

Social Care and Support

December 2022

A quick guide to social care for children in England

Please note this guide contains rights-based information, it is not intended as legal advice

What does social care mean?

Social care is a general term for practical assistance and personal care that may be required by children, young people and adults who need extra support. Social care, or the means to purchase it, is provided by the Local Authority (LA).

Register of disabled children

LAs must maintain a register of disabled children within their area. Registration is voluntary but, even if you don't require social care support now, it is a good idea to register so the LA is aware of your child. Parents tell us that being known to local children's social care services can make the transition to adult social care easier. Registration is useful to the LA because it helps with planning future service provision.

If you join the register, the LA may contact you occasionally with information they believe to be relevant to you and your child. Choosing not to register your child will not affect future entitlement to assessment or support in any way.

As a parent of a child who has Down's syndrome, will I need social care?

Not necessarily, some parents find they do not have any contact with the social care team at the LA until their child is in their teenage years (see information below about transition assessments). Each family and child will have their own unique set of circumstances and needs.

Does my child have a right to social care?

Social care is provided according to assessed individual need. Not every child who has Down's syndrome will be eligible to receive social care support.

However, all children who have Down's syndrome are eligible to have their needs assessed. Assessments are carried out to find out about the needs of the child and their family. Undertaking an assessment helps the LA to decide what, if any, support and services should be provided to meet the needs that are identified and who is best placed to provide these. There is more about eligibility for needs assessments below.

Short breaks

Each LA must publish a 'Short Breaks Services Statement' that contains information about short breaks and details of any eligibility criteria that must be met to access them. Short breaks may be provided as a result of a social care assessment. However, some short breaks may be available without an assessment. We suggest you take a look at your LA's Short Breaks Services Statement' to find out what is available in your area.

Transition assessments

Between ages 14 and 17 years, your child should have a transition assessment (also known as a 'child needs' assessment) from the adult social care team. This assessment will not result in the provision of services at the time of assessment. It is purely a planning tool for the LA to ascertain if your child will need services when they turn 18. It means that the adult team have a record of your child when they become an adult. In theory, the assessment should enable a smoother transition from children to adult services.

For whatever reason, the LA may not be aware of your child and so you may not automatically be offered an assessment. In which case you will need to put a request in writing to your LA for a transition assessment.

When they receive a request for a transition assessment, the LA must gather information from you about your child. They must use this information to decide whether a transition assessment would be of 'significant benefit' to your child at that particular time. They do not have to carry out an assessment if they do not believe it would be of significant benefit. However, they must gather information from you before a decision about next steps is made. The decision as to whether or not to assess should be based on your child's individual circumstances.

After weighing up the information, the LA must inform you of their decision in writing. If the LA decides not to carry out the assessment, they should give you an indication as to when they believe the assessment should be done in the future and put plans in place to ensure that this happens.

NB: this assessment is not the same as a 'child in need' assessment about which more is written below.

The first step - Asking for a 'Child in need' assessment

If you feel that you and your child may need some support, you can ask your LA for a child in need assessment. This is also sometimes known as a 'section 17' (of the Children Act 1989) assessment. It is often (but not always) the children with disabilities team at the LA who deal with assessment requests and carry out the assessments.

You should be able to find information about needs assessments and social care support on your LA's 'local offer' website (search local offer and the name of your LA).

We suggest you ask for an assessment in writing and include information about your child's diagnosis and needs. Remember to keep a copy of the letter/email for your own records. There are template letters available online that you can use to ask for an assessment. If you contact us, we can signpost you to some examples. Alternatively, you can ask a professional, who knows your child well (e.g., GP or Paediatrician) to request an assessment on your behalf.

Families with a child who has Down's syndrome are sometimes told their child does not qualify for an assessment. Some LAs may cite eligibility criteria as a reason to refuse to assess. They may tell you they only assess children who have 'severe disabilities', for example, or children who are 'at risk'.

The LA should not refuse to assess your child. Children who have Down's syndrome have a right to have an assessment; we explain why in the box below. Some of the language used here may seem a little outdated. This is because it comes from law that, whilst still in use, was passed a few decades ago. Knowing what it says will help you to get an assessment for your child.

