be involved
- Hesitancy on steps, at pavement edges or in poorly lit areas
- Depression
- Anger or frustration
- Eye poking or rubbing
- Reduction in social or domestic skills and participation
- Loss of interest in family, friends, TV or social activities
- Undue alarm at unfamiliar noises or when approached

Source: Ophthalmic Services Guidance – Eye Care for Adults with Learning Disabilities (The Royal College of Ophthalmologists, 2015)

Eye conditions

Refractive errors

Long-sight (hypermetropia) and short-sight (myopia) are collectively known as 'refractive errors'. These 'refractive errors' happen when there is an issue with how your eye bends and focuses light. Both conditions are more likely in people who have Down's syndrome and can be more severe. Presbyopia, covered in this resource, is also a 'refractive error'.

People who are long-sighted can see objects at distance better than at near, and the closer objects are, the more blurred they appear (Note: some people with minor long-sight can see clearly at distance, but others with more long-sight will be blurred at distance and more so at near). Glasses or contact lenses are the usual method of treatment for both conditions.

Short-sight can worsen in adulthood if a person develops cataracts and/or Keratoconus.

Conjunctivitis

This is an inflammation of the outer clear membrane covering the eye. The most common symptom is red eye. It is often caused by an infection. In the first instance, make an appointment with your optometrist. If the cause is bacterial infection, antibiotic eye drops may be prescribed.

Blepharitis

This is inflammation of the eyelids, often caused by infection, and it is quite a common issue for people who have Down's syndrome. It causes redness and flaking around the eyelids and sticky discharge around the eyelids and eyelashes. It responds very well to lid hygiene measures. In the first instance, make an appointment with your optometrist. Rare stubborn cases may benefit from referral to a hospital eye clinic. Treatment of blepharitis is important both for the person's wellbeing and comfort, and also because untreated blepharitis can lead to a severe eye infection and ulceration.

Keratoconus

This condition of the cornea (the clear structure covering the front of the eye) is more common in people who have Down's syndrome. The cornea, instead of being the normal curved shape, becomes conical, thin and potentially fragile. The condition is extremely rare in childhood, may start to develop in adolescence and ultimately affects 10 - 15% of adults though for many the effects will not be serious. During the early stages keratoconus makes vision distorted, but as many people who have Down's syndrome are unable to report this, it can go unnoticed.

Many cases do not progress any further than this stage, but other cases progress and if not treated, vision can be badly affected. There is a new treatment called 'cross-linkage' now available, although patients may currently have to travel to specialist centres for treatment through the NHS. Cross-linkage is available privately throughout the UK. The treatment stops progression of keratoconus and maintains good vision. However, it is only feasible in the early stages of the condition, so early diagnosis is crucial. This is why it is very important for people who have Down's syndrome to have regular eye checks.

Further, research has shown that retinoscopy (used to test for glasses) is the most reliable method of detecting early keratoconus, but some optical practices have moved away from retinoscopy in favour of automatic instruments, and these are unlikely to pick up keratoconus. It is essential for parents/supporters to find an optometrist who is very experienced with retinoscopy, as well as, of course, with working with people with learning disabilities. If keratoconus is diagnosed, then the first step is to monitor, and if the condition progresses, a referral to a corneal specialist should be made without further delay.

If keratoconus is not progressing, or treatment is not feasible, then it can be managed successfully with contact lenses.

Untreated cases may go on to develop scarring in the centre of the cornea and a small number of those affected develop sufficient thinning of the centre of the cornea to require a corneal graft.

Information and support is available from the Keratoconus Group Website.

Helpline: 020 8993 4759

Depth perception

Some adults who have Down's syndrome have difficulties with depth perception. This may be something that has been present since childhood, but there is anecdotal evidence that some people develop difficulties with activities which require them to judge depth. Some adults will find stairs and steps difficult (this can also be due to issues with balance and musculoskeletal issues) and mistake changes in floor covering for a step. Difficulties with depth perception may sometimes occur because someone is anxious, but in all cases, if the symptom is recent, a full eye examination is advised.

