



Cerebra

Positively Different

Disabled Children Parents' Guide: Social Care, Housing and Health.

Introduction

This guide has been prepared for parents of disabled children who want to know how to get help for their child's social care, housing and health needs.

This guide is the second of a series of guides to be published by Cerebra that aim to give parents of disabled children (whether or not they have special educational needs) information on how to get the help and support they need. It gives information on the responsibilities of NHS bodies and Local Authorities for providing health and social care as well as accommodation for disabled children and their families. Other topics covered in this series are as follows:

- Education
- Employment
- Money Matters

The Education Guide is available on Cerebra's website (see the Resources section on page 44). The guides on Employment and Money Matters are due to be published later in 2012.

The importance of disabled children getting the support that they need

Disabled children are first and foremost children. They have the same rights and basic needs as all children. However, they may need additional support, such as social care, health care and accommodation services, to enable them to exercise their rights and achieve their goals in life. Such services and support should be based on the needs of disabled children and their families rather than the convenience of the organisations responsible for providing these services.

The guide focuses on the social care, health and housing needs of disabled children under the age of 18. However, the Resources section (pages 41-46) provides sources of information for parents of young people who are reaching

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the age of 18 and therefore about to move from children's services to services that support adults (this is commonly referred to as 'Transition'). This guide covers the following areas:

- Overview of responsibilities
- Decision-making, sharing information and confidentiality
- Social care: Local Authorities' duties
- Accommodation – housing services: Local Authorities' duties
- Health: NHS duties to provide health care
- The Equality Act 2010 and social care, housing and health services
- Complaints: Summary of Potential Remedies.

The guide provides information on these areas through a series of questions and answers. It also includes a Glossary (see page 36) which provides an explanation of commonly used terms – these are highlighted in bold in the text.

The guide is no substitute for specialist advice – the Resources section (see pages 41-46) provides information on where to obtain further help and assistance and gives details of useful guidance.

Overview of responsibilities

Q.1. When might my child have a right to additional support?

If your child has a disability and/or has complex health care needs then **NHS bodies**, for example your child's GP, and your **Local Authority children's social care services** (referred to in this guide as 'the Local Authority') must assess your child's needs and identify what services and support are required to meet these needs. If you are concerned that your child needs support with learning at school, the Cerebra Parents' Guide on Education explains how you can seek help for your child (see Resources section at page 44).

Q.2. What are the responsibilities of the NHS and Local Authorities?

The laws setting out the responsibilities of the NHS bodies and Local Authorities are complex and can be confusing. In some cases you may need to obtain specialist advice. Details of organisations that work in this area and can offer more detailed information and advice are set out in the Resources section (see page 41). However, you might find it helpful to keep in mind the following points:

- You have a right to ask for assessments of your child's needs to be carried out, be involved in the assessment process and be informed of the decision on what, if any, services and support are to be provided.

- NHS bodies and Local Authorities are public bodies – they must:
 - act reasonably – this means (amongst other things) that they must act fairly; must give logical reasons for their decisions; must not cause unnecessary delay and must honour their promises;
 - comply with the law, including the **Human Rights Act 1998** and the Equality Act 2010 (see Q.43 – Q.49). This means that individuals working for them must be able to show that they have lawful and sound reasons for the decisions that they take. These reasons should be recorded in writing.
- Subject to issues of confidentiality (see Q.8 below) you and your child should be given records of assessments, plans or reports concerning your child and these should be explained to you and, so far as possible, with your child.
- If you are told that you and your child cannot be helped, or not in the way in which you think is best for your child, ask for this decision to be confirmed in writing with the reasons why you cannot be helped in the way you have suggested. (See Complaints: Summary of Potential Remedies on page 33 for information on what action you can take if you are not happy with the decision.)

Q.3. What is the Children's National Service Framework?

The National Service Framework for Children, Young People and Maternity Services ('the Children's NSF for England') was published by the Department of Health in 2004. A similar NSF was issued in Wales (with the same name) in 2005 (referred to in this guide as 'the Children's NSF for Wales').

The Children's NSF for England sets out 11 standards 'for promoting the health and well-being of children and young people; and for providing high quality services that meet their needs'. Standard 8 concerns 'Disabled Children and young people and those with complex needs'. It states:

'Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to lead ordinary lives.'

Other standards that are likely to be relevant to you and your disabled child are Standard 6 (concerning children and young people who are ill), Standard 7 (concerning children and young people in hospital) and Standard 9 (concerning children and young people with mental health needs). (See the Resources section on page 41 for further information). Chapter 5 of the Children's NSF for Wales concerns disabled children and young people.

Although these standards provide only markers of good practice, they are useful reference points

to establish what is expected of NHS bodies and Local Authorities as a matter of best practice. Since they have been issued by the Department of Health / Welsh Government they must be taken into account by NHS bodies and Local Authorities when making decisions and/or developing policies and are cited by the Ombudsmen (see Q.52 below) as benchmarks when seeking to determine whether the actions of a public body have fallen below an acceptable standard. This guide therefore includes references to both the Children's NSF for England and the Children's NSF Wales where this is relevant.

Q.4. What can I do to prepare for my discussions concerning my child's needs?

Remember that you bring an expertise that professionals working with your child do not have. You know your child very well and you know how your child's disability and/or health care condition affects both your child and other members of your family. You should be involved in assessments of your child's health, social care and accommodation needs and related meetings, such as reviews of your child's care plan. You may also receive a parent/carer's assessment.

In order to prepare for such meetings and assessments you might find it helpful to:

- Make a note of the discussions that you have with practitioners about your child's health and wellbeing, for example confirmation of your child's diagnosis.
- Keep all relevant papers together in one place (this might include for example, letters you receive from health, social care and other practitioners, copies of your letters to such professionals concerning your child's and notes of your discussions with them).
- Prior to an important meeting or assessment of you or your child, make a note of the points that you want to discuss. These might include:
 - your child's needs and aspirations (what your child is able to do, what s/he is not able to do and what might help to enable your child achieve his or her aspirations);
 - your caring role and its impact on you and your family (how much care you provide and how often; whether this is impacting on your health, ability to work, see friends, spend time with other members of your family; whether you have any financial concerns);
 - how other members of the family are affected by your child's disability;
 - what you want to happen as a result of the meeting, including the timescale and who is to do what; and clarifying whether past undertakings have been completed, and if not why not, and when these will be completed.

Q.5. What should I do during and after the meeting?

During the meeting, try to keep a note of all key statements and promises – especially who has agreed to do what and when – and any outstanding questions. Then email or post a letter to the person in charge of the assessment, confirming these points and raising any questions that are of concern to you.

Decision-making, sharing information and confidentiality

Q.6. Will my child and I be involved in decisions about my child's care and support?

Your views and those of your child are central to the decisions that are made about your child's care and support. Standard 8 of the Children's NSF for England states that parents and their disabled children should be given timely, appropriate, accessible and accurate information to enable them to 'make choices about the treatment, care and services they wish to use'. In addition Local Authorities and **NHS bodies** should ensure that:

- Disabled children and young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support, and in shaping services. (Standard 8).
- Facilities, equipment, and skilled workers are available to enable children who do not use speech, children who find engagement and interaction difficult, and very young children to participate in assessment and decision-making processes. (Standard 8).

Similar advice is provided in the equivalent Children's NSF for Wales (at Chapter 5).

