



Cerebra

Positively Different

Disabled Children Parents' Guide: Parent/Carers

Introduction

This guide has been prepared for parents of disabled children who are under 16 who want to find out more about the support that is available to them in their role as parent carers.

This guide is one of a series of guides published by Cerebra that aim to give parents of disabled children information on how to get the help and support they need. Other guides cover the following areas:

- Education
- Social Care, Housing and Health
- Money matters
- Employment

Carers come in many different guises. They may be paid to work as carers or come from a voluntary organisation as a carer (such carers do not have a right to a carers' assessment) or be a friend or relative (providing support for which they do not get paid), for example. This guide is written specifically for unpaid parent carers of disabled children who are under 16.

It is important to remember that there is nothing wrong in asking for help when you are caring for a disabled child. This guide explains different sources of help including how your needs as a carer can be assessed by your **Local Authority children's social care services department** (referred to as 'the Local Authority' in this guide), in order to access additional services and support. Even if you do not want such support, as your child's carer you are entitled to have your views taken on board by your Local Authority when it is carrying out an assessment of your child's needs.

Jo Honigmann and Luke
Clements.

The main legislation covering carers' assessments in England and Wales is in the form of three key Acts of Parliament and associated regulations:

- The Carers (Recognition & Services) Act 1995
- The Carers and Disabled Children Act 2000
- The Carers Equal Opportunities Act 2004

These three Acts are explained in the Glossary on page 16. This guide refers to guidance documents issued in relation to these Acts. Links to such guidance are provided in the Resources section on pages 17-20.

In both England and Wales there are proposals to streamline the law governing carers legislation (the draft Care and Support Bill covering adult care in England and the draft Social Services and Well-being Bill in Wales, to be introduced in early 2013). Any changes are unlikely to be implemented before 2014 and later editions of this guide will explain them.

This guide covers the following areas:

- Support for your child
- Support for you as a carer (not including welfare benefits)
- Payments to buy the service /s your Local Authority has decided you need
- Getting help from the NHS
- If you and your child disagree about the support your child needs
- Employment

This guide provides a summary of these areas through a series of questions and answers. It also includes a Glossary (see page 16) which provides an explanation of commonly used terms (these are highlighted in **bold** in the text).

This guide is no substitute for specialist advice – the Resources section (see pages 17-20) provides information on where to obtain further help and assistance and gives details of useful guidance, such as the detailed Carers UK guide, 'Carers and their Rights', written by Luke Clements, which has been a key source of information for this guide.

Support for your child

Q1. Is my child entitled to an assessment of their needs?

If your child is a **child in need**, including a **disabled child (see the Glossary below)** the Local Authority must carry out an assessment of the needs of your child and of your family. This is one of the specific duties a Local Authority has towards children who are disabled and children who meet the definition of a child in need.

Q2. How do I arrange to have this assessment carried out?

You should write to your Local Authority requesting that an assessment of the needs of your child and your family is carried out, explaining that your child is **disabled** and a **child in need**. The letter should describe his or her impairment, and (if you have one), it should enclose a copy of any diagnosis of your child's disability. You should also describe what difficulties you are having and the type of help you would like. You can ask a professional who knows your child and provides care for them, such as your GP, to write on your behalf.

The Local Authority should respond immediately, letting you know whether it will carry out the assessment. (The Local Authority's response should be within one working day of receiving your letter). If there is any delay – or the Local Authority refuses to undertake an assessment - you should consider making a complaint (see 'Resources' section below).

Q3. What does the assessment involve?

The purpose of the assessment is to establish the needs of your child and your family; to advise you of what support and resources may be available to help you; what (if any) services and/or support should be put in place to meet those needs; and the best way of providing these services and/or support. It will consider the issues arising out of three main areas: your child's development needs; the care you provide as a parent; and family and environmental factors.

The Local Authority will take the lead in conducting the assessment which will normally be carried out by a social services staff member but other agencies may also be involved, such as health and education.

The assessment will involve gathering information (which will include talking to you, your child and other key people in your child's life); assessing this information and deciding whether any of your child's or family's needs are so significant that they require support services from the Local Authority; and ensuring that this support is then put in place. This can be by way of a 'direct payment' (see question 16) or a care plan setting out how the support will be put in place.