In older adults, difficulties with depth perception may be associated with dementia. Assessment is essential when any changes in later life are observed, as such change may not be due to dementia but to another condition that presents with similar symptoms but is treatable. A diagnosis of dementia should not be made without first eliminating the other possibilities. DSA resources about getting older and dementia are free to download from our website.



Getting older

Adults who have Down's syndrome are just as likely to develop typical age-related sight issues as those in the general population. The difference will be that, if they develop, they will probably develop at an earlier age. If you observe a loss of confidence and ability around walking and climbing stairs in the person whom you support; book them in for an eye test to find out if sight issues are contributing to, or behind, the changes.

If the person you support seems to be losing sight very rapidly, take them to Accident & Emergency to be checked out.

Presbyopia

This is the loss of accommodation (near focusing) with age, which becomes noticeable in adults in the general population at around 45 years of age. The loss of near focusing can be helped with 'reading glasses' Since age-related health issues can occur earlier in people who have Down's syndrome, it may be that presbyopia appears at an earlier age than is seen in the general population.

Presbyopia is often ignored in adults with learning disabilities, perhaps because of the common use of the term 'reading glasses'; if a person does not read, it may be that family and carers do not consider spectacles for other near tasks. Many adults who have Down's syndrome do read, and others will certainly have work or hobbies that require good near vision, so need 'near' glasses.

Cataracts

A cataract is the clouding of the lens of an eye. It can affect one or both eyes. Cataracts are common and they appear in adults who have Down's syndrome at a much younger age than would be expected in the general population. The major symptom in early cataract is glare; vision is highly dependent on the amount or direction of light. This may mean that a person's visual abilities appear to fluctuate; he or she may be able to perform a task in some situations and not in others. The frustration of fluctuating vision can cause a change in a person's behaviour.

Understanding the condition in the early stages will help you to make changes to reduce some of the difficulties it creates for the person you support. Preventing glare by rearranging lighting and household furniture, increasing contrast of tasks and the simple provision of a wide-brimmed hat for outdoor use can make a big difference to quality of life. Removal of cataracts is highly successful procedure. It may help to get an early referral from the GP to the hospital clinic so that the person can become familiar with the setting and so that appropriate planning for aftercare can be put in place in plenty of time.

SeeAbility has some easy read resources about having a cataract and cataract surgery

Cataracts (easy read) | SeeAbility

Having a cataract operation (easy read) | SeeAbility

Glaucoma

Glaucoma can happen at any age but it is more likely to occur in older people. This is where the optic nerve becomes damaged by a rise in pressure inside the eye. If undetected it can lead to loss of vision; often gradual. Testing for Glaucoma should form part of the normal eye test. If Glaucoma is detected, a referral should be made to an ophthalmologist to discuss treatment options. Whilst it is not possible to recover lost sight, treatment should stop the condition getting worse. The most common form of treatment is eye drops which help to reduce the pressure in the eye. In some cases, surgery may be recommended.

Age-Related Macular Degeneration (AMD)

AMD is a condition whereby a blind spot develops in the eye causing a loss of central or middle vision. It can happen in one or both eyes. It does not affect the peripheral vision (around the edge of your sight). AMD does not cause total sight loss. The first symptoms are often blurred and distorted vision which may make reading or recognising faces difficult. The exact cause of AMD is unknown although it has been linked to having high blood pressure, being overweight, smoking and having a family history of AMD.

It has been suggested that macular degeneration is less common in people who have Down's syndrome when compared to the general population. If it happens, this condition seems to occur in people who have Down's syndrome who are aged 50 years and over. AMD can sometimes be picked up during an eye test before symptoms develop. If you think the person you support may have AMD, make an appointment for them at the optometrist. Depending on what they find, the optometrist may make a referral to an ophthalmologist or specialist AMD service. Treatment will depend on the type of AMD present; dry or wet AMD.

