



Disabled children's services in Scotland

Information for families

Scotland

Incorporating **The Lady Hoare Trust**

Introduction

Many children have additional support needs and disabilities, and some are more severely affected than others. Many disabled children and their parents will need practical support at home. This guide explains your right to get the support you need.

Social work departments are responsible for arranging support for children and their carers. You have a right to have your child's and family's needs assessed by social work and other departments.

Contents

What is a social work assessment?	3
How do I request an assessment of my child's needs?	4
Carer's assessments.....	5
What services can I expect for my child and family?	6
Transition to adult services	7
Charging for services.....	9
Direct Payments	9
Adaptations to housing	10
When to make a formal complaint	11
Some frequently asked questions.....	12
Tips for attending meetings with social work	14

Duties of social work to disabled children and their families

These duties include:

- providing a social worker service
- providing information about services which may be available
- assessing the needs of disabled children and their carers
- providing a range of services to meet these needs.

Scottish local authorities have a general duty under the Children (Scotland) Act 1995, to safeguard and promote the interests of children in need. The law recognises disabled children as being in need.

This means your local authority must carry out an assessment of your child if you ask them to under Section 23 of this Act. This assessment will set out the services that are considered necessary. An assessment is important because it can lead to a number of services being provided, such as practical help in the home and short-term breaks (sometimes called 'respite care').

Local authorities are required by law to let parents of disabled children know about their right to a carer's assessment.

What is a social work assessment?

The assessment should identify all of your child's needs, whether or not

services exist to meet them. Social work should assess your child in an open way and the assessment should focus on the circumstances of both your child and the rest of the family. As well as your child's disability and health needs, social work should also consider other aspects of your child's life, for example, educational needs and religious or cultural needs.

The social worker will usually come to your home to talk to you. They should ask you for information about your child, for example, about sleeping patterns, eating habits, how your child communicates, what activities they enjoy and whether or not you have any other children to look after. Do not be worried about asking for clear information about the focus of the assessment and about what services are available. Remember that the assessment should be needs-led and not based on services already available.

Beforehand, you should be told how the assessment will be carried out and given information about what services are available, not just those which are provided by social work departments (for example, a local play scheme or other help provided by local voluntary organisations).

Make a list of questions if you think that will help. You are entitled to have a friend or advocate there with you. The social worker may also want to speak to your child's health visitor, doctor or school to help them get a full picture of his or her needs.

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

How do I request an assessment of my child's needs?

Many social work departments have children with disabilities teams. You should find the number in the telephone directory under the name of your local authority or social work department, or phone our helpline. Alternatively, you can ask your GP, health visitor, community nurse or paediatrician to contact social work on your behalf. It is usually a good idea to put your request for an assessment in writing and to keep a copy of your letter. The request does not need to be detailed but should include:

- your name and address
- details of who is in your household, including any other children
- a brief description of your child's disability
- what kind of extra help your child needs
- whether you need help urgently.

Assessments should be carried out within a reasonable time. You should be informed if there is likely to be any delay. If you feel there is an unreasonable delay in assessing your child you should consider making a complaint.

What if an assessment has been carried out in the past?

When services are already being provided the assessment should be reviewed regularly. However, if your circumstances

have changed, you can ask for a re-assessment or review in the same way as above.

What if social work refuse to carry out an assessment?

If your child is disabled and in need of services, you cannot legally be refused an assessment and you should consider making a formal complaint (see page 11).

Taking account of your views

The law makes clear that your views are important in the assessment process. Section 10 of the 2002 Community Care and Health (Scotland) Act amends section 23 of the 1995 Children's (Scotland) Act so that the local authority must take into account the views of the child and their parents as far as this is 'reasonable and practical'. You also have the right to ask for a carer's assessment.



Combining assessments

Parents can often find themselves involved in different assessments of their children by many agencies such as social work, health and education at the same time. This can be time consuming and sometimes seems to be an unnecessary duplication. It is good practice if these assessments can be combined. Often there is a considerable overlap in terms of the information being collated. Combining assessments can certainly reduce the time and stress involved in multiple assessment appointments.

After the assessment

After social work have carried out an assessment and made a decision as to whether your child is 'in need', they will consider which services your child needs and how they should be provided.

Social work may decide that there is no need for services, which could result in your case being closed and social work taking no further action. If you disagree with the decision you can challenge this using the local authority complaints procedure (see page 11).