It may be that you have to meet with a range of professionals several times as part of the assessment.

Q4. How should I prepare for the assessment?

- Put together a file containing all the relevant information about your child, such as correspondence with the various professionals involved, details about your discussions

- with various professionals and medical reports;
- Think about who you would like to be involved in the process. If you would like someone to act as your advocate you should make sure that they will be available on the day of the assessment/s;
- Be clear about what you want to say, for example, about your child's needs, the impact the caring role has on you and your family and the outcome you are hoping for from the assessment;
- A particularly important factor is the risks you, your disabled child and any other family member may experience if help is not provided. It is important to get letters / statements from family members, friends, professionals and any other persons who know of your situation – which describe the likelihood of harm (physical, emotional, social etc) that is likely to occur if support is not provided – and if possible these letters / statements should spell out exactly what support is required in order to avoid these risks.
- At the assessment meetings, keep a detailed note of the important statements or promises made by the professionals involved as you may need to refer to these later or confirm them after the meeting.

Q5. What support might my child be entitled to?

This will depend on how your child's needs have been assessed. If s/he has been assessed as requiring additional services, these will be set out in a care plan which should be reviewed at least every six months. Examples of the types of services include:

- assistance in and around your home such as home help, personal care, equipment or a sitting service;
- services based outside the home such as an after-school club or holiday play scheme;
- travel and other social care assistance to enable your child to take part in recreational activities or education;
- adaptations to your home.

In addition, temporary short break or respite care or the provision of accommodation on a longer term basis may be required.

Local Authorities can charge for services for disabled children and (in the case of children aged under 16) include their parents' means when calculating the charge (taking on board means exemptions). However, most Local Authorities do not do so.

Your Local Authority must offer you the option of a direct payment (discussed in relation to carers at question 16 below). In England you may also be offered a 'personal budget' – which (if not

paid as a 'direct payment') is a sum of money managed by the Local Authority but the way in which services are commissioned and purchased by the Local Authority takes your wishes and preferences fully into account.

Q6. Will my needs be taken into consideration as well?

Your needs, and those of other family members and 'significant' others, must be taken into account as part of your child's assessment. Wider family and environmental factors will be looked at: the Local Authority must take into account whether you are working or wish to work or to return to work and whether you are undertaking or wish to undertake education, training or leisure activities. You are also entitled to a separate assessment as a carer (see questions 8 to 15 below). However this is something that you may not consider necessary if you have had an appropriately detailed assessment of your needs carried out as part of your child's assessment.

Q7. What if I have concerns about any aspect of the assessment process?

As with the Carers Assessment process (see questions 8 to 15 below), you have the right to complain to the local authority (through the relevant complaints procedure) if you are not happy with an aspect/s of the assessment process, such as a refusal to carry out an assessment, the services provided or the manner in which they are provided. If you are thinking of making a complaint, you should obtain information about the procedure and the time limits involved as soon as possible after the matter giving rise to the complaint occurred so that you do not miss the deadlines. This information should be on the local authority's website.

It may be that legal proceedings, such as a judicial review (in connection with whether a decision or action by the Local Authority is lawful or about its failure to act), can be taken. There are, however, strict time limits for such action and so it is essential to seek legal advice as a matter of urgency, if you are considering taking legal action.

Other potential routes are complaints about 'maladministration' (which could relate to how a service is delivered) to the Local Government Ombudsman (England) or the Public Services Ombudsman for Wales. Usually you will be expected to have exhausted the Local Authority's complaints procedure first. Further details can be found on the Ombudsmen's websites (see Resources section pages 17-20).

For more detailed information about the procedures involved in getting social services support for your child please see the Cerebra Parents Guide on Social Care, Housing and Health (see Resources section pages 17-20).

Support for you as a carer

Q8. Am I entitled to an assessment of my needs as a carer?

You have the right to a carer's assessment if you provide (or intend to provide) a substantial amount of care on a regular basis for your **disabled** child. There is no requirement that the care you provide for your child is much more than is normally expected for children of their age. The same Local Authority as assesses your child will carry out the assessment.