Even with young children, health and social care practitioners should seek to encourage the child to take part in the decisions about their care and support.

Q.7. Who makes decisions about my child's care?

This will depend on the age of your child and your child's ability to make decisions for him or herself.

As a parent with '**parental responsibility**' you should be involved in decision making in relation to the care and support of your child (although in exceptional circumstances this may be limited – see Q.8 below).

The extent of your involvement may lessen as your child gets older. This is because as children develop and mature they will generally become more able to make decisions about their care and support for themselves. Practitioners providing care and support to your child will need to be aware that:

- The Mental Capacity Act 2005 applies to young people aged 16 and over. This means that the health, social care and other practitioners providing care and support to your child

will work on the basis that from the age of 16, your child is able to make decisions for him/herself, unless this is shown not to be the case. If there are concerns that your child lacks capacity to make certain decisions for him or herself, an assessment of their capacity should be undertaken in accordance with the Mental Capacity Act 2005 and the Code of Practice that accompanies this Act.

- If your child is found to lack the capacity to make certain decisions for him or herself, the law (which includes the Mental Capacity Act 2005 if the child is 16 or over) allows 'acts in connection' with your child's care and treatment to be taken if they are in your child's 'best interests'. In such circumstances you should be consulted on what is in your child's best interests.
- Before children reach the age of 16, the law assumes that they are not able to make decisions for themselves. However, if it is thought that a child has attained sufficient understanding and intelligence to understand the particular decision being considered, for example the provision of medication for an illness, then the child will be able to decide on whether to consent to the proposed treatment or not. (In such cases the child is referred to as being 'Gillick competent'.)
- Where your child is not able to make such decisions for him or herself as a person with parental responsibility, you may be asked to make decisions on your child's behalf.

The law relating to the children's care and treatment will be explained in more detail in Cerebra's guide for parents on decision-making in health and social care, sharing information and confidentiality which is due to be published by the end of 2012.

Q.8. When might I not be given information, or involved in decisions, about my child?

As your child develops and matures you may find that s/he may want to discuss personal matters with health care and other professionals without you being present. If your child is considered to be able to make this decision (see Q.7 above) then your child's views should be respected. This is because the right to confidentiality applies to individuals of all ages.

This means that if a child or young person is able to make decisions about the use and disclosure about the information that they have given in confidence, their views on who should, or should not, be given such information should be respected in the same way as an adult's request for confidentiality. Information may only be disclosed without your child's consent in limited circumstances such as to prevent serious harm to your child. However it is important to note that even if your child has the necessary decision making capacity:

- If your child is happy for you to continue to be involved, then this should also be respected.

- Even if your child does not want you to be given personal information, this does not prevent you from giving information to those providing care and support to your child. This is particularly important if you are continuing to provide care and support to your child.
- If your child does not wish you to be involved in decisions about his/her care then every effort should be made to understand the reasons for this. In some cases it may be that your child is happy for you to be involved in some aspects of care and not others.
- If you are concerned that the lack of certain information will prevent you from providing adequate care, you should inform your child's care team and ask that the care plan be reviewed to take account of your concerns.

Social care: Local Authorities' duties

Local Authorities are responsible for providing a wide range of services for all children, such as nurseries, leisure centres and schools. They also have specific responsibilities to disabled children. This section explains the additional services (known as 'social care' services) that might be available to you and your child and the process involved in seeking such support.

Q.9. What social care services can Local Authorities provide to disabled children and their families?

Local Authorities have the power to provide a very wide range of social care services that can safeguard and promote the interests of children. Some of the more commonly provided services are listed in Box 1 below.

Box 1: Local Authority services for disabled children and their families

- Accommodation (see Q.26 – Q.29 below)
- Assistance in finding accommodation
- Day centres and other facilities
- Social work service advice and support
- Occupational, social, cultural or recreational activities
- Advice, guidance and counselling
- Home adaptations and 'additional facilities designed to secure the person's greater safety, comfort or convenience'
- Services in the home:
 - practical assistance in the home, including home help and laundry facilities
 - provision of meals, whether in the person's home or elsewhere)
 - domiciliary and care services to people living in their own homes and elsewhere
- Provision of travel and other assistance to enable the person to participate in services provided

- Providing, or helping the person to obtain, 'a telephone and any special equipment necessary to enable him to use a telephone'
- Providing, or helping the person to obtain, 'wireless, television, library or similar recreational facilities'
- Provision of lectures, games, outings or other recreational facilities outside the person's home or assistance in helping the person in taking advantage of available educational facilities
- Services to minimise the effect on disabled children of their disabilities or give such children the opportunity to lead lives which are as normal as possible (such as short-term breaks)
- Facilitating holidays
- Short term breaks ('respite care') (See Q.18, Q.27 and Q .28 below)
- Direct payments and personal budgets (see Q. 22 below).

Q.10. When might my child be provided with additional services and support?

If your child is a **disabled child** the Local Authority may be required to provide additional services and support. This is because Local Authorities have specific duties towards disabled children and children who fall within the definition of a 'child in need'. Their main duties are set out in **Children Act 1989** and the **Chronically Sick and Disabled Persons Act 1970**.

The definition of a '**child in need**' under the Children Act 1989 includes a **disabled child** if that child 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 as may be prescribed.'

This is a wide definition – particularly because it includes a 'mental disorder of any kind' (which of course would include not just a child with learning disabilities or a mental health problem but one with, for example, 'high functioning autism' or Asperger Syndrome, or Attention Deficit Hyperactive Disorder).

Despite this wide definition of 'disabled child', you may be told that the Local Authority does not consider that your child falls within it. (This might be because you are told that your child's disabilities are not considered substantial enough, or there is no diagnosis of mental disorder.) If this happens, you should ask for a written explanation for this conclusion. In any event, your child may still be a 'child in need'. This is because the definition of a child in need includes those children who, for reasons such as their physical or mental impairments, are unlikely to reach or maintain a satisfactory level of health and development, or their health and development will be significantly impaired without the provision of services.

Guidance issued by both the Department of Health and the Welsh Assembly Government in 2001 states that the critical factors to be taken into account in deciding whether a child is in need are:

- What will happen to a child's health and development without services, and
- The likely effect the services will have on the child's standard of health and development.

Accordingly, if you are told by the Local Authority that it does not consider your child to be a child in need, you should ask the Local Authority to reconsider its decision, taking into account the points raised by the Department of Health/Welsh Assembly Government.

Services and support can be provided not only to your child but also to any members of your family if that will assist your child. For example, it is recognised that providing services which meet the needs of parents is often the most effective means of promoting the welfare of children, in particular disabled children.

In order to ascertain whether to provide additional services and support to your child and your family, the Local Authority will carry out an assessment of your child's needs.

Q.11. How can I seek support to help me care for my disabled child?

You should write to your Local Authority requesting an assessment of the needs of your child and your family. Alternatively you could ask a professional involved in the care of your child, such as your child's GP, to make the request to the Local Authority on your behalf. In either case, you should explain what problems you are having and would like help with (and if possible, the kind of help you would like to have).

The letter to the Local Authority should explain that your child has a disability, giving details of what that disability is (including any diagnosis that your child has been given). If you have written confirmation of your child's diagnosis, include a copy of this with your letter. Your GP should be able to provide confirmation of your child's condition.