Carer's assessments

The Community Care and Health (Scotland) Act 2002, introduced a right for parents to request a carer's assessment at any time, so long as they are providing care on a 'substantial and regular' basis. The carer's assessment specifically focuses on you as a parent and your needs.

Social work should discuss with you various issues such as the help your child needs and whether there is anyone else who helps, or if you are providing all of your child's care. The assessment should also consider your well-being, including health and safety issues, and important commitments such as relationships and employment. The aim of an assessment is to give you a chance to tell social work about the things that could make looking after your child easier for you.

Local authorities should:

- not assume that a child's attendance at school necessarily provides a break for the child's carer
- be aware that carers of disabled children are often expected to be 'on call' in case of difficulties when the child is in school
- be aware that some carers may need to attend the school regularly where the child has significant health care needs or behavioural difficulties
- take into account in the assessment that a carer may have particular difficulties during the school holidays
- be aware that siblings may also be assessed as a 'child in need' under the 1995 Act
- be aware that carers under the age of 16 have an independent right to an assessment if they are providing 'substantial and regular' care.

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

What services can I expect for my child and family?

Services for disabled children are available under Section 2 of the Chronically Sick and Disabled Persons (Scotland) Act 1972 and under the Children (Scotland) Act 1995. The Chronically Sick and Disabled Persons Act sets out what kind of help should be provided. Under this Act, the duty to provide services is to the individual disabled child and does not extend to other members of the family.

The services detailed are:

- practical assistance in the home such as help with the personal care of your child, for example help with getting in and out of bed
- provision of equipment to satisfy a recreational need, such as a TV, radio or computer
- provision of leisure facilities (this could mean outings)
- travel and other assistance
- home adaptations/disabled facilities such as fitting of handrails and hoists
- holidays
- meals
- telephone equipment.

The Children (Scotland) Act 1995 sets out a range of support services which should be available. This includes short breaks.

The regulations and guidance for the Children (Scotland) Act 1995 say:

‘Respite services are an important part of the range of services that should be available to help families with children



in need. They are particularly relevant to helping children with disabilities but can also meet other needs, for example to provide a child’s parents or carers under stress with a break where the absence of such support might lead to breakdown of the usual arrangements for the child’s care.’

There are other services listed in the regulations and guidance. Family support services should cover both day care and home care services. These may include:

- home help
- family centres offering childcare
- support to parents and education to increase parenting skills
- access to suitable housing
- occupational therapy
- special equipment and adaptations.

Importantly, The Children Act allows social work to provide help which will benefit other family members, such as siblings and other carers.

The transition to adult services

The transition to adult services is a time of particular concerns and tensions. Guidance to the 2002 Community Care and Health (Scotland) Act makes it clear that local authorities should:

- anticipate the need for equipment and adaptations to the home as a disabled child grows older
- plan and make arrangements for the child's eventual transition from children's to adult services.

When should services be provided?

Services available under these Acts should be provided when there is an assessed need, and services are necessary to meet those needs. In practice, most local authorities use 'eligibility criteria' to help them make this decision.

Eligibility criteria

There are many disabled children in a local authority area who need help but social work have limited financial resources. Using 'eligibility criteria' is a way they can prioritise to make sure the people most in need get help. The criteria differs from one authority to another. This means that if you move to a different local authority area you may no longer qualify for the same help.

For example, one of the services listed under the Chronically Sick and Disabled Person's Act is 'holidays'. This does not mean every disabled child must be given a holiday each time they ask. There will be local eligibility criteria. The local authority might say, for instance, that holidays will normally only be given if a child has not had a holiday for five years and there is a risk of family breakdown if a holiday is not given.

Local authorities should not apply their eligibility criteria without taking into account the particular needs of an individual child and their family. In addition, when drawing up their eligibility criteria, local authorities should take into account the duties placed upon them by the Disability Discrimination Act (for example, to have regard to the need to eliminate discrimination, to promote equality of opportunity and to encourage participation of disabled people in public life).

In using eligibility criteria, local authorities need to be clear whether they are under a duty to provide a particular service or merely have a discretionary power to do so. Where they are under a duty to provide a service, the role of eligibility criteria is limited. For example, where a service is provided under the Chronically Sick and Disabled Persons Act, eligibility criteria can only be used to decide whether a child falls into that group of children who are eligible for a service. Once it has been established that a

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

child falls into the eligible group, the local authority cannot then use further eligibility criteria to limit provision. Instead it must arrange sufficient services to meet that child's assessed needs.