Key information for you to remember when asking for an assessment

Children who have Down's syndrome fall within this definition – they are disabled children for the purposes of eligibility for assessment.

All disabled children are children 'in need' under section 17 of the Children Act 1989. LAs have a duty to safeguard and promote the welfare of children in need.

All children who have Down's syndrome are therefore children in need.

If a child meets the definition of a child in need, the courts have made it clear that LAs must then identify the child's needs and those of their wider family through assessment.

An assessment should be carried out even if a child may be in need.

All children who have Down's syndrome should receive a 'child in need' assessment if one is requested.

THE DEFINITION OF A 'DISABLED CHILD'

'Blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed.'

Source: Children Act 1989 (legislation.gov.uk)

What happens next?

Within one working day, the LA should confirm that your assessment request has been received. They should then decide whether to start an assessment, what type of assessment it should be, and whether or not your child needs any immediate support/intervention.

If the LA decides that a child in need assessment should be carried out, a social worker should be allocated to undertake that work.

Although the LA will co-ordinate the assessment, other agencies may be involved. Your LA should give you information about the process, timescales, how the assessment will be done and by whom, and about what services are available.

Getting ready for an assessment

You may like to keep a diary over a period of time that details the care and support you provide for your child. It may also be helpful to make some notes of the key information/issues you wish to raise during the assessment. It is important to be as open and honest as you can about any challenges you and your child experience on a daily basis.

When you are making notes, don't forget to put together a list of professionals (e.g., health and education) who know your child and who may be able to provide the assessor with valuable information.

Remember, you can ask a friend and/or advocate to attend the assessment with you.

The LA should publish their eligibility criteria for receiving support and services on the local offer website (see above for further information). Before the assessment, take a look at the eligibility criteria and think about where your child and family sit within the criteria, and why. This knowledge may help you to focus on what information to provide to the assessor and how you present that information.

We would suggest you take a look at the statutory guidance 'Working Together'. The LA must follow this guidance when they are carrying out assessments - [Working together to safeguard children - GOV.UK](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/626232/Working_together_to_safeguard_children.pdf) (www.gov.uk)

What to expect

It is good to keep in mind that the assessment is a means to help the LA understand your child and family's situation. They are not trying to find failures in your ability to parent. The assessment will help them to find out:

- **about the needs of your child arising from their having Down's syndrome, their health issues and any other diagnosis they may have. 'Working Together' says that in order to carry out good assessments, social workers should have the relevant knowledge and skills – this includes knowledge about Down's syndrome.**
- **whether you are able to meet those needs.**
- **the impact of wider family, community, and environmental circumstances.**
- **what extra help and services may help your child and family.**

The assessment should consider issues such as the impact of your child's Down's syndrome on things like whether it affects their growth, development and physical or mental wellbeing and what action could be taken to ensure that they have maximum access to family, education, and community life. It should be an open conversation about you and your child's needs.

Sometimes other assessments may be organised alongside the child in need assessment. Where appropriate child in need assessments may be combined with EHC needs assessments or an assessment by a Child and Adolescent Mental Health Service (CAMHS) for example.

Generally, if practical to do so, assessment will take place in the family home.

How long will the process take?

Assessments should be completed within a reasonable timeframe although what is reasonable may vary from family to family. The timescale should be agreed at the start of the process, and it should meet the child's needs.

'Working Together' sets out a maximum timeframe of 45 working days from a referral being received.

Should my needs as a parent be assessed as well?

The LA should be looking at your needs and those of other significant family members as part of the assessment process.

Any members of a family can also receive services and support if that will help the disabled child. It is recognised that providing services that meet the needs of parents (e.g., by 'short breaks' or respite care) is often an effective way of promoting the wellbeing of children, particularly disabled children.

However, you may like to consider specifically asking for a carers assessment of your needs. This assessment should focus on your needs as a parent including your general well-being. It might result in you getting services (or the means to purchase them) to meet your own assessed needs. You have a right as a carer to ask for this assessment at any time. As with a request for a child in need assessment, we would suggest you make the request to the local authority in writing.

What happens after the assessment?

Once the LA has completed the child in need assessment, they should give you a chance to record your views of it, including anything in the assessment you disagree with. If you notice anything that's wrong or missing, you can ask the LA to correct it.