You should explain that you have been advised that given your child's disability s/he is a **child in need** under section 17 of the Children Act 1989 and that this means that your child has a right to an assessment of his/her needs.

The Local Authority is required to inform you whether it will carry out an assessment within one working day of receiving the request for the assessment. You should therefore include in your letter the date on which you want a response to your request, giving your contact details (address, phone number, email address etc). Put this date in your diary and be prepared to telephone the Local

Authority if you have not received a reply. The Local Authority should inform you of its decision i.e. whether it is going to carry out an assessment or not and the reason for this decision.

- If you live in England you should contact the Local Authority's Children's Services Directorate.
- If you live in Wales you should contact the social services department.
- You should be able to find the contact details in your local telephone directory or on the internet (the Local Authority should have the contact details on its website).

Q.12. Does the Local Authority have to carry out an assessment of my child's needs?

If your child has a disability then the Local Authority must carry out an assessment to identify the needs of your child and your family. This is why it is important to make clear in your letter requesting an assessment why you consider that your child is a child in need. (If the Local Authority refuses to do so or fails to let you know when it intends to do so, you may wish to make a complaint – see page 33.)

Q.13. What is the assessment for?

The purpose of the assessment is to find out what needs your child and your family have and what, if any, services and support should be provided to meet those needs and who could best provide that help. The decision on what services are to be provided will depend on whether the Local Authority considers that your child's needs meet the '**eligibility criteria**'. This is explained in Q.17 below.

Although in most cases the Local Authority will be responsible for co-ordinating the assessment, it is likely that other agencies will be involved, such as health and education.

An assessment is part of a process that consists of three phases:

- (1) The gathering of relevant information (which will of course include talking to you and your child and all the other key persons in your child's life);
- (2) The considering of the information and documents gathered in the first phase and then deciding which of your child's needs and your family's needs are so significant that they require additional social care support services to be provided; and
- (3) Ensuring that this support is in place – either by making a direct payment to cover these costs (see Q.22 below) or by way of a detailed 'care plan' which explains how these support services will be arranged: in essence a specification of how the necessary services and equipment will be put in place (what the courts have referred to as the 'how, who, what and when').

The assessment may involve a number of assessments from different agencies (such as health and education). However the assessment should be as unintrusive to the child and family as possible.

The assessment will look at a wide range of issues falling within three broad areas:

- Your child's developmental needs: such as health, education, emotional and behavioural development, family and social relationships and self-care skills
- The care that you provide as a parent (referred to as 'parenting capacity'): such as basic care, ensuring safety and stability
- Family and environmental factors such as housing, employment and income.

The assessment will consider issues such as the impact of your child's impairment, for example whether it affects his/her growth, development and physical or mental wellbeing and what action could be taken to ensure that your child has maximum access to family, education and community life.

Q.14. Who will be involved in the assessment and how will it be carried out?

In most cases a social worker from the Local Authority will take the lead role in co-ordinating the assessment of your child's needs, although professionals from other agencies may also be involved. The social worker must of course meet with you and your child as well as other key persons (such as other members of your family) and may need to meet you a number of times.

The professionals undertaking the assessments should follow the policy and practice guidance for the assessment of children in need. This guidance is called (in both England and Wales) the Framework for the Assessment of Children in Need and their Families. (For further details see the Resources section on pages 41-46.) This guidance (referred to in this guide as 'the Assessment Framework') expects that:

- If your disabled child and any other children are old enough to take part in the assessment, the social worker will encourage and help them to do so.
- The assessment will take into consideration your ethnic and cultural background.
- If required, help will be provided in your first language.
- When other people are already helping you and your family, it is likely the social worker will talk to them too. This will be discussed with you.

A key part of the planning for this assessment will be deciding who is to be involved for example which professionals and which family members will be included. Your child's GP and a professional from your child's school may be invited to provide information and give their views on your child's needs (which may mean that they will want to talk to you and your child).

The people who will be involved in the assessment will need to be discussed and agreed with you and your child. This is so that you know what assessments are needed and why; who will be involved in these assessments; when they will be carried out; how the various assessments will be used to inform overall judgements about your child's needs; and what services are required to

meet those needs.

You should be informed about where the assessment(s) will take place (generally this should take place in your home) and how long they will take.

In addition to your child's assessment, your needs as a parent carer must also be considered (see Q.16 below). This is because recognising your needs and services to meet those needs will be central to promoting your child's welfare.

The Assessment Framework comments that:

- In many cases practical help is most effective for a family with a disabled child, for example advice about benefits or the timely provision of aids and adaptations in the home.
- The needs of disabled children and their families for specialist disability equipment and assistive technology should be included in the assessment process. (Equipment could range from a wheelchair and communication aid for the disabled child to special beds and lifting equipment to help parents or other carers.)

You may hear professionals refer to other assessment procedures, such as the **Common Assessment Framework** (CAF) and, if your child has mental health problems, the **Care Programme Approach** (CPA). However both of these should be used in conjunction with the Assessment Framework, which is the framework professionals are expected to use when assessing a child in need.

Q.15. Will my views and the views of my child be taken into account?

Your views will be of great importance and you should be encouraged to contribute to the process. If you would like a friend, advocate or relative to support you during the assessment, this should be arranged.

Your child should also be told, in a manner appropriate to his/her age and understanding, why these assessments are being carried out and be encouraged to be involved in the assessment process. Those responsible for planning the assessment should consider whether your child or other family members have any communication needs and if so, how these might be met.

Q.16. Will my needs be assessed as well?

Yes, your needs are an integral part of the assessment of your child's needs. Your child's assessment should take into account your needs and the needs of other family members (and 'significant others'). In addition, you can request an assessment of your needs as a carer under the **Carers (Recognition and Services) Act 1995**.

The Local Authority must take into account whether you work or wish to work and whether you have undertaken, or wish to undertake, any education, training or regular leisure activities (under the **Carers (Equal Opportunities) Act 2004**).

The Local Authority must take the results of your assessment into account when deciding what services, if any, to provide to your child and your family. It must also consider whether you have any needs independent of your child's needs (for example because you have a disability or illness). If so you should be informed of your right to a 'community care assessment' (an assessment carried out for people aged 18 and over to decide whether they require adult community care services).

Q.17. What will happen after the social worker has obtained all the relevant information?

Taking into account all the relevant information concerning your needs and the needs of your child and your family, the Local Authority must decide, which of the needs that have been identified require a response ie whether it is 'necessary' that support be provided to address these needs. This may be referred to as deciding whether 'an intervention is required'.

In deciding whether support is required, the Local Authority will consider its '**eligibility criteria**'. These criteria are largely concerned with the seriousness of the consequences if support is not provided. The more serious the consequences, the greater the obligation on the Local Authority to ensure that support is available.

A key question in making this decision is whether by not responding to a need that has been identified this would cause 'significant harm' to your child or your family. 'Significant harm' means harm that is more than minor or trivial.

If you do not agree with any of the findings of the assessment, you should be given an opportunity for you to record your point of view on the assessment record.

Q.18. What help and support might my child and family receive?

If the Local Authority decides that your child and your family require help and support, then it must decide what type of help and support should be given. The type of help and support offered to you and your family will depend on your assessed needs.