Dry AMD is caused by the build-up of a fatty substance called drusen at the back of the eye. There is no treatment for dry AMD but those with the condition can be helped with largeprint resources and magnifying lenses for everyday activities. Dry AMD tends to be slow acting with sight deteriorating over several years. Wet AMD is less common; it is caused by the growth of abnormal blood cells at the back of the eye. It can lead to quite a rapid deterioration of sight over months or even weeks. The treatment available on the NHS for wet AMD is with a group of medications called anti-vascular endothelial growth factor (anti-VEGF) drugs. Anti-VEGF drugs work by stopping new blood vessels from growing, preventing further deterioration of sight. The medicine is injected into the vitreous, the gel-like substance inside the eye.

Information and support is available from the Macular Society Website.

Helpline: 0300 3030 111 **Eye tests**

Adults should have a full assessment by an optician/optometrist every year.

Many adults who have Down's syndrome can attend a high street optometrist, but it may be necessary to ask the practice if they can make **reasonable adjustments** (according to the individual's needs) such as offering the person a longer appointment.

Here are some useful resources about reasonable adjustments to eye care services:

<u>Ophthalmic Services Guidance - Eye Care for Adults with Learning Disabilities (The</u> <u>Royal College Of Ophthalmologists, 2015)</u>,

This guidance is written specifically in relation to facilitating access to an eye clinic setting but the reasonable adjustments at Annex B can easily be applied to other settings.

Making Reasonable Adjustments to Eye Care Services for People with Learning Disabilities (Learning Disability Observatory, 2013)

https://www.ndti.org.uk/uploads/files/IHaL-2013 -01 Reasonable adjustments.pdf

There is some general information about reasonable adjustments towards the end of this resource.



Here are some questions to think about when choosing an optometrist:

- Does the optometrist regularly see adults who have Down's syndrome?
- Will the optometrist assess for Keratoconus during the eye examination?

• Does the optometrist use retinoscopy with ALL patients, not just those with learning disabilities?

It is important that adults who have Down's syndrome are examined by an optometrist who is very experienced with retinoscopy (see information about Keratoconus in this resource)

• Is the optometrist familiar with the visual issues of people who have Down's syndrome?



Free NHS eye tests

You're entitled to a free NHS sight test if you:

- are under 16
- are 16, 17 or 18 and in full-time education
- are 60 or over
- are registered as partially sighted or blind
- have been diagnosed with diabetes or glaucoma
- are 40 or over and your mother, father, sibling or child has been diagnosed with glaucoma
- have been advised by an ophthalmologist that you're at risk of glaucoma
- are eligible for an NHS complex lens voucher, your optometrist can advise you about your entitlement

You also qualify for a free NHS sight test if you get any of the benefits listed here:

- Income Support IS
- Income-based Jobseeker's Allowance JSA
- Income-related Employment and Support Allowance IR ESA
- Pension Credit Guarantee Credit
- Universal credit, if your monthly earnings are less than £435
- Working tax credit with a disabled worker element or severe disability element with income less than £15,276 per annum

You also qualify for a free NHS sight test if you have a low income and are named on a valid NHS HC2 certificate, for full help with health costs. (see below under Low Income Scheme)

You may be entitled to a reduced cost sight test if you have a low income and are named on a valid NHS HC3 certificate for partial help with health costs.

There are a range of NHS optical vouchers available depending on the strength of the lenses you need. If, for clinical reasons, you need tints or prisms in your glasses, the value of the voucher will be higher to reflect this. If you receive an NHS optical voucher, you can take it to any supplier of your choice, provided they accept NHS optical vouchers. They will ask you to show proof of your entitlement to the voucher. If your glasses or contact lenses cost more than your voucher value, you will have to pay the difference.

Applying for help - Low Income Scheme

You can apply for the scheme as long as your savings, investments or property (not counting the place where you live) don't exceed the capital limit. In England, the limit is:

£23,250 for people who live permanently in a care home.

