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This Factsheet is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request.

incorporating
The Lady Hoare Trust

Introduction

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

Social services departments of local authorities 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 services.

Assessments

What is a social services assessment?

An initial assessment may be carried out to help social services determine whether or not a core assessment (an in-depth assessment) should be carried out. Timescales given to social workers indicate that the initial assessment should be completed within a maximum of seven working days and the core assessment should not take longer than 35 working days.

Beforehand, you should be told how the assessment will be carried out and be given information about what services are available, not just those which are provided by social services (for example, a local playscheme).

It is very important to remember that your child should not only be assessed for specific services which are already available. Instead the assessment should identify all of your child's needs regardless of whether or not services exist to meet them.






Social services 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 services should also consider other aspects of your child's life, for example, educational 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 however that the assessment should be needs led and not based on services already available.

Make a list of questions if you think that will help. You are entitled to have a friend or advocate there with you, too. 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/her needs.






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

Many social services departments have children with disabilities teams. You should find the number in the telephone directory under the name of your local authority or social services or ring our freephone helpline, Tel: 0800 808 3555 for information. Alternatively, you can ask your GP, health visitor, community nurse or paediatrician to contact social services 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 at the least 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.

Duties of social services to disabled children and their families

Duties include;

-  Providing a social work service;
-  Maintaining a register of disabled children;
-  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.

Social services departments have a general duty under Section 17 (10) of the Children Act 1989, to safeguard and promote the interests of children in need. The law recognises disabled children as being in need.

A child in need is entitled to an assessment from the social services department. 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 breaks.

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 services refuse to carry out an assessment?

If your child is disabled and in need of services, you cannot legally be refused an assessment. Also, if you need help urgently, you can ask for services to be put in place straight away without waiting for the outcome of an assessment.

Carers' assessments

The Carers (Recognition and Services) Act 1995, means that parents can request a carers' assessment. The carers' assessment specifically focuses on you as a parent and your needs.

Social services 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 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 services about the things that could make looking after your child easier for you.

The Carers (Equal Opportunities) Act 2004, which came into force in April 2005, gives additional rights. This requires local authorities to inform carers of their rights to an assessment. The Act also ensures that work, life-long learning and leisure are considered when a carer is assessed. The booklet "Balancing Life and Caring" contains further advice and is available from Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT
Tel: 0808 808 7777 CarersLine (Wed & Thurs, 10am-12noon & 2-4pm).

Combining assessments

The Children Act also says that various assessments can be combined, for example an assessment under the Education Act 1996 or the Chronically Sick and Disabled Persons Act 1970. This means that if your child's special educational needs (SEN) are being assessed, for example, then social services could assess your child's needs under the Children Act at the same time.

After the assessment









After social services 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.

Social services may decide that there is no need for services which could result in your case being closed with no further action taken. If you disagree with the decision you can challenge this using the local authority's complaints procedure. Further advice about making a complaint can be found on page 7. Or they may decide that there is a need for services and these should be provided.

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 Act 1970** and under the **Children Act 1989**.

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 include:

-  Practical assistance in the home, such as help with the personal care of your child, e.g. help with getting in and out of bed;
-  Provision of equipment to meet a recreational need, such as a TV, radio or computer;
-  Provision of leisure facilities (this could mean outings or a placement at a day centre) or educational facilities (this could mean home-based education or even funding of personal care requirements of students so that they can study);
-  Travel and other assistance such as travel to and from a day centre;
-  Home adaptations/disabled facilities such as fitting of handrails, hoists etc.;
-  Holidays;
-  Meals;
-  Telephone equipment.

Children Act 1989

The **Children Act 1989** sets out a range of support services which should be available. This includes the right to residential accommodation, whether permanent or temporary, where your child needs it. This forms the legal basis for **residential short breaks**. If your child needs this service, then it should be provided. If there are no suitable facilities locally, your local authority can look outside its own area. There are other services listed in the Children Act. Here are some examples:

- Occupational, social, cultural or recreational activities;
- home help;
- assistance to enable your child and family to have a holiday;
- advice, guidance or counselling;
- travel assistance.

Under **The Children Act 1989** local authorities have a general duty to make a range of services available to help children in the area.

Importantly, **The Children Act 1989** allows social services to provide help which will benefit other family members, such as siblings and other carers.

When should services be provided?

Services available under both 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 an area who need help but social services have limited financial resources. Using 'eligibility criteria' for deciding who has a 'need' for services is a way in which they can prioritise to make sure that the people most in need get help. The criteria differ from one authority to another and this means 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 Persons Act is 'holidays'. This does not mean that every disabled child must be given a holiday each time they ask. There will be local eligibility criteria. It might say for instance, that holidays will normally only be given if a child has not had a holiday for 5 years and there is a risk of family breakdown if a holiday is not given.