If such needs can be addressed by services in your home or in a community setting, then they will generally be provided under section 2 of the Chronically Sick and Disabled Persons Act 1970 and the Local Authority must provide for such needs. This includes the following services:

- Practical assistance in the family home such as home help, personal care, equipment and a

sitting service

- Community based services such as a day centre, after-school club; holiday play scheme etc.
- Travel and other assistance to help your child participate in activities such as recreation or education
- Adaptations to the home (see the section on Accommodation - Housing Services below).

If you and your family are finding it difficult to cope then the Local Authority will need to consider what support is required. This may mean that you are provided with services known as 'respite care' or 'short term breaks'. While these may be described as services to you and your family, they are in fact services for your disabled child in that these services are helping you and your family support your child and also help to address your child's need to have a family that is not pulled apart due to the pressures of caring for a disabled child.

Short term breaks include the provision of a 'sitting service' (i.e. someone to look after your child in your home), an overnight 'in home' service or your child spending time in a community-based day care facility. Such breaks could also include your child spending a short time in residential accommodation. The provision of accommodation for your child both on a temporary basis (as 'respite care' or 'short breaks'), or on a longer term basis is discussed below (see Q.26 – Q.29).

The help and support that is to be given to your child and your family must be set out in a care plan (which might also be referred to as 'a plan of action' or a 'support plan'). The contents of the care plan should be discussed and agreed with you and your child. If you are informed that no services or support will be provided to you and/or your child you may wish to make a complaint about this – see page 33.

Q.19. What should be in my child's care plan?

Your child's care plan must be based on the findings of the assessment of your child's needs and how you and your family might be helped to respond to these needs. You should be given a copy of the care plan.

The care plan must set out the services to be provided, when they are to be provided and by which person or agency and the purpose of such services and professional contact. It should include agreed objectives for your child, such as your child's health and development, and how progress is to be measured. These are necessary in order to check that your child and your family are being given the right kind of services and support.

Q.20. How often will the care plan be reviewed?

Your child's care plan should state clearly when and how it will be reviewed. This should be at least every 6 months. You and your child should be involved in the review and the professionals who have

a key role in providing the care and support to your child and family should also be involved. If you are not happy with the care plan and feel that your concerns have not been addressed then you may wish to make a complaint (see page 33).

Q.21. How long should this process take?

Although the binding guidance issued in England and Wales specifies a timescale for the assessment process, this is not always adhered to. The key issue is however 'reasonableness'. Is the time taken reasonable? If the need is urgent, then the assessment process should be done quickly. If the need is complex and non-urgent, then it may of course take longer – especially if it necessitates meetings with many professionals. However, even in such cases, a Local Authority could implement part of the care plan as a short term measure. What is reasonable will be for you to decide. If you believe that there is delay, due to the relevant persons not acting with due diligence, then you should consider making a complaint about this (see Q.50 – Q.52). The guidance issued in England and Wales specifies the following timescale:

- The Local Authority should acknowledge your request for an assessment within 1 working day.
- An initial assessment: 7 working days (in England) or 10 working days (in Wales). This is a brief assessment which includes determining whether your child is a child in need and the nature of the services required. It may include interviews with your child and family members.
- A core assessment: maximum of 35 working days. This is an in-depth assessment which addresses the central or most important aspects of the needs of your child and your capacity as his or her parents or caregivers to respond appropriately to these needs within the wider family and community context.

When the initial or core assessment has been completed you and your child (if appropriate), should be informed in writing, and/or in another more appropriate medium, of the decisions made. You should be offered the opportunity to record your views, any disagreements and you can ask for corrections to recorded information.

Q.22. Can we arrange the services ourselves?

If you would like to do so, you can ask that rather than arranging services for your child, the Local Authority makes a regular payment to you, so that you can purchase the services for your child. These payments are known as 'direct payments'. They can cover the cost of a wide range of services, although they cannot be used to purchase services actually provided by the Local Authority – or to purchase long periods of residential care.

Direct Payments can be paid to you on behalf of your disabled child until your child reaches the age of 18. However, young people aged 16 and over have the right to manage their own direct payments so long as they have the capacity to do so, even if they need some help. If you use direct

payments to employ someone (such as a carer or personal assistant), the amount of the payment should be sufficient to pay all additional costs – such as Employer’s NI contributions, holiday pay, employers liability insurance.

Q.23. What is a ‘personal budget’?

Personal budgets are Local Authority money apportioned to individuals to manage their care costs in line with an agreed support plan, following a full assessment and financial allocation by the Local Authority. Personal Budgets can be paid in the following ways:

- As a direct (cash) payment held by the individual (in which case, they are, at law a ‘direct payment’ – see above);
- An account held and managed by the Local Authority in line with the person’s wishes;
- An account placed with a third party and managed by the individual or by carers, friends or trustees;
- As a mixture of the above.

Not all Local Authorities have developed ‘personal budgets’ for disabled children’s services. Personal budgets are, however, merely a way that the Local Authority can meet your child and your family’s assessed needs. Your child or you and your family can still insist on the Local Authority providing services to meet these assessed needs or if your child or you and your family so choose, you can still opt for a direct payment. The amount of the payment must be sufficient to purchase the services identified as necessary as a result of the assessment.

Q.24. Will we be charged for the services that are provided?

Although Local Authorities are able to charge for services that they provide to children, in general they do not do so. Any charges that a Local Authority makes for the services that it provides will be subject to a means test of the person being charged. In the case of children under 16, this would be the parents; young people aged 16 or over would be charged for the services provided (i.e. the amount of the charge is assessed on their income alone).

Q.25. What services for children does my Local Authority provide?

Your Local Authority should be able to provide you with information about the services it provides for disabled children. (Local authorities must publish such information.)

Accommodation - Housing services: Local Authorities' duties

Having somewhere suitable to live is an important aspect of most people's lives. It is also crucial to meeting the health and developmental needs of children. This section considers the responsibilities of Local Authorities to ensure that disabled children and their families have suitable accommodation. This may require adaptations to be made to the family home, providing suitable accommodation for the family or providing residential accommodation for the disabled child. This section covers residential respite care and short breaks, accommodation under the Children Act 1989 and adaptations to the home.

Q.26. What should I do if my family needs a break from caring?

You should ask for an assessment of your child's needs (see Q.11 above) as well as a parents/carers assessment (see Q.16 above).

The need for families to have breaks from caring is now well recognised. As discussed under Q.16 above, it may be possible for short term breaks to be arranged by providing additional services in the family home, such as a sitting service for your child while you and other members of the family go out. However, in some cases it may be necessary for your child to spend a short time away from the family home. This is when short term residential accommodation should be considered. Local Authorities may provide short term breaks under the Children Act 1989.

Q.27. Is it true that I will only get help if my family is in a crisis situation?

If you and your family have reached a crisis point and the only appropriate means of supporting you is to provide accommodation for your child, then the Local Authority must do so under section 20 of the Children Act 1989. However this is not the only time that you can get help.

Guidance issued by the Department of Education in 2011 emphasizes that 'families should not have to reach crisis point before they receive a short break'. It gives examples of when short term breaks will have a positive impact, namely where a carer is:

- unable to attend regular training, education or leisure activity because of the level of care required by the child;
- unable, or limited in their ability, to provide care for other members of the family or attend to maintenance of the household because of the care needed by the child;
- struggling to find the capacity to care for the disabled child without a short break; and
- where the provision of short breaks would clearly enable a carer to provide more effective parenting and care.

(Short Breaks for Carers of Disabled Children Advice for Local Authorities, page 8).