£16,000 for everyone else.

If you have savings between £6,000 and £16,000 then you can fill out a HC1 form.

££

You can order an HC1 form online or pick one up at your local Jobcentre Plus office and most NHS hospitals. Your doctor, dentist or optometrist may also be able to give you a form.

If you need help making your claim or you have questions about the Low Income Scheme, call them on 0300 330 1343 to speak to an adviser. They can also fill in the form for you and post it to you to sign. All you need to do then is post it back in the envelope provided

Depending on your circumstances, you can receive "full help" (HC2 certificate) or "partial help" (HC3 certificate).

You will qualify for full help if your income is less than or equal to your requirements, or is greater than your requirements by no more than half the current English prescription charge. – currently £9.65 (as at July 2023).

If your income exceeds this limit, you may be entitled to partial help. Your certificate will show how much you have to pay towards your health costs.

For details, go to:

www.nhsbsa.nhs.uk/nhs-help-health-costs

If you have any questions about free eye tests, please call our benefits adviser on 0300 1212 300.

There are some variations with the scheme and we would advise checking on the relevant country links below:



<u>www.gov.wales/get-help-nhs-eye-care-costs</u> <u>www.mygov.scot/free-eye-tests</u> <u>www.nhs.uk/nhs-services/opticians/free-nhs-eye-tests-and-optical-vouchers/</u>

Resources – Eye Tests

A series of videos about having an eye test (SeeAbility)

Telling the optometrists about me (easy read)

Feedback from my optometrist (easy read)

Glasses Frame Fitting

Spectacle frames these days tend to all be designed and produced in the same way.

They have a particular standard set of dimensions that fit most of the population. For people who have Down's syndrome it can become a challenge to find frames that fit correctly.

It is a common sight to see a pair of glasses perched on the end of the nose of someone who has Down's syndrome. This is because they typically have a flat, broad bridge to their nose and the standard nose fitting on that average spectacle frame tends not to fit properly.

How to Achieve a Good Fit?

To achieve a comfortable and sturdy fit, the spectacle frame needs to be fitted so that it is balanced correctly on the nose and anchored securely around the ears and head. The weight of the glasses should be spread evenly between the nose and ears.

Standard Frames

Adjustments to more traditional frame designs can be made to help them fit smaller, flat noses and if a better fitting nose piece can be obtained, then everything else slots into place. Metal frames are easier to adapt because they come with more adjustable nosepieces. These nosepieces can be manipulated and angled to fit the shape of a flat nose better.

The nose pads themselves can also be changed to slightly more slip-resistant pads to give a little more friction and stop the frame moving so much.

If it is not possible to achieve a good balanced fit on the nose, sometimes by adjusting the arms of the glasses to take more of the weight a reasonable fit can still be obtained. This reduces the need for the nose to hold up the weight of the lenses. This can be done by altering the curvature of the arms so that they grip around the head a little more. Or, alternative arms can be used that add more stability such as curl sides or headbands. It is important when picking frames to check that the length of the arm of the frame can be adjusted.

Specialist Frames

There are also manufacturers that produce frames specifically for a range of face shapes and some that are solely produced for people who have Down's syndrome.

Erin's World frames are specifically made for people who have Down's syndrome. They feature a lowered bridge, extra-wide frame fronts and shortened temples.

There are also frame manufacturers that produce spectacle frames made specifically to fit flatter faces with a small nose. These are sometimes referred to as 'Asian-Fit' frames.

These will tend to have narrower, deeper bridges and longer nose pad arms. Companies such as Swiss-flex will produce alternative nose pieces for their frames, or other companies such as Charton Eyewear produce frames solely for this niche market.

Do not put up with a poorly fitting spectacle frame. We need to make sure that glasses fit correctly for all people who have Down's syndrome so that their vision is as good as is possibly can be.