If the service is not actually assessed as a need (perhaps seen as only useful), or if it is assessed as a need but does not fit the local criteria, the local authority does not have an obligation to provide the service. However, it should still try to meet the need, for example by contacting a local charity or other voluntary agency to help. If the decision is that services are not needed, or that you do not fit the eligibility criteria, you should be given clear reasons. This is to help in case you want to challenge the decision using the complaints procedures.

Know your rights

It is quite common to hear statements like 'our local authority no longer provides short breaks' or 'we don't do carer's assessments here'. These statements are unlawful and you should have good grounds for a complaint.

In fact, the local authority should not put a ban on any service and should always consider the needs of your individual child and family. Some families have challenged statements like these in court, and the courts have decided that a local authority cannot 'unlawfully fetter its discretion'. This means they must always be prepared to consider requests which do not fit into the eligibility criteria.

Using the holiday example from earlier, it would be illegal for a local authority to

say, 'we never give holidays to children unless they have not had one for five years'. They can say, 'we do not usually give holidays', but they must always listen to any reasons you have and why you should be treated as an exception.

Waiting lists

It is common to be told there is a waiting list for services. You may be told this even when it is agreed your child has an assessed need. If the delay is long or you feel the need is urgent, you can consider making a formal complaint.

The care plan

Once social work has gathered enough assessment information, a decision is made on which of your child's needs are eligible for services. A plan should then be agreed between social work and the family, in order to meet the identified needs.

The plan should give details of:

- what services will be provided
- for how long the services are required
- what the local authority plans to achieve by providing the services
- what each person and agency is expected to do
- date of next review.

Importantly, the care plan should be reviewed regularly to make sure that any services provided remain appropriate.

Charging for services

Will I have to pay for any services provided?

Local authorities do have the power to charge for services they provide. This can be a complex area and it can be helpful to get expert advice if you encounter difficulties. It is usually your financial situation as a parent which is assessed rather than your child's.

Each local authority has its own charging policy but you should not be asked to pay more than you can afford. Guidance issued by the Scottish Executive also says that local authorities should consider carefully whether to charge for disabled children's services, if supporting the disability of a child imposes significant additional costs on the parents. When a child reaches 16 years of age, they are assessed in their own right. This means it is their ability to pay which is taken into account and not the parents' ability to pay.

When should I not be charged?

If you are getting Income Support, income-based Jobseeker's Allowance or income-related Employment and Support Allowance, no charge should be made for services under the Children Act. Parents who get Working Tax Credit or Child Tax Credit (above the family element) should also be exempt from charges for Children Act services.

What if I cannot afford to pay the assessed charges?

If you feel you are being charged wrongly or at a level which is more than you can reasonably be expected to pay, you

can ask for the charges to be reduced or waived completely. If you are still unhappy with the amount being charged you can make a formal complaint.

Direct payments

Local authorities can give payments, instead of services, to disabled people to buy in the services they have been assessed as needing. Parents can also receive direct payments to buy services for their disabled children. Local authorities must offer the choice of a direct payment to anyone who is eligible. Direct Payments are seen as a way of increasing choice and flexibility in how your child's care needs are met.

If your child is under 16 years of age, direct payments will usually be made to you as their parent. When a child becomes 16 years of age, she or he can receive payments in their own right to buy in services.



Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

A direct payment can only be used to buy services your child has been assessed as needing. The amount you receive should be enough to allow you to meet all the costs involved. If you decide to employ someone directly this should include tax and national insurance, as well as the fee for a police check. Social work will usually deduct an amount from the payments, the same as what you would have been charged if they had arranged the services. Or, they may pay you in full and ask you to repay them any assessed charge.

The general rule is that you cannot use a direct payment to buy care from a close relative. However, social work can agree to make an exception to this where they believe that such an arrangement is necessary in order to meet your disabled child's needs. Ring our freephone Helpline for further information about direct payments and to get a free copy of *A parent's guide to direct payments in Scotland*.