Although this is English guidance, it describes good practice and so must be equally applicable in Wales. If your situation is similar to these examples you may wish to consider asking for a short term break. In deciding whether to provide such a service, the Local Authority will apply its **eligibility criteria** (see discussion above at Q.17). However, the Local Authority will be required to meet the needs of your child by taking some action if such intervention is 'required to secure' your child's wellbeing.

Q.28. What if my child's support needs means that I cannot provide care at home?

If you and your family are finding it difficult to cope with caring for your disabled child then you should ask for an assessment of your child's needs (see Q.11 above) as well as a parents/carers assessment (see Q.16 above). It may be that by revising your child's care plan so that you are provided with more support, including, but not necessarily limited to, short-term breaks, you and your family find that you can provide your child with the help and support that s/he needs.

The Local Authority should try to do everything possible to enable your disabled child to remain with your family and in order to do so is likely to invite other agencies, such as NHS bodies, to assist in the assessment of your child's needs.

You, together with your child and other members of your family should be involved in deciding what help and support can be provided so that your child can continue to live at home. However, it may be that your child's disability and/or health care needs are of such a high level and/or severity that it is no longer feasible for your child to be cared for in the family home.

If the Local Authority concludes that you and your family are not able to provide your child with care or accommodation then under section 20 of the Children Act 1989, it must provide your child with accommodation. It does not matter whether the situation is likely to be temporary or permanent, nor does it matter why this situation has arisen. If your child is of school age, it may be that a residential placement is appropriate (further information on this issue may be available from organisations specialising in education advice and information – see Resources section at pages 41-46 below).

Q.29. Will I and my child be consulted about a placement away from home?

The Local Authority will not be able to place your child away from home if you or anyone else with **parental responsibility** objects to this. (If they wanted to take such action without your agreement they would need to start care proceedings.) In addition, before providing the placement, the Local Authority will need to take steps to ascertain the wishes and feelings of your child and take these into account.

If your child has complex health care needs, the NHS may take a lead in providing care and support. (See the Health section below, in particular Q.39.)

Q.30. I have been told that my child is a 'looked after child' – what does this mean?

The definition of a 'looked after child' includes children who are subject to a care order under section 31 of the Children Act 1989. It also includes some children and young people under the age of 18 who have been accommodated under section 20 of the Children Act 1989, including those who are accommodated away from home, for a short period as part of the Local Authorities short break services (see Q.26 above).

Local Authorities are required to provide a range of support to young people that are, or have been, 'looked after children' as they make their transition to the responsibilities of adulthood.

If your child is receiving short term break services under section 17 of the Children Act 1989 s/he will not be a 'looked after child'. However if the short term breaks are being provided under section 20 of the Children Act 1989, s/he may fall within the definition of a 'looked after child'. It is therefore important to clarify whether the accommodation provided to your child is under section 17 or section 20 of the Children Act 1989. In summary:

- If your child is being provided with accommodation under section 20 of the Children Act 1989 s/he will be a looked after child if the placements lasts for a continuous period of more than 24 hours.
- If your child is being provided with short break accommodation for 24 hours or less, then s/he is not a looked after child even if the accommodation is being provided under section 20 of the Children Act 1989.
- If your child is provided with accommodation under section 17 of the Children Act 1989 your child will not be a looked after child.

The Resources section on page 43 provides sources of further information on the range of 'leaving care' support that Local Authorities must provide to young people.

Q.31. How can we get help to carry out necessary adaptations to our home?

You may be able to get assistance from the Local Authority (responsible for children's social care services), the housing department of the Local Authority or, in some cases, the NHS. This is because:

- Your child may have a right to a Disabled Facilities Grant (DFG). DFGs are grants paid by housing authorities towards the cost of building works which are necessary in order to meet the needs of a disabled occupant. The maximum mandatory grant (see below) is currently £30,000 in England and £36,000 in Wales, although Local Authorities are empowered to make higher awards.
- Your Local Authority may also have a duty to provide adaptations to your child's home under **section 2 of the Chronically Sick and Disabled Person's Act 1970**. Where a need for adaptations has been identified, children's social care services should refer this to the housing

authority who will then consider whether a DFG should be made. However, if the housing authority refuses or is unable to approve the grant (for example because the works in question do not come under the mandatory scheme) this does not necessarily absolve the children's social care services of its duty to meet an assessed need under **section 2 of the Chronically Sick and Disabled Person's Act 1970**. (The Local Ombudsman (see Complaints: Summary of Potential Remedies on page 33) has found that it is maladministration for a Local Authority to fail to appreciate that it has a duty under the 1970 Act to provide adaptations.)

- **NHS bodies** have extensive statutory powers to transfer monies to social services and government guidance (England 2006 and Wales 2002 - see the Resources section at page 42) advises that these can be used to facilitate housing adaptation, particularly if in so doing it 'releases beds by expediting discharge'. The NHS has the power to fund or jointly fund adaptations where the need is health related – for example an immobile patient who requires a ceiling track rail in his/her home before being discharged from hospital.

To start this process you should request an assessment of your child's needs and in this letter state that your home is no longer suitable for your disabled child and your family unless adaptations are carried out, explaining why this is necessary. This should initiate an assessment of your child's needs by the Local Authority children's social services. If they consider that a DFG is needed, then they must make a referral to the local housing authority.

The housing authority is responsible for assisting you with the completion of the DFG forms and for arranging the necessary evaluations (which will often require a report from an occupational therapist). Unreasonable delay can occur in this process and if you feel that this is happening (for example because the relevant persons are not acting with due diligence) then you should consider making a complaint about this. If your child has complex health needs and the adaptations relate to the provision of health care, the housing authority can request the assistance of the NHS.

In England, the government is considering reform in this area, namely whether to enable people entitled to a DFG to receive this as a direct payment and also to choose the contractor to undertake the works.

Q.32. How will the housing authority decide whether we are eligible for a DFG?

The housing authority is responsible for the administration of the DFG through all stages from initial enquiry to post-completion approval. It must decide whether it is reasonable and practicable to carry out the proposed adaptation works. In making its assessment, the housing authority must have regard to the age and condition of the dwelling or building. It must also decide whether the proposed works are necessary and appropriate to meet the needs of the disabled occupant. In determining what 'meets' the assessed needs of your disabled child, the housing authority may consider any alternative way of meeting his or her needs.

DFGs will only be available to your child if s/he falls within the definition of a **disabled child** (see Q.10 above) and lives (or intends to live) in the accommodation as their only or main residence (this includes rented accommodation). It must be intended that this will be your child's only or main residence for a period of five years (although this might be a shorter period due to health or other reasons).

Although there is a means test for disabled people aged 19 or over, if the adaptations are required for someone under that age, there is no means test.

Q.33. What adaptations can be carried out using DFGs?

While housing authorities have a wide ranging power to give discretionary assistance, in any form, for adaptations or other housing purposes, their mandatory grants can only be applied for more limited purposes; the main purposes for which mandatory grants are made are to facilitate access and provision. Box 2 sets out the primary purpose of such grants.

Box 2 Mandatory grants: primary purpose

- facilitating a disabled person's access to:
 - the dwelling;
 - a room usable as the principal family room, or for sleeping in;
 - a WC, bath, shower, etc (or the provision of a room for these facilities);
- facilitating the preparation of food by the disabled person;
- improving/providing a heating system to meet the disabled person's needs;
- facilitating the disabled person's use of a source of power;
- facilitating access and movement around the home to enable the disabled person to care for someone dependent upon him or her;
- making the dwelling safe for the disabled person and others residing with him or her,
- facilitating the disabled person's access to and from a garden; or
- making access to a garden safe for the disabled person.