Once your child's assessed needs match the set local eligibility criteria, the Local Authority has a duty to provide or arrange services to meet those needs. If your child had not had a holiday for 5 years and you could show that your family was under such stress that family breakdown was



possible, there would be an obligation to fund the holiday regardless of the Local Authority's financial difficulties.

However, the Local Authority can then take its resources into account in deciding how it will actually meet the needs. It might limit the type of holiday it provides, or it might arrange for another organisation to do so. It could even try to apply for a charitable grant to fund the holiday.

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 has no actual obligation to provide or arrange provision of the service. The Local Authority should still use its best endeavours 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 (see page 7).

Beware!

It is quite common to hear statements such as "Our Local Authority no longer provides short breaks" or "We don't do carers' assessments in this Local Authority." These statements are unlawful and you should have good grounds for a complaint (see page 7). In fact, the Local Authority should not put a blanket ban on any service and should always consider the needs of the individual child and the family. Other families have challenged such statements in court and the courts have decided that a Local Authority cannot 'unlawfully fetter its discretion.' This means that a Local Authority must always be prepared to consider requests which do not fit within its 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 why you should be treated as an exception.



The care plan

Once the social worker has gathered enough information through the assessment, s/he then decides which of the child's various needs warrant the provision of services. A plan should then be agreed between social services 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.

Waiting lists

It is very common to be told there is a waiting list for services. You may be told this even when it is agreed there is an assessed need. Where there is an assessed need, in law the Local Authority has a duty to provide a service straight away although, in practice, this often does not happen. If the delay is lengthy or you feel the need is urgent, you may wish to consider making a formal complaint (see page 7).

Charging

Will I have to pay for any services provided?

Local authorities do have the power to charge for services they provide under the Children Act 1989. It is usually your means as a parent which are assessed rather than your child's and you should not be asked to pay more than you can afford. Each Local Authority will have its own charging policy.

When a child reaches 16, they are assessed in their own right. This means it should be their ability to pay which is taken into account and not the parents.

When should I not be charged?

If you are in receipt of Income Support, no charge should be made for services under the Children Act. Recipients of Working Tax Credit and Child Tax Credit (above the Family element) should also be exempt from charges for Children Act services.

Arguably, your Local Authority cannot charge for any services which are provided under the Chronically Sick and Disabled Persons Act. If your child has been assessed as being in need of any of these services, s/he is disabled and you are being charged, you should seek further advice from the Contact a Family Helpline.

Also, you should not be charged for advice, information and social work services.

Do I have to pay for services provided to me as a carer?

Services for carers of disabled children are normally provided under the Children Act and the same charging rules apply.

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 given your circumstances, you can ask for the charges to be reduced or waived completely. If you are still unhappy with the amount you have been asked to pay you can make a formal complaint (see page 7).



Direct payments

What are direct payments?

Local authorities can give payments, instead of services, to allow disabled people and carers to buy in the services they have been assessed as needing. Direct payments are seen to promote the independence of parents and their disabled children who would like to manage their own social care needs.

If your child is under 16, direct payments will usually be made to you as their parent. When a child becomes 16 she or he can receive payments in their own right to allow them to buy in the services they have been assessed as needing.

In the past you could not insist on direct payments, however, in England, a request should now be refused only in very limited circumstances. In Wales, direct payment schemes became mandatory in November 2004.

The amount you receive should be enough to allow you to meet all the costs involved, including tax and National Insurance as well as the fee for a police check (should you employ help directly). Social services will usually deduct an amount from the payments equivalent to what you would have been charged had they arranged the services (see 'charging' on page 5). Alternatively, social services may make the payments in full and ask you to reimburse them any assessed charge.

Any payments you receive must be used to pay for services to meet the assessed needs.

The Department of Health together with the Council for Disabled Children have produced 'A Parent's Guide to Direct Payments'. Copies are available from: Department for Education and Skills Publications, PO Box 5050, Annesley, Nottingham NG15 0DL
Tel: 0845 602 2260 Fax: 0845 603 3360
e-mail: dfes@prolog.uk.com

The following link lists Frequently Asked Questions (FAQs) on direct payments for families with disabled children and disabled young people.

<http://tinyurl.com/g4lfc>

The source is government website:

<http://www.everychildmatters.gov.uk>

Vouchers

The voucher scheme allows carers and disabled children to receive vouchers for short breaks. This should mean more freedom to choose when and where to take a break. In both England and Wales the scheme is discretionary which means that local authorities don't have to offer this. If you would like to know more about the scheme the Contact a Family Helpline should be able to provide further information.