What counts as a 'substantial' amount of care or indeed 'a regular basis' is not defined by law; your Local Authority must have regard to the relevant guidance. The 1995 Carers Act Practice guidance (see Resources section pages 17-20) explains that care that is provided regularly includes care that is given as and when a fluctuating condition requires it. The 2000 Carers Act Practice guidance (again, see Resources section pages 17-20), states that the key test that should be applied by a practitioner when considering whether a substantial amount of care is given on a regular basis is to consider the impact of the caring role on an individual carer.

Q9. I no longer live with the father / mother of my child. Are we both entitled to an assessment?

Yes, if you both provide a substantial amount of care for your child on a regular basis and have **parental responsibility** for them.

Q10. Should I be told about my right to a carer's assessment?

Your Local Authority must let you know of your right to a carer's assessment if they are carrying out or considering carrying out an assessment for your child and have decided that you are providing or intend to provide a substantial amount of care for your child on a regular basis.

You should also be informed about the benefits of having an assessment, since it may result in increased (or better targeted) support for your child – or in you being provided with 'carer support services'.

In Wales, there are new additional information requirements requiring Local Health Boards to publish strategies together with partners, including social services, for identifying and supporting carers of disabled children (amongst others), which should include detailed information provisions.

Q11. How do I arrange to have this assessment carried out?

You need to ask the Local Authority social services department responsible for your child for an assessment and it is advisable to put this request in writing as well as asking for it verbally. Keep a copy of your letter / e-mail so that you can prove a request was made.

Q12. What does it involve?

The assessment will usually be carried out by a staff member of the social services authority. It can take place at your home or somewhere else that is suitable or over the phone if you would prefer. Your child can be present or you can have a private meeting. You can also have another family member or advocate present. Your local authority may ask you to fill in a questionnaire but this must not be in place of a proper assessment.

The purpose of the assessment is to consider what your needs are in terms of your ability to provide and to continue to provide care for your disabled child, as well as your work, education and leisure needs, with a focus on how you would like to live your life, not just on the potential services available.

Providing care

In assessing your ability to provide and to continue to provide care for your child, the assessor will consider four key areas: autonomy (your views about your role as a carer), health and safety (the impact of your caring role on your wellbeing), managing daily routines (how these may be affected by caring for your child) and involvement (whether your participation in other aspects of life is diminished because you are a carer).

Work, education and training needs

The assessment will also look at whether you are working or wish to work and whether you are taking part in, or would like to take part in, education, training or leisure activities. The purpose of the assessment is not to force you into work.

The assessor should help you to think about ways you can work or continue to work if that is what you want to do, or ways in which you can take part in education, training and leisure activities. You should also be told where you can find useful information about options.

The assessor will then decide whether the risk to your ability to care for your disabled child is critical, substantial, moderate or low. This decision will have a bearing on the outcome of the assessment.

Q13. How should I prepare for my carer's assessment?

Think about, and ideally prepare, a written record which covers relevant factors including:

- the level of your caring responsibilities
- your concerns in relation to these
- how your caring responsibilities impact on your life
- what would make things easier for you
- if you are in work, whether your ability to work is affected
- if you would like to work, study or take part in leisure activities, what support you would need to make this happen

Decide if you would like anyone to be present with you at the assessment and make sure it is scheduled for a day when they are free. Meet with them beforehand so you can explain what your concerns are about the current situation and what you would like to achieve.

You may find it helpful to talk to another parent who has been through this process. In addition consider the factors identified in relation to Q. 4 above.

Q14. How quickly will the assessment be carried out?

There is no time limit required by law, but as a rule of thumb, the assessment should be undertaken within four to six weeks from your request, which the Local Government Ombudsman has decided is generally an acceptable time for an assessment of a disabled person.

Q15. What support might I be entitled to?

There is no duty on local authorities to provide services for carers, only a power. It should be appreciated, however, that 'short breaks' or 'respite' care are not 'carers services' – see below.

Following the assessment, the Local Authority will decide what, if any, additional support or services are required. These may take the form of additional services for your child which will also help you, or additional services for you. The support / services that are provided should be recorded in your child's care plan or in a separate carer's plan for you. Your carer's plan should be reviewed every year but it can be reviewed more frequently if your needs change.