Q.34. What if my child needs to spend time at my ex-partner's home?

Although it may be necessary to provide for adaptations in both homes a mandatory DFG (see above) is only available at the 'main residence' of the 'disabled occupant'. However, if a community care assessment determines that adaptations are required at the other location this may trigger a duty under section 2 of the Chronically Sick and Disabled Person's Act 1970 to facilitate those adaptations.

Health: NHS duties to provide health care

All disabled children like everyone else, are entitled to general health care services from a GP, to appropriate health care when they are ill, and to opportunities to maximise their wellbeing. However some disabled children will be dependent on specialist intervention for their health, development and wellbeing. This section considers some aspects of health care that are likely to be of particular importance to you and your disabled child.

Q.35. What are the responsibilities of NHS bodies?

Unlike Local Authorities, which are subject a range of specific statutory duties to assess individuals' needs for social care and housing and determine how such needs should be met, the duties of NHS bodies in relation to health care are far less explicit. Nonetheless, NHS bodies are subject to following significant duties:

- **Ensuring a comprehensive health service:** The Secretary for State for Health / Welsh Ministers must ensure that a comprehensive health service is provided. Such services include general medical services (provided by GPs), hospital accommodation and 'services or facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness'.
- **Commissioning and providing health care:** The responsibilities for commissioning and providing NHS services have been delegated to NHS bodies. NHS Trusts and NHS Foundation Trusts have the primary responsibility for providing these services. As at May 2012, Primary Care Trusts (PCTs) have the primary responsibility for commissioning health care services in England. However, with the introduction of the Health and Social Care Act 2012, the commissioning of local health services will be taken over by 'Clinical Commissioning Groups'. These groups, known as CCGs, are due to be established across England by April 2013. In Wales, this responsibility is discharged by local health boards (LHBs).
- **Comply with general public law:** All NHS bodies must act reasonably – this means (amongst other things) that they must act fairly; must give logical reasons for their decisions; must not cause unnecessary delay and must honour their promises. They must also, of course, comply with the law, respect fundamental human rights and ensure that their decisions are reached in accordance with established public law principles. (See also Q.2 and Q.3 above.)
- **Duty to assess:** Although there is no specific duty on NHS bodies to carry out an assessment of an individual's health care needs, in many cases this will be implied because such assessment will be an essential part of a process that must be followed by NHS bodies in order to exercise their statutory duties.

- **Responding to requests from Local Authorities:** There are a range of duties on Local Authorities and NHS bodies to co-operate. For example, under section 27 of the Children Act 1989, if a Local Authority seeks the assistance of a PCT (England) or LHB (Wales) in relation to its duties to a child in need, the NHS body must comply with this request for help unless to do so would be incompatible with its own duties. A not dissimilar obligation exists in relation to the support of family carers under section 3 Carers (Equal Opportunities) Act 2004.

As noted above (see Q.3) the Children's NSF for England, published by the Department of Health in 2004, stipulates at Standard 8, that disabled children and young people who require ongoing health interventions have access to high quality, evidence-based care, delivered by staff who have the right skills for diagnosis, assessment, treatment and ongoing care and support. (See also the Children's NSF for Wales (2004), Chapter 5.) These Children's NSFs are important documents in holding the NHS to account, since they must be taken into account by NHS bodies when making decisions and developing policies and are cited by the Ombudsmen (see Q.52) as benchmarks when seeking to determine whether the actions of a public body have fallen below an acceptable standard.

Q.36. How can my GP help me get help in caring for my child?

In addition to providing medical services and arranging for the provision of services provided by the GP practice, your GP can refer your child on to more specialist health care services.

Some parents have found that after their child has received a diagnosis from health care professionals, they are left with little or no support. If you are in a similar situation you should:

- Contact your child's GP to discuss your child's diagnosis, what this means for your child's future health and development and what support you and your child might need, for example whether your child may need physiotherapy and/or speech and language therapy.
- Ask that your GP ensures that regular reviews of your child's health are arranged so that your child can be referred to specialist health professionals as and when necessary.
- Your GP can also help you in getting support from children's social care services by either supporting your request or making a referral to the Local Authority on your behalf. (See the section above on Social Care.)

Your child's GP may be asked by children's social care services to provide information to assist in the assessment of your child's needs and may also be asked to take part in the assessment process.

Chapter 5 of the Children's NSF for Wales states:

'Following diagnosis or identification of additional needs, families receive:

- Time to ask questions, and continuing opportunities to participate, in an informed manner, in decisions that affect the care of their children;
- Assessment reports which record a description of the child's additional needs or diagnosis, written in a language that is easily understood by parents;
- The opportunity for a follow-up contact 7-14 days later by an appropriately trained professional to discuss any queries;
- Contact details to enable the family to contact a professional for advice when they need it;
- Contact details for local and national support organisations, if appropriate.'

The Children's NSF for England (Standard 8 - Disabled Children and Young People and those with Complex Health Needs) states that Local Authorities, PCTs, NHS Trusts and schools ensure that:

- Children with possible impairments have prompt access to a diagnostic and assessment facility that is as close to the child's home as possible. Where appropriate, multi-agency assessments are carried out in convenient settings, such as the child's home or school; and services are co-located to aid access for families e.g. in child development centres, children's centres, extended schools, or one-stop shops;
- Diagnosis and identification of disability or complex health needs (which may not be a single consultative event) is followed quickly by a multi-agency comprehensive needs assessment which follows the Framework for the Assessment of Children in Need and their Families. (See Q.11 – Q21.)

Q.37. My child's wheelchair is too small – how do we get a replacement?

Local NHS wheelchair services in England (and in Wales, the Artificial Limb and Appliance Service) are responsible for the provision of wheelchairs. These (including replacements) are supplied after the disabled person has had a specialist assessment arranged by the relevant NHS service.

Not infrequently there is an inappropriate delay in the provision of suitable wheelchairs and that this can cause considerable hardship: leading to isolation and sometimes pain (for example severe postural pain). It has been suggested that this is not merely unlawful (in terms of constituting unreasonable behaviour by a public body) but also a violation of the disabled person's human rights (under article 8 European Convention on Human Rights – inhibiting the child's interaction with other people and the environment, and article 3 – causing such severe pain as to amount to degrading treatment).

Where delay in providing or replacing a wheelchair arises, then it may be appropriate to make a formal complaint (see Q.50 – Q.52 below). Many families also seek help from the charities in such cases – including the charities Cerebra (www.cerebra.org.uk) and Whizz-Kidz (www.whizz-kidz.org.uk).

Q.38. My child is about to leave hospital – how can I get help to care for my child?

When a child is discharged from hospital there is a public law duty on the NHS and social services authorities to work together to ensure that the discharge is a safe one – and most importantly, that the community support services that the child and their family will need are put in place without delay. This will require, not only that appropriate social care services are put in place (for example respite / sitting services and the like) but also that the GP surgery and the district nursing team (for example) are fully briefed and that the family know what to do (and who to contact) if they feel they need help.