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. Judicial Review is a procedure where the High Court looks at the way a decision was reached to see if this was legally correct. You can also apply for Judicial Review if you have exhausted the complaints procedure and are still unhappy with the outcome. To do this you will need legal assistance. If you have a low income you may qualify for the Legal Help Scheme. Also, some solicitors offer a free first interview. The Contact a Family Helpline can send you information about getting help with legal costs and also contact details of solicitors in your area which specialise in community care law.

Before seeking judicial review it may be worth complaining to the Local Authority Monitoring Officer. The Monitoring Officer (usually the Chief Executive or Borough Solicitor) is responsible for ensuring that decisions are lawful and procedures correctly followed.



Making a formal complaint

You have a right to complain about any social 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 – the Contact a Family Helpline 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, although 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 services department and they will try and sort out the problem. If you prefer, or if the problem is not resolved, you can make a formal complaint. Every social services department should have a leaflet outlining the complaints procedure, so you may wish to obtain one.

Once a formal complaint has been made, social services have 28 days to give a written response to the complaint. You can request a meeting to explain your complaint, but social services do not have to agree to this meeting. If you are still not satisfied, you can request a review hearing before a panel of 3 people. You have 28 days from receiving the Local Authority's response to request a review.

Tips for attending meetings with social services

- 1. Be prepared:** For example, you might want to have visited a school or a residential home, if you are planning to talk about placements.
- 2. 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.
- 3. 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.

- 4. 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.
- 5. Do not be frightened to ask:** If you do not understand what is being said, ask questions until you do.
- 6. Keep calm:** Do not lose your temper if things are going wrong. Try and give reasoned counter arguments.
- 7. Follow up:** Compare notes and draw up a summary of the main points made at the meeting, what was agreed, and what still needs agreement to be reached.

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 or MP (or Assembly Member if you live in Wales) or complaining to the respective **Local Government Ombudsman**:

England:

There are three local government Ombudsmen in England. Each of them deals with complaints from different parts of the country. For further information visit
Web: <http://www.lgo.org.uk> or Tel: 0845 602 1983

Wales:

Public Services Ombudsman for Wales,
1 Ffordd yr Hen Gae, Pencoed, Bridgend CF35 5LJ
Tel: 01656 641150
Fax: 01656 641199
e-mail: ask@ombudsman-wales.org.uk
Web: <http://www.ombudsman-wales.org.uk>
Web: <http://www.ombwdsman-cymru.org.uk>

The Ombudsman can investigate complaints against principal councils (not town, parish or community councils) and certain other bodies. By law the ombudsman must look for 'maladministration' by a council. Examples of maladministration include delays and failure to provide information. The Ombudsman will basically decide whether or not the council has done something wrong which has

directly affected you and caused you an injustice. The Ombudsman will not investigate a complaint against the council simply because you disagree with it. The Contact a Family Helpline can send you the leaflet 'How to Complain to your Local Government Ombudsman'.

Changes to the local authority complaints procedure

A new local authority complaints procedure is currently being introduced in England during 2006. Stage One of the new procedure will still require an initial investigation of complaints by social services departments. If the complainant is not happy with the outcome of the Local Authority investigation, then the complaint passes to Stage Two where it is referred to the Commission for Social Care Inspection (CSCI) Review Service to decide how best to deal with it. Available options include referral to an independent complaints panel; conducting a further investigation; referral to the Ombudsman; or taking no further action where the CSCI is satisfied with the local response. Further information about planned changes can be found on Web: <http://www.csci.org.uk> or contact our Helpline.

In Wales a new complaints procedure is also being introduced from April 2006 along very similar lines to the new English system described above. This places an emphasis on local resolution in the first place followed by a Formal Consideration stage. If you're not satisfied



with the outcome then you can make a request for it to be considered by an independent panel. The request should be made to the Independent Complaints Secretariat within 4 weeks of completing Stage 2. The contact number for the Secretariat is 01495 332487 or you can write to: Hayley Johnson, Independent Complaints Secretariat, The BSC, Pontypool, Mamhilad House, Park Estate, Pontypool NP4 0YP. Contact a Family's office in Wales can also provide further information. Tel: 029 2049 8001.

National Service Framework

In England the National Service Framework for Children is the government's 10 year plan to improve services for children. By 2014 service providers must meet certain standards set out in the NSF. This represents a major change in the way that families with disabled children are helped and supported. The overall aim is to develop services which are based around the needs of children and their families instead of the needs of organisations delivering the services.