When the assessment has been finalised, the LA will use eligibility criteria to help them decide what, if any, action to take next. Eligibility criteria may differ from one LA to another. As mentioned above, eligibility criteria should be available on your LA's local offer website. They should explain in clear language how services are allocated on the basis of need.

The LA should write to you to let you know what they have decided.

Care plan

If the LA decides your child's assessed needs meets their eligibility criteria, they have a duty to meet those needs either through the provision of services and/or the means to purchase them (e.g., through a direct payment). The LA cannot refuse to meet eligible assessed needs on the grounds of cost, but they can take their resources into account when they decide how they will actually meet those needs.

They will draw up a detailed care plan in which services will be provided by the LA and/or they will offer you a direct payment to cover the cost of arranging support services yourself. Direct payments are optional, it is your choice whether to have one or not. The plan should detail who is going to do what, where and when, to help your child and family. The plan should be agreed with you and your family.

Care plans should be reviewed regularly to make sure services remain appropriate and that needs are being met. If you have a care plan and your needs change, you can ask for a review.

Personal budgets

The LA may offer you the option of a personal budget (aka an individualised budget). This is an amount of money that the LA considers sufficient to meet your child's needs. Personal budgets may provide some of the benefits of a direct payment without you having to take on the full responsibilities of managing a direct payment.

LA's may use a Resource Allocation System (RAS) to decide on an 'indicative amount' of money/resources to be allocated to you. This is usually an upfront allocation of the resources the LA is willing to expend on care. However, it must be noted that this may happen before the actual care planning process has been completed. The idea is that you can opt for the sum offered and make your own arrangements before the proper and whole care planning process has taken place. This sidesteps the detailed assessment of the actual cost of a real care package and can lead to a shortfall in services/support. We believe this practice is becoming less common. If you are offered a personal budget, you should ask the LA for a breakdown of the budget to show how it meets your child's assessed needs.

You do not have to accept the indicative amount or personal budget, you can ask for the LA to provide services and/or a direct payment to meet needs.

The LA has a legal duty to carry out assessments and to provide support and services to meet eligible assessed needs.

Education, Health and Care Plans (EHCPs)

If your child has an EHCP, details of the support provided by the LA should be included in their plan

Not eligible for support

The LA should provide you with a clear explanation as to why you are not eligible for support and services.

Although certain needs may have been identified during the assessment, these may not meet the LA's eligibility criteria for support. Even if you are not eligible for social care support from the LA, they should still flag up other sources of support (e.g., voluntary agencies, local charities) that may be able to help.

If you disagree with the LA's decision, you can make a complaint. Information about how to make a complaint should be provided when the LA inform you of their decision. Details of the complaint's procedure should be available at the LA's website.

If you have used your LA's complaints procedure but you are unhappy with the outcome, you can take your case to the Local Government Ombudsman (LGO).

[Home - Local Government and Social Care Ombudsman](#)

They will look to see if the LA has done something wrong such as maladministration or is at fault in any way.

Will I have to pay for services?

Although they have the power to charge for services they provide, not every LA does so. Your LA will have a charging policy which sets out what they charge for and how they do so. This should be available at the LA's website.

If your child is under 16, charges will usually be based on your financial means. If they are over 16, charges will be based on your child's means.

However, if you are in receipt of certain benefits (e.g., income support) you cannot be charged. You can call our Benefits Adviser, Helen Wild, for further information about this (Helpline: 0333 1212 300).

The LA cannot ask you to pay more than you can afford.

Here are some things that shouldn't happen!

If any of the following happen to you, we would advise you to give us a call. You may need to make a complaint and/or seek legal advice.

- **Your child has been assessed by the LA as needing services, but these are refused on the grounds of cost.**
- **Your local authority has a 'blanket policy' or policies. Some examples include where families are told 'we don't provide this', 'we don't fund this' and/or 'this cannot be done'. In legal language the use of blanket policies in this way would be deemed 'fettering of discretion'.**
- **Your child has a care plan that meets assessed need which has been drawn up by qualified social care professionals. An LA funding panel, which is essentially a means of rationing services, refuses to fund assessed need by overruling the care plan.**

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 with 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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