Such action should therefore be taken when your child is due to leave hospital. In addition the Children's NSF for England (Standard 6) advises:

- Services ensure that when children or young people are discharged from secondary or tertiary services, as part of routine practice, a letter is sent to the general practitioner and all professionals involved with the child's care (copied to the patient or parent), and a briefing is given to the patient and their parent about likely after-effects, any follow-on treatment needed, any continuing drug therapy, and the implication for school attendance, together with a contact point in case of difficulty or confusion.
- Where appropriate, the social worker needs to be effectively involved in planning the child's discharge from hospital. Primary Care Trusts ensure that children or young people who require ongoing care have access to a children's community team regardless of condition or geographical location. This is taken into consideration when writing care plans and planning discharge from hospital. Where appropriate, there may need to be 24 hour access.
- Hospital and community services discuss recommendations for care at home before the child or young person is discharged from hospital services.

One of the key action points for LHBs, NHS Trusts and the Health Commission Wales in the Children's NSF for Wales concerns discharge from hospital (Chapter 7, 7.27). It states:

'Children with complex health needs are not discharged from hospital without a written care plan. Systems are in place between health, social services and education to ensure that equipment suitable to the child's needs, and follow-up care, is provided in a timely fashion.'

Q.39. I have been told that my child may have Continuing Health Care Needs – what does this mean?

The term 'continuing health care needs' refers to those children and young people whose health care needs are so significant that the primary obligation for meeting their health and social care

needs falls on the NHS rather than children's social services. These children and young people are eligible for NHS Continuing Healthcare Funding (sometimes referred to as 'Continuing NHS Healthcare'). Although the responsibilities of the NHS for the provision of health care do not change, guidance makes a distinction between those under 18 and those aged 18 or over, reflecting that the responsibilities of other agencies, such as social care and education may change.

In England, the Department of Health's National Framework for Children and Young People's Continuing Care (2010) provides guidance on the process for 'assessing, deciding and agreeing bespoke packages of continuing care for those children and young people under the age of 18 who have continuing care needs that cannot be met by existing universal and specialist services alone'. Such needs 'generally arise from congenital conditions, long-term deteriorating conditions, accidents or the after effects of serious illness or injury' and are likely to be 'one or more of the following: challenging behaviour, communication, mobility, nutrition, continence or elimination, skin and tissue viability, breathing, drug therapies and medicines, psychological and emotional needs, or seizures'.

To date no equivalent guidance has been issued in Wales although in December 2011 the Welsh Government issued draft guidance for consultation (closing March 2012). The draft is silent as to when implementation is proposed.

The National Framework for Children and Young People's Continuing Care explains that whereas the NHS will be responsible for providing care for adults who have been assessed to have a 'primary health need', the situation is different for children and young people:

- Given that 'childhood and youth is a period of rapidly changing physical, intellectual and emotional maturation alongside social and educational development' a wider range of agencies is likely to be involved in relation to children and young people with continuing care needs. For example, in addition to ensuring that all children of compulsory school age (5 to 16) receive suitable education, either by regular attendance at school or through other arrangements, these children and young people may also have social care needs.
- Furthermore, most care for children and young people is provided by families at home, and it will therefore be important to maintain relationships between the child or young person, their family and other carers, and professionals. Accordingly:

'Children and young people's continuing care needs are best addressed holistically by all the agencies that are involved in providing them with public services or care: predominantly health, social care and education. It is likely that a continuing care package will include a range of services commissioned by PCTs, Local Authority children's services and sometimes others.'

Q.40. My child is receiving palliative care – what help can we expect to receive?

The governments in both England and Wales have stressed the importance of the NHS providing appropriate and timely support for patients in need of palliative care – including children. If you believe that the care is not being properly delivered and/ or coordinated, then it may be appropriate to make a complaint (see Q.50- Q.52 and perhaps take this up with your MP – given that it is likely to be an issue of urgency). Relevant guidance includes:

- Guidance issued in England, Better Care, Better Lives: Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions, aims to ensure that children and young people ‘with a life-limiting or life-threatening condition will have equitable access to high-quality, family-centred, sustainable care and support, with services provided in a setting of choice, according to the child and family’s wishes.’
- Standard 8 of the NSF covers palliative care, stating ‘When services are provided, it is particularly important that these are easily accessible, timely and in the setting of the family’s choice’. It sets out a range of actions to be undertaken by Local Authorities, PCTs and NHS Trusts, including that they are to ensure that:
 - Palliative care services provide high quality, sensitive support that takes account of the physical, emotional and practical needs of the child or young person and their family, including siblings. Services are sensitive to the cultural and spiritual needs of the child, young person and family;
 - Services maximise choice, independence and creativity (access to preferred interests or activities) to promote quality of life;
 - Services are delivered where the child and family want, for example in the home, hospital, hospice or other setting;
 - Services include the prompt availability of equipment to support care, access to appropriate translation services, and workers skilled in using communication aids;
 - Palliative and terminal care services are regularly reviewed with parents or carers, children and young people, and gaps in provision identified and addressed.
 - The list of services to be provided, where appropriate, includes: - 24-hour access to expertise in paediatric and family care; 24-hour expertise in paediatric palliative care; pain and symptom control; psychological and social support; spiritual support which takes account of the needs of the whole family; where required, formal counselling or therapy; arrangements to avoid unnecessary emergency admission to hospital are in place. Such services can also include short-term breaks.

Q.41. My child has continence difficulties – what help can we expect to receive?

Continence supplies (such as pads and other equipment) are provided free of charge by the NHS in both England and in Wales. The relevant NHS guidance requires that all patients (whether living

in a care placement or at home) should have an individual assessment of their needs for such services. There must be no rigid policy about how many pads are provided – since these should be made available on the basis of clinical need alone. If there is such a policy, then a complaint may be appropriate (see Q.50 – Q.52 below).

Q.42. My child is about to be discharged from a Child and Adolescent Mental Health Services (CAMHS) in-patient unit – what should happen to ensure that we get the help and support that we need?

Guidance issued by both the governments in both England and Wales have emphasised the importance of ‘aftercare’ planning for individuals (children and adults) leaving hospital, after a period of psychiatric in-patient care. This means a care plan, which sets out how your child’s needs are to be met, should be in place before your child leaves hospital. Accordingly an assessment of your child’s needs, and a decision on how to meet these needs, should be undertaken in good time before your child’s discharge from hospital.

While the **CAMHS** team may lead on planning your child’s aftercare, the assessment should not focus only on your child’s mental health needs. Your child will be a ‘child in need’ for the purpose of the Children Act 1989 and accordingly the Local Authority should be invited to carry out an assessment of your child’s needs under the 1989 Act. As explained in the section above on social care (see Q.10 – Q.25) this assessment should consider the needs of your child and your family and you will also be entitled to an assessment of your needs (see Q.16).

You may hear some of the professionals refer to the **Care Programme Approach** (CPA). This is guidance issued by the Department of Health to provide a framework for the planning of care for people with serious mental health problems. It states that it should be used for children and young people under the age of 18 if they are discharged from in-patient services into the community. Delivering the Care Programme Approach in Wales: Interim Policy Guidance was published by the Welsh Assembly Government in July 2010 (see Resources section at pages 41-43). It applies to adults and also young people (aged 16 to 18 years) who are referred to, or receiving services from, adult secondary mental health services.