If the risk to your ability to carry on caring for your child is critical or substantial (see question 12 above) the Local Authority must take action. As there is no duty to provide services for carers, this action could take the form of additional services for your child or for you.

Types of service for carers

There is a huge range of possible services that can be provided so long as they help a carer look after the person they care for.

Examples from the guidance issued in relation to the 2000 and 2004 Carers Acts (see Resources section pages 17-20) include:

- Driving lessons
- Repairs / insurance for a car
- Training
- Laundry
- Help with housework
- Trips (for example a short holiday for a carer)
- Travel assistance
- Moving and handling classes
- A computer (as a carer may be unable to leave the person s/he cares for to go to the local library)

Underlying these services is a grant making initiative for carers in England and Wales that has been paying money to local authorities for several years with the purpose of enhancing their carers services so that carers can have time out from caring. This has been found to have been successful in encouraging flexible breaks for carers.

Your Local Authority can charge you for services provided to you but most do not. If it does, it must discount any amount you pay for your child in your carer's role such as paying for help privately to help you look after your child.

Types of service for your child

- Respite care / short breaks
Technically (ie at law) these are services for your disabled child, but the effect is to give

you a break from your caring responsibilities. New legislation which came into force in England in 2011 and in 2012 in Wales has strengthened local authorities' obligations toward carers of disabled children, to help them to provide care or continue to do so more effectively, by enabling them to have breaks from caring.

Regulations accompanied by guidance set out a range of actions a local authority must take including providing information about the types of breaks available at different times into which parents must have input, and taking into account the needs of different types of carer. Having decided that respite care / short breaks are required, the local authority must ensure the provision is put in place.

- **Voucher schemes**

A few social services departments run voucher schemes. The purpose of these is to offer flexibility for carers and the person they care for as to when the carers have caring breaks and choice as to who provides the respite care.

There are detailed provisions governing the voucher scheme in England but in essence, vouchers may be issued for a specified amount of money or for a period of time, in which case the particular service must be specified while a particular supplier may be specified.

Payments to buy the service/s the Local Authority has decided you need

Q16. What are direct payments and why might they be helpful?

If, following your carer's assessment, you have been assessed as needing a particular service, you can ask to have the service provided as a direct payment to you, which you then undertake to use to buy the particular service. This may give you more control over the delivery of the service but you can choose to have the Local Authority make the arrangements for you.

Direct payments are disregarded for social security benefits purposes.

A different type of direct payment is one you receive on behalf of your child in order that you can buy the services they have been assessed as needing, on their behalf. If you use the direct payment to employ someone to provide the care, then the direct payment should cover all of the additional costs such as the employees' NI contributions, holiday pay and your employers' liability insurance. For more information see the Cerebra Disabled Children Parents' Guide: Social Care, Housing and Health (see Resources section pages 17-20).

Getting help from the NHS

Q17. As a carer, am I entitled to any support from the NHS?

There is no direct obligation on the NHS in England to consider the needs of carers. In Wales the Carers Strategies (Wales) Measure 2010 obliges Local Health Boards to have in place Health, Social Care and Well-Being Strategies – which in particular require NHS bodies to work in partnership with local authorities to provide information and ‘signposting’ for carers.

In both England and Wales, however there are a number of additional provisions of benefit to carers:

The duty to cooperate

The NHS and a Local Authority are required to work together cooperatively in a number of ways. In particular, if a Local Authority asks an NHS authority (defined in legislation) to help plan for

services for carers and the person they care for or provide services, the NHS authority must give due consideration to the request.

Leaving hospital

The NHS owes a duty of care to your child when they are in hospital. When they are about to leave, your Local Authority shares this duty, which also covers you as their carer. You should be given sufficient information about the discharge process, and be involved throughout, including being part of the decision making process surrounding your child’s discharge. No assumptions should be made about your desire or ability to continue to provide the care you were providing (if any) before your child went into hospital.

The NHS and your Local Authority should work together with you to ensure the discharge is safe and that there is no delay in putting in place all the community care support that your child and your family needs.

More information about discharge arrangements for your child (and NHS Continuing Health Care) can be found in the Cerebra Disabled Children Parents’ Guide: Social Care, Housing and Health (see Resources section on pages 17-20).