Resources - General

Glasses for adults with learning disabilities

People with Down's syndrome – Looking after your eyes (easy read)

Ophthalmic Services Guidance - Eye Care for Adults with Learning Disabilities (The Royal College Of Ophthalmologists, 2015)

Community Learning Disability Teams (CLDTs)

CLDTs have been set up to serve the particular health needs of people with a learning disability and their family members, family carers and paid staff. CLDTs vary in size and make up but typically they will contain community learning disability nurses, a psychologist and a psychiatrist.

You can discuss with your GP whether or not a referral to the local CLDT is appropriate. Some CLDTs take direct referrals from people with learning disabilities, their families or paid supporters thus cutting out the need to ask your GP to make a referral.

You can find your local CLDT by searching online.



Annual health checks for people who have Down's syndrome (aged 14 years plus)

Annual Health Check – Visual

'Ophthalmic issues such as cataract, glaucoma, keratoconus and refractive errors need to be checked:

• Full assessment by optometrist at least every 2 years

• If examination difficult, refer to specialist optometrist or ophthalmologist for assessment'

Source: Annual Health Checks for Adults who have Down's syndrome Check List (DSA)

Please note an annual health check is not a replacement for a full assessment (at least every <u>two years</u> or more frequently if sight issues are detected) by an optometrist.

An annual health check should take place in addition to other regular health screening and general GP/hospital appointments.

In the past people with learning disabilities have not had equal access to healthcare compared to the general population. This, amongst other reasons, has given rise to poorer mental and physical health and a lower life expectancy for people with learning disabilities. Free annual health checks for adults with learning disabilities, with their GP, were introduced in 2008 as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, members of staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

Who can have one?

Annual health checks have been extended to include anyone with learning disabilities aged 14 years or above. So anyone who has Down's syndrome, aged 14 years or over, can have an annual health check.

The benefits of annual health checks

- Additional support to get the right healthcare.
- Increased chance of detecting unmet, unrecognised and potentially treatable health conditions.
- Action can be taken to address these health needs.

How to get an annual health check

The GP may get in touch with the person who has Down's syndrome to offer an annual health check but this doesn't always happen.

A person who has Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.

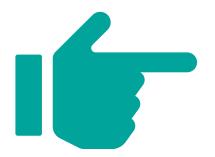
How to get an annual health check

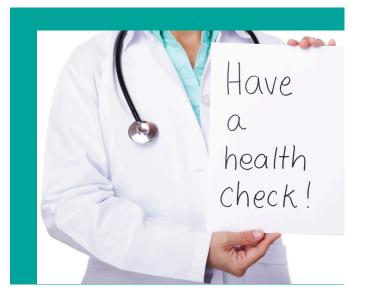
The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.

The GP may arrange for the person who has Down's syndrome to have a routine blood test a week or so before the annual health check.

Who attends the annual health check?

If the person who has Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.





How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

What areas of health should be looked at as part of the annual health check?

We have produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an annual health check and a list of checks specific to people who have Down's syndrome. You can find the health check list on our website <u>here</u>.

What happens after the annual health check?

Your GP should tell you what they and the nurse have found during the annual health check. You should have a chance to ask any questions you have. Your GP may refer you to specialist services for further tests as appropriate. Your GP should use what they have found during your annual health check to produce a health action plan. This should set out the key actions agreed with you and (where applicable) your parent or carer during the annual health check. Your GP has to do this as part of the annual health check service.

GPs learning disability register

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centred health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record (SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent (see section in this resource about the Mental Capacity Act 2005):

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age. It's a good idea for children with a learning disability to join the learning disability register at an early age. This means adjustments and support can be put in place before they reach adult services.

Reasonable adjustments in healthcare

You may have heard of the term 'reasonable adjustments' and may have wondered what it means. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training.

If a patient who has Down's syndrome is NOT on their GP's Learning Disability Register, then reasonable adjustments to care for that person cannot be anticipated and made.



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The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people who have Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.





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