Adaptations to housing

If you are an owner-occupier or a private tenant you may be able to get help from your local council with the costs of adaptations. A new system of grants to meet the costs of adaptation has been introduced in Scotland. This includes mandatory grants to meet the costs of providing not only standard amenities such as baths, showers and toilets but also for structural-adaptation work deemed essential to meet the needs of a disabled occupant.

There is no fixed upper limit on the amount of a mandatory grant. The grant must be sufficient to cover the costs of the work that has been identified as required in the assessment of need.

If a mandatory grant is awarded on the basis of disability, it must cover at least 80% of costs. However, where the applicant, or anyone living with the applicant, is in receipt of income support, income related Employment and Support Allowance, income based Job Seeker's Allowance or pension credit (guarantee credit) it must meet 100% of costs. Where someone does not receive one of these benefits, a council may still decide to give a grant covering more than 80% of costs – each council must develop their own policy on the circumstances where this might apply.

A mandatory grant cannot be made to extend a property in order to provide additional living accommodation. If an extension provides a standard amenity (for example, a bathroom) alongside additional living accommodation, then a grant can only be awarded for the appropriate portion of the work. If an extension solely creates space for a standard amenity and no additional living space is created then full costs can be met. Where you have no entitlement to a mandatory grant, your council may consider offering you a discretionary grant instead.

Councils are only under a duty to offer grants where an adaptation has been assessed as 'essential' to the needs of a disabled person. Scottish government

guidance envisages that local councils will develop their own eligibility criteria to help them make decisions about whether the work required is to be treated as essential or not. Once a council has accepted that an applicant is entitled to a grant, it should be approved and paid within a reasonable timescale. Guidance makes clear that applicants should not be put in a queue or on a waiting list.

If you have been refused a grant for adaptations, or been awarded 80% of costs but are unable to meet the balance of costs, you may wish to consider approaching your local social work department for help. Regardless of the decisions made by your council in relation to a housing grant, a social work department may still have a responsibility under community care legislation to meet your child's need for an adaptation.

If you are a tenant of a local authority or a housing association you are normally expected to approach your landlord for help with adaptations. However, in very exceptional circumstances it may be possible to get a grant under the rules above.

When to make a formal complaint

You have a right to formally complain about any social work service provided by the local authority. Complaints can be made about an assessment of whether a child is in need or not, or about the provision or lack of provision of services for your family and disabled child. Some people are worried about making a

complaint because they fear that the services already provided will be taken away. You can always request the help of a local parent support group or advocacy service – Contact a Family can let you know about any in your area.

Each local authority has a 'designated officer' who receives all complaints. In the first instance, you can make either a verbal or a written complaint. It is advisable to put the complaint in writing or keep a note of your complaint if you telephone. An informal complaint can be made to any officer at the social work department and they will try and sort out the problem. If you prefer, or



Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

if the problem is not resolved, you can make a formal complaint. Every social work department should have a leaflet outlining the complaints procedure.

Social work have 28 days to give a written response once a formal complaint has been made. You can ask for a meeting to explain your complaint, but they do not have to agree to this meeting. If you are still not satisfied, you can ask for a review hearing before a panel of three people. You have 28 days from getting the local authority's written response to ask for a review.

If you are not happy with the decision of the review panel, there are various other options, such as taking the issue up with a local councillor, MP or MSP. You can also complain to the Scottish Public Services Ombudsman:
Tel: 0800 377 7330
www.spsso.org.uk

The Ombudsman can investigate complaints against local authorities and certain other bodies. By law, some kinds of complaint can't be considered, like complaints about personnel and about the internal running of schools.

Judicial Review

If your complaint is very urgent and you cannot wait for the complaints procedure to resolve the matter, you can apply to the courts for a Judicial Review. This is a procedure where the Court of Session looks at the way a decision was reached to see if it was legally correct. You can also apply for judicial review if you have

exhausted the complaints procedure and are still unhappy with the outcome.

You will need legal assistance to apply for a judicial review. If you have a low income, you may qualify for legal aid but otherwise it could be a costly process. Some solicitors offer a free first interview. Before seeking judicial review, it may be worth complaining to the local authority monitoring officer. The monitoring officer is responsible for ensuring that decisions are lawful and procedures are correctly followed.

Some frequently asked questions

My daughter is disabled and I'm wondering if I can get a Blue Badge?