NHS Continuing Health Care

Your child’s needs may be so significant that the NHS is primarily responsible for ensuring they are met, rather than your Local Authority. Such needs are referred to as ‘continuing health needs’ and

they may have arisen as a result of a congenital condition or a long-term deteriorating condition, for example.

The continuing health care process is led by a health care professional rather than a social worker and consists of three phases: assessment, decision making and implementation of provision. As well as an assessment of your child's needs, your needs will be considered in a carer's assessment. If it is decided that your child does have continuing care needs, a care package (which is likely to involve a number of different agencies including the Local Authority and education) will be determined.

Q18. What if I have a complaint against an NHS body?

The starting point is usually to make a complaint through the NHS complaints procedure. The complaint should be made within one year of the incident giving rise to the complaint (or when you first became aware of it). If the complaint is about your child's treatment, in England your child can make the complaint or you can make it on their behalf (unless the NHS body does not think there are reasonable grounds for you representing your child); in Wales, either you or your child can make the complaint (see the Resources section pages 17-20 for more information).

It may be that legal proceedings, such as a judicial review (in connection with whether a decision or action by the NHS body is lawful or about its failure to act) can be taken. There are, however, strict time limits for such action and so it is essential to seek legal advice as a matter of urgency, if you are considering taking legal action.

It may be that a complaint to the Parliamentary and Health Services Ombudsman (England) or the Public Services Ombudsman for Wales is appropriate, if you are alleging 'maladministration' (for example about how a service is delivered). Usually you will be expected to have exhausted the NHS complaints procedure first. Further details can be found on the Ombudsmen's websites (see Resources section pages 17-20).

If you and your child disagree about the support your child needs

Q19. My child does not want to access help from social services but I think we need to – what can I do?

The question of who can make a decision in such a situation will depend on your child's age and ability to make decisions for him / herself.

Both you and your child should be given sufficient, accurate and accessible information in good time to enable you to make informed choices about the care and services you want from your

Local Authority.

As a parent with **parental responsibility** you should generally be involved in decisions about your child's care. There is a legal presumption in relation to children under the age of 16 that they are not able to make decisions for themselves; nevertheless they should be involved in the decision making process from a young age wherever possible. However, some children can demonstrate that they have sufficient understanding to make decisions for themselves before they reach the age of 16 in which case they will generally be able to make decisions about their care.

As a rule of thumb, as your child grows older, they will usually be more capable of making decisions about their care and support for themselves. From the age of 16 there is a legal presumption that your child can make decisions for him / herself unless this is shown not to be the case.

If your child is under 18 and a **child in need** under the Children Act 1989 the Local Authority is under a duty to assess your child whether or not s/he wants the assessment, although your child can refuse to take part. Your family needs would be assessed as part of this assessment (see question 6 above). You can ask for a separate carer's assessment provided the conditions as set out in question 8 above are met.

The law relating to children's care and treatment will be explained in more detail in Cerebra's Parents' Guide: decision-making in health and social care, sharing information and confidentiality, which is due to be published in the Spring of 2013.

Employment

Q20. I am finding it difficult to manage my caring responsibilities alongside my work. Do I have any rights as an employee?

There are various statutory rights concerning absence from work (in addition to your contractual rights such as those concerning annual leave and sick leave) that may help you. Not all of these statutory rights will apply to you if you are self-employed, employed under a short term contract, or employed through an agency.

Q21. Can you explain more about these statutory rights?

The main statutory rights for carers concerning absence from work are:

Dependant leave / time off for emergencies

The Employment Rights Act 1996 gives all employees (not just carers) the right to take time off work in order to manage an emergency involving a dependant. In this context a dependant includes

your child or someone living with you as one of the family.

The Act sets out the situations when leave might be taken which include:

- A dependant falling ill
- An unexpected disruption to or ending of care arrangements
- Your child being involved in an incident which occurs unexpectedly during the school day

In order to benefit from this right, you must tell your employer as soon as possible about the reason for your absence. Your employer has a discretion as to whether or not to regard this absence as unpaid leave.