Although the NSF is not law, it is government policy which must be followed. As a parent if you find that a service provider is not following the NSF then you have a right to make a formal complaint. Further information can be found in the leaflet 'Making a Difference - the NSF and parents of disabled children'. There is also a separate guide for parent groups 'Making a Difference - how parent groups

can use the Children's NSF to influence local services'. Contact the helpline for copies.

In Wales a National Service Framework will be launched in September (2006) with similar targets and key standards. Further information can be found on the Wales NHS website: <http://www.wales.nhs.uk>. Contact a Family's office in Wales can also provide further information. Tel: 029 2049 8001.

Children's Trusts (England)

Another major change in the way families can access services and support is the introduction of Children's Trusts which will bring together all services for children and young people in an area. These include local education, social care (assessment and services) and some health services for children and young people. Other services may include: housing, leisure services and independent sector organisations such as voluntary organisations. By integrating key services it is hoped that Children's Trusts will support families to deliver better outcomes for children and young people.

Not all local authorities currently have a Trust but most areas should have Trusts by 2006. Contact the helpline for further information or visit

Web: <http://www.everychildmatters.gov.uk/>

Some frequently asked questions



My social worker has said I should put my disabled child on a register of children with disabilities. What does this mean?

Social services have an obligation to keep a register of disabled children. This is not the same as the Child Protection register and does not suggest in any way that your child is at risk. You do not have to agree to your child's name being added to the register and it does not affect entitlement to services. A register enables social services to try and plan services for disabled children more effectively in their area. It is sometimes used as a way of getting relevant information to families with disabled children. For example you may start to receive a newsletter.

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

The Blue Badge Scheme (formerly Orange) is a UK 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 component of Disability Living Allowance, you may be eligible. The earliest you can receive a blue is from age 2. You should apply to your local social services department.

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

Yes, social workers do have a duty to provide advice and guidance. They should explain to you what benefits are available and ensure that you are receiving the benefits to which you are entitled. 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. They may also direct you to a voluntary organisation, such as the Family Fund, for further help. Further advice about entitlements can also be found within the following factsheets available from the Contact a Family Helpline: 'Benefits, Tax Credits and other financial assistance' and 'The Tax Credits Guide'. Helpline advisors can also help with benefit enquiries and possibly identify further sources of help.

My son has ADHD and is also autistic. Social services refuse to assess my child saying that they can only help children with physical disabilities and they don't have any suitable services.

Under the Children Act 1989 a local authority has a duty to assess any child in need. Children in need are defined as children who are under 18 and who are 'unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining a reasonable standard of health or development without the provision of services by a local authority'; or whose 'health or development is likely to be significantly

impaired or further impaired without the provision of such services by a local authority; or who is disabled'. **A disabled child** is defined as one who is chronically sick or has a mental or physical disability which has substantial and long-term affect on the child's ability to carry out ordinary day-to-day activities. **'Development'** means physical, intellectual, emotional, social or behavioural development and **'health'** means physical or mental health.

Given the above definition it is clear that social services have acted incorrectly by refusing your request for an assessment. Social services have a general duty to provide a range of services for all disabled children as defined above. However, local authorities are also allowed to set eligibility criteria for specific services. This should help ensure that those in greatest need will receive the service in question. You may find that your child will not qualify for a service because he doesn't satisfy the criteria. If this is the case and you're unhappy about this or any other decisions made by social services, then you can make a complaint using the local authority complaints procedure. See page 7 - 'Making a formal complaint'.

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 the consent of the subject**. This applies to children as well as adults, provided that if they are under 16 'they have the ability to understand the choices and their consequences'. Even though there is a duty not to disclose the public body concerned (eg Health or Local Authority) still retain 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.

Can I use direct payments to employ my sister-in-law who lives with me to look after my son.

The 2003 Direct Payments Regulations make it that clear that a direct payment should not be used to employ a spouse, partner or close relative living in the same household as the disabled person.

However, employing a close relative may be possible, if this is the only effective way to meet a child or young person's needs. For example, if a child has complex communication needs or specific cultural needs then it may acceptable to employ a family member who could meet those needs.

Further information

For further information, please contact your local **Carers Centre, Citizens Advice Bureau, Law Centre** or **disabled person's advice centre**. For details call our freephone Helpline,
Tel: **0808 808 3555** Text: 0808 808 3556
(Mon-Fri, 10am-4pm & Mon 5.30pm-7.30pm)
e-mail: helpline@cafamily.org.uk
Web: <http://www.cafamily.org.uk>

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