The Blue Badge Scheme (formerly Orange) is a UK-wide arrangement of on-street parking concessions for disabled people. The badge can also be used in many European countries. If you regularly drive your disabled child and s/he has severe walking difficulties, is registered blind, has severe upper limb disabilities or receives the higher rate mobility component of Disability Living Allowance, you may be eligible. The lower age limit is currently two years although there are plans to extend entitlement to certain children under two (for example, those who require bulky equipment). You should apply to your local social work department.

Can my social worker advise me on which benefits my family is entitled to?

Yes, social workers do have a duty to



provide advice and guidance. They should explain to you what benefits are available and make sure you are receiving any benefits you are entitled to. However, most social workers are not benefits experts and they may rely on the local authority's welfare rights service or similar advice agency to help you. Benefits and tax credits advice is available from the Contact a Family helpline.

Do I have a right to see my child's records?

Under the Data Protection Act 1998 professionals and agencies have a duty not to disclose information about disabled children and their families, without their consent. This applies to children as well as adults, provided that if

they are under 16 years of age 'they have the ability to understand the choices and their consequences'. Even though there is a duty not to disclose, the public body concerned (for example, health or local authority) still has a discretion to allow access to the information.

In most cases parents should have no difficulty in seeing their child's records. Guidance also states that advocates should be given access to relevant information concerning the person they're representing.

The Contact a Family helpline can provide further advice on access to personal records, Tel: 0808 808 3555.

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

Further information and advice

For further information, please contact your local carer's centre, Citizens Advice Bureau (CAB), law centre or disabled person's advice centre.

For details of your nearest branches, call our Edinburgh office, Tel: 0131 659 2930, e-mail: scotland.office@cafamily.org.uk or our free helpline: Tel: 0808 808 3555, Textphone: 0808 808 3556 (Mon-Fri 10am-4pm; Mon, 5.30-7.30pm).

Tips for attending meetings with social work

- **Be prepared:** for example, if you are planning to talk about placements you might want to have visited a school or a residential home.
- **Keep copies of everything:** for example, letters you have written about your child to the authorities, as well as those they send to you. Keep everything in a file, making sure you read everything you think might be relevant before the meeting to refresh your memory.
- **Make notes:** it is easy to forget something so having a few notes handy at a case conference will help to make sure you cover all the points you want to make. Listen to what the professional workers have to say and make notes of what is said.
- **Take someone with you:** if you have a partner, make sure you both attend the case conference. If that is not possible, or you are a single parent, take a friend or someone from a local support network.

- **Do not be frightened to ask:** if you do not understand what is being said, ask questions until you do.
- **Keep calm:** do not lose your temper if things are going wrong. Try and give reasoned counter arguments.
- **Follow up:** compare notes and draw up a summary of the main points made at the meeting, what was agreed, and what still needs to be agreed.

Published by Contact a Family

Written by Derek Sinclair and Lesley Gray

Social networking

Contact a Family is on Facebook and Twitter. Join us at:

Facebook

www.facebook.com/contactafamily

Twitter

<http://twitter.com/contactafamily>

Podcasts

You can download podcasts from our website at: www.cafamily.org.uk/news/podcasts.html

iTunes users can listen to our podcasts at: <http://bit.ly/96EVT>

Videos

You can watch videos on our YouTube channel at: www.youtube.com/cafamily

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Textphone

0808 808 3556

Open Mon–Fri, 10am–4pm

Mon, 5.30–7.30pm

Access to over 100 languages

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:

209-211 City Road, London EC1V 1JN

Tel **020 7608 8700**

Fax **020 7608 8701**

Email **info@cafamily.org.uk**

Web **www.cafamily.org.uk**



Language Line
services

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. Titles available include:

- Fathers ^(UK)
- Understanding your child's behaviour ^(UK)
- Living without a diagnosis ^(UK)
- Grandparents ^(UK)
- Siblings ^(UK)
- Additional support for learning ^(Scotland)

A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

Registered Office: 209-211 City Road,
London EC1V 1JN
Registered Charity Number: 284912
Charity registered in Scotland No. SC039169
Company limited by guarantee
Registered in England and Wales No. 1633333
VAT Registration No. GB 749 3846 82

® Contact a Family is a registered trade mark
Although great care has been taken in the
compilation and preparation of this guide to
ensure accuracy, Contact a Family cannot take any
responsibility for any errors or omissions.