Parental Leave

Parents (including adoptive parents and people with parental responsibility for a child) who have worked for their employer continuously for at least a year can take up to:

- 18 weeks unpaid leave to look after a child under 5; this leave must be taken before the child's 5th birthday (or, if the child is adopted, within 5 years from the date of placement or before their 18th birthday whichever comes first);
- 18 weeks unpaid leave to look after a child who is under 18 on Disability Living Allowance; this leave must be taken before the child's 18th birthday.

The Government has announced it will introduce a new system of flexible parental leave in 2015. Further details are available from the GOV.UK website (see Resources section pages 17-20).

You will need to give your employer 21 days' notice of your wish to take parental leave. In certain circumstances, an employer can postpone the leave but it must then be allowed within six months of your original request.

Parental leave is normally given in blocks of a week, up to 4 weeks a year. It can however be given in blocks of a day if the purpose is to care for a disabled child and again this is up to four weeks a year.

Flexible working

As a carer, under the Work and Families Act 2006, if you have 26 weeks of continuous employment you can ask your employer for a change in your working arrangements in order to manage your

caring responsibilities more easily.

Examples of flexible working include part-time working, term-time working, job-sharing, working from home and compressed hours (where for example your 4 day working week is compressed into a 3 day working week).

You can make 1 application per year which must be in writing. There are detailed requirements about what you need to cover in this application. The ACAS website (see Resources section pages 17-20) provides more information about this.

Your employer must consider your request seriously and cannot refuse unless one of several business reasons for doing so applies.

The Government intends to extend the right to ask for flexible working to all employees in 2014, not just those with caring responsibilities.

Q22. In my role as a carer, do I have any protection from discrimination at work under the Equality Act 2010?

Yes. You are protected from direct discrimination against you at work (for example, not being promoted because of your caring role may amount to direct discrimination by association) or harassment (for example, offensive jokes are made about your child's disability) because of your association with your disabled child. Victimisation is also unlawful. The Equality Act 2010 definition of a disabled person is different to the Children Act definition (see Glossary on page 16). Your child will have a disability for the purposes of the Equality Act 2010 if s/he has a physical or mental impairment which has a substantial, long-term adverse effect on his /her ability to carry out normal day to day activities.

You are also protected from direct discrimination and harassment because of your association with your disabled child and from victimisation in contexts other than work, such as when accessing or seeking to access goods, facilities and services, including social care or healthcare services.

For more information see the guidance available on the Equalities and Human Rights Commission's website (see Resources section pages 17-20).

Glossary

Child in need: under the Children Act 1989 (Section 17(10)), a child is in need for the purposes of the CA 1989 if:

- s/he is 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 for him or her by a Local Authority; or
- his/her health or development is likely to be significantly impaired or further impaired without the provision for him or her of such services; or
- if s/he is disabled (see below for definition of a disabled child under the CA 1989)

Disabled child under the Children Act 1989: ‘...a child who is ‘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 that may be prescribed’ (Section 17(10) Children Act 1989).

Key legislation affecting carers:

- **The Carers (Recognition and Services Act) 1995:** introduced the concept of a carer’s assessment and contains the main statutory responsibilities towards carers;
- **The Carers and Disabled Children Act 2000:** extended the rights of carers, in particular the right to support services for them;
- **The Carers (Equal Opportunities Act) 2004:** developed the obligations surrounding assessments by introducing the duty to inform carers of their right to an assessment and requiring carers’ assessments to consider a carer’s desire to work or undertake education, training or leisure activities. It also imposes a duty on different relevant authorities to cooperate by giving due consideration to a local authority’s request for assistance in planning services for a carer or a person they look after or to provide a service.

Local authority children’s social care services department: this term is used in this guide to describe the department of the local authority that is responsible for the provision of services to children in need (including disabled children). In England, the authorities divide the responsibility for the provision of social care to disabled children between a children’s services directorate and an adult social services department. In Wales, adult and children’s services fall within the responsibility of the social services department.

Parental responsibility: this is a term defined in section 3 of the Children Act 1989 as ‘the rights, duties, powers, responsibilities and authority which by law a parent has in relation to a child and his property’. It will be important for professionals to work out who has parental responsibility for a child particularly when that child is unable to make decisions for him or herself, as in that situation a person with parental responsibility may be able to make the decision on the child’s

behalf.

Resources

Useful organisations:

ACAS (Advisory, Conciliation and Advice Service) – provides advice and guidance for workers and employers and promotes best practice in the workplace:

<http://www.acas.org.uk/index.aspx?articleid=1461>

Carers Direct – provides information advice and support for carers:

<http://www.nhs.uk/CarersDirect/Pages/CarersDirectHome.aspx>

Carers Trust – national charity formed by the merger of The Princess Royal Trust for Carers and Crossroads Care in April 2012. It seeks to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems: www.carers.org

Carers UK – is a charity set up to help people who care for family or friends. Its work includes providing information and advice about caring: www.carersuk.org

Citizens Advice Bureau – a source of advice and support if you want to complain about the NHS, social services or Local Authorities: www.citizensadvice.org.uk

Contact a Family - provides support, information and advice to families of disabled children:

www.cafamily.org.uk

Equality and Human Rights Commission (EHRC) – its role is to promote and monitor human rights; and to protect, enforce and promote equality across the nine 'protected characteristics' under the Equality Act 2010 – age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation:

www.equalityhumanrights.com

GOV.UK – the official UK government website for citizens: <https://www.gov.uk/>

Independent Complaints Advocacy Service (ICAS) – is a national service that supports people who wish to make a complaint about their NHS care or treatment. Contact details are available at www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx

Local Government Ombudsman (England) – looks at complaints about councils (Local Authorities) and some other authorities and organisations. It is a free service: www.lgo.org.uk

Parliamentary and Health Services Ombudsman – considers complaints that government departments, a range of other public bodies in the UK and the NHS in England, have not acted properly or fairly or have provided a poor service: www.ombudsman.org.uk

Patient advice and Liaison Service (PALS) – officers from PALS are available in all hospitals in England. They offer confidential advice, support and information on health-related matters to patients, their families and carers: <http://www.pals.nhs.uk/>

Public Law Project (PLP) – is an independent, national legal charity which aims to improve access to public law remedies for those whose access is restricted by poverty, discrimination or other similar barriers. Its website includes a guide to making a complaint: <http://www.publiclawproject.org.uk/>

Public Services Ombudsman for Wales – has legal powers to look into complaints about public services in Wales: www.ombudsman-wales.org.uk

Further information and guidance

Assessments

Framework for the Assessment of Children in Need and their Families (Department of Health), April 2000:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4014430.pdf

Framework for the Assessment of Children in Need and their Families National Assembly for Wales Home Office London The Stationery Office 2001:

<http://wales.gov.uk/docs/caecd/publications/110323frameworken.pdf>

Carers

Carers and Their Rights The Law Relating to Carers Fifth Edition 2012 (Luke Clements) – available from Carers UK for £15:

<http://www.carersuk.org/professionals/order-publications/item/981-carers-and-their-rights-the-law-relating-to-carers-5th-edition-uk7508>

Complaints

Guidance on social services complaints procedures for adults in Wales:

<http://wales.gov.uk/docs/dhss/publications/110510adultcomplaintsen.pdf>

Guidance on social services complaints procedures for children and young people in Wales:
<http://wales.gov.uk/docs/dhss/publications/110426childcomplaintsen.pdf>

Please note: the Welsh Assembly is currently (2012 and ongoing) reviewing the social services complaints system in Wales.

Information on making a complaint against an NHS service:
<http://www.nhs.uk/chq/pages/1084.aspx?categoryid=68&subcategoryid=162>

Guidance on taking a discrimination claim to the Employment Tribunal:
<http://www.equalityhumanrights.com/advice-and-guidance/guidance-for-workers/what-to-do-if-you-believe-youve-been-discriminated-against/>

Continuing Care

National Framework for Children and Young People's Continuing Care (Department of Health, 25 March 2010):
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_116469.pdf

Key Guidance issued in relation to the Carers (Recognition and Services) Act 1995

Practice guidance and Policy guidance (England) both available at:
<http://carersworldradio.ihoststudio.com/resdocs.html>

(This guidance was issued in Wales with the reference WOC 16/96 and WHC (96) 21).

Key Guidance issued in relation to The Carers and Disabled Children Act 2000

Carers and Disabled Children Act 2000: Carers and people with parental responsibility for disabled children: Practice Guidance (England) available at:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005560

Similar guidance was issued in Wales called Guidance 2000 Act.

Guidance on Carers assessments (England) available at:
<http://www.devon.gov.uk/practitionersguide-2.pdf>

Guidance on Carers assessments (Wales) available at:

<http://wales.gov.uk/dhss/publications/socialcare/carers/practitionersguidetocarersa1.pdf?lang=en>

Key Guidance issued in relation to The Carers (Equal Opportunities) Act 2004

Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004 Combined Policy Guidance (England) available at:

<http://carersworldradio.ihoststudio.com/resdocs/combined.pdf>

Social Care Institute for Excellence Practice guide on Implementing The Carers (Equal Opportunities) Act 2004 (England) available at:

<http://www.scie.org.uk/publications/guides/guide09/files/guide09.pdf>

Social Care, Housing and Health

Cerebra's Disabled Children Parents' Guide: Social Care, Housing and Health, available at:

<http://www.cerebra.org.uk/English/getinformation/disabilityrightslegalissues/Documents/Disabled%20Children%20Parents%E2%80%99%20Guide%20Social%20Care,%20Housing%20and.pdf>

Information about the Project Team

Jo Honigmann is a partner of Just Equality and specialises in discrimination, disability and education law and policy. Having practised as a solicitor for several years, both in private practice and the not for profit sector, Jo has been working as a legal and policy consultant since 2008. Projects have included drafting Equality Act 2010 education guidance as part of a small consortium for the Equality and Human Rights Commission and training for the NHS. During her career, Jo has also been responsible for a university's policy and provision for its disabled students. She has written, trained and presented on education and discrimination law and policy to a wide range of specialist audiences. Jo chaired the Law Society's Mental Health and Disability Committee from September 2008 to September 2010 and has been a member of the Committee since 2003. She has an MSc in Disability Management in Work and Rehabilitation.

Luke Clements is a professor at Cardiff Law School and a solicitor. He is a leading expert on community care law. He has drafted and assisted in the parliamentary passage of a number of Private Members bills. He has provided training for many Local Authorities, national organisations and charitable bodies. His books include: *Community Care and the Law* (Legal Action Group 5th ed 2011 - jointly written with Pauline Thompson), *Disabled Children: a legal handbook* (Legal Action Group 2010 - jointly written with Stephen Broach and Janet Read) and *Carers and their Rights* (Carers UK 4th ed 2010).

Camilla Parker is a partner of Just Equality. Just Equality provides training and consultancy services on human rights and equality, and other areas of law and policy relevant to education, health and social care. Camilla specialises in mental health, disability and human rights law and policy and has written, presented and trained extensively on issues relevant to these areas, for specialist and non-specialist audiences, both nationally and internationally. She is a member of the Law Society's Mental Health and Disability Committee and an LLM tutor at Cardiff Law School. She was a member of an NHS Trust Board (non-executive Director, then Special Adviser) 2000-2006 and a Mental Health Act Commissioner 1995-2000. Camilla has a particular interest in the human rights of young people in need of mental health care, which is the subject of her (part-time) doctoral research at Cardiff Law School.

All three authored *Transitions in Mental Health Care: A guide for health and social care professionals on the legal framework for the care, treatment and support of young people with emotional and psychological problems during their transition years*, YoungMinds (in association with National Mental Health Development Unit and National CAMHS support service).





The Cerebra In-house Research Team carries out desk-based research into a number of areas, based upon parent and professional requests, new scientific evidence and issues raised by our staff. We aim to provide information that is relevant to parents and carers of children with disabilities as well as the professionals who come into contact with them. By empowering parents and professionals with knowledge, we can help them to improve the lives of the children they care for and support.

If you require further information or would like to suggest avenues for further research, please get in touch.

These reports are made possible only by the kindness and generosity of Cerebra's supporters. Cerebra is a charity that works for a future where children living with neurological conditions enjoy lives filled with learning, opportunities and joy. We fund vital research that aims to improve children's lives and those of their families. We directly support more than 10,000 affected children and families around the UK.

With your help we can reach out to so many more. To find out how, visit www.cerebra.org.uk or call 01267 244 221.

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The findings of this report are those of the author, not necessarily those of Cerebra.