Key points common to both the Assessment Framework, which is applied in the assessment of a ‘child in need’ and the CPA, which is applied in relation to the care planning in mental health services are that: there should be an assessment of your child’s needs as well as your needs; a care plan, that sets out how these needs are to be addressed should be agreed with you and your child and there should be a regular review of this plan.

If your child is being detained in hospital under section 3 of the Mental Health Act 1983 then section 117 of the Mental Health Act 1983 applies. This requires health and social services authorities to provide ‘after care services’ (which are broad ranging and include social support,

day care arrangements and can also include accommodation) until such time as both authorities agree that such services are no longer required. These services must be free of charge.

The Resources section provides sources for further information on mental health (see pages 41-46).

The Equality Act 2010 and social care, housing and health services

The Equality Act 2010 brings together wide ranging provisions to protect certain groups of people, including disabled people, from discrimination. It also requires public bodies such as Local Authorities and NHS bodies to take action to eliminate discrimination from within their organisations (an obligation known as the 'public sector equality duty'). This section summarises how the Equality Act 2010 will be relevant to you and your disabled child when receiving (or seeking to receive) social care, accommodation or health services from Local Authorities and NHS bodies.

Q.43. What protection does the Equality Act 2010 offer my child?

The Equality Act 2010 offers protection from discrimination and harassment to people based on a 'protected characteristic'. Victimisation is also unlawful. The protected characteristics that apply (with varying degrees of protection) in relation to services provided by Local Authorities and NHS bodies are:

- Disability
- Gender reassignment
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation.

The Act also covers age discrimination. It contains a provision for a ban on age discrimination in relation to the provision of services for people aged 18 or over. This is unlikely to come into force before October 2012.

This guide focuses on the protected characteristic of disability. Your child will have a disability for the purpose of the Equality Act 2010 if they have a physical or mental impairment which has a substantial, long-term adverse effect on their ability to carry out normal day to day activities. As a disabled child, your child will receive protection when seeking to use services, using services and in certain circumstances, once they are no longer receiving the service.

The Equality and Human Rights Commission (EHRC) has issued a range of guidance on the Equality Act including the Services, public functions and associations Statutory Code of Practice ('the Services Code') - see Resources section on pages 41-46.

Q.44. What protection does the Equality Act 2010 offer for my child when receiving social care, health and housing services?

The Act makes it unlawful for service providers to discriminate against your child:

- by not providing them with a service;
 - including refusing to provide them with the service and
 - not providing them with the same level of service or in the same manner or on the same terms as they would usually give to members of the public or to a section of the public to which they belong, such as hospital outpatients.
- in relation to the terms on which they provide the service;
- by terminating the provision of the service;
- by subjecting your child to any other detriment.
 - 'Detriment' is not defined in the Act and has a broad meaning. The Services Code (paragraph 9.7) explains that while it does not need to have any physical or economic consequences, it should amount to something a service user 'might reasonably consider changed their position for the worse or put them at a disadvantage'.

In addition a service provider must not engage in discrimination, harassment or victimisation when exercising a public function. The interpretation of this is broad. The Services Code (paragraph 11.26) explains that 'refusing to allow someone to benefit from the exercise of a function, or treating someone in a worse manner in the exercise of a function' are examples of the types of discrimination that would be covered by this provision.

Q.45. What are the different forms of discrimination?

These are summarised below:

- **Direct discrimination** – treating a person less favourably because of their protected characteristic.

Example: an Accident and Emergency service refusing to treat a child who has fallen out of a tree because the child has Downs Syndrome and the service does not believe it has the necessary expertise to treat the child as a result.

Direct discrimination by association (see Q.49) and direct discrimination by perception are also unlawful.

- **Indirect discrimination** – applying a provision, practice or criteria in the same way for all people but which has the effect of putting people who share a protected characteristic at a particular disadvantage compared with people who do not have that protected characteristic, unless this can be shown that it is a ‘proportionate means of achieving a legitimate aim’.

Example (adapted from the Services Code): a GP’s surgery sets up a website to enable the public to access its services more easily. However the website has all of its text embedded within graphics. Although it did not intend to discriminate indirectly against service users with a visual impairment, this practice places those with a visual impairment at a particular disadvantage because they cannot change the font size or apply text-to-speech recognition software and cannot access the website as a result. As well as giving rise to an obligation to make a reasonable adjustment to their website, this practice will be indirect disability discrimination unless the surgery can justify it.

- **Pregnancy and maternity discrimination** – treating a girl / woman unfavourably because she is or has been pregnant, has given birth within the last 26 weeks or is breastfeeding a baby who is 26 weeks old or under.
- **Discrimination arising from disability** (for disabled people only) – treating a disabled person unfavourably for a reason relating to their disability unless it can be shown that the treatment is a ‘proportionate means of achieving a legitimate aim’.

Example: a child with ADHD is turned down for a respite break as his social services department considers his behaviour (which is an involuntary consequence of his disability) will be too disruptive for other children. It would be for the social services department to justify this treatment. If it fails to make a reasonable adjustment which could have prevented or minimised the unfavourable treatment, it will be hard for it to do so.

- **A failure to make reasonable adjustments** (for disabled people only) – see Q.46 below.

Q.46. How does the reasonable adjustments duty apply to services provided by Local Authorities and NHS bodies?

The reasonable adjustment duty is an anticipatory and continuing duty owed to disabled service users generally. This means that Local Authorities and NHS bodies need to think about and plan for the needs of their disabled service users in general and not wait until an individual disabled service user approaches them.

Both service providers and those exercising a public function are required to take reasonable steps to:

- avoid substantial disadvantage where a practice, provision or criterion puts disabled service users at a substantial disadvantage;
- avoid substantial disadvantage where a physical feature puts disabled service users at a substantial disadvantage; this covers removing the feature in question, altering it or providing a reasonable means of avoiding it;
- provide an auxiliary aid or service where a failure to do so would put a disabled service user at a substantial disadvantage.

(Note: 'Substantial' means more than minor or trivial in relation to the provision of services; there is a particular meaning given to substantial disadvantage when someone is subjected to a detriment in the exercise of a public function.)

Example: A physiotherapy service extends the usual time of their appointments to accommodate the extra time required by a girl with cerebral palsy who communicates by way of a communication aid assisted by her personal assistant. This is likely to be a reasonable adjustment to make.

If the provision, practice or criterion or the auxiliary aid or service involves the provision of information, the steps it is reasonable to take include taking steps to ensure the information is provided in an accessible format.

Q.47. Can Local Authorities or NHS bodies charge us for the cost of making a reasonable adjustment?

No – your child cannot be charged for the cost of making a reasonable adjustment.

Q.48. What is the public sector equality duty and how is it relevant to Local Authorities and NHS bodies?

The public sector equality duty (which seeks to eliminate discrimination from within a public body) has two parts: a general duty and set of specific duties. Not all public bodies are subject to both parts of the duty. NHS bodies and Local Authorities are public bodies and are subject to both the general and the specific public sector equality duties. Some individual members of staff may exercise a public function in the course of their duties and when doing so will be subject to the general public sector equality duty. The public sector equality duty covers all the protected characteristics which apply in a services context.

The general duty has three aims. It requires public bodies and people exercising a public function to have due regard to the need to:

- eliminate discrimination, harassment, victimisation and any other conduct which is prohibited by the Equality Act 2010
- advance equality of opportunity between people who share a protected characteristic and those who do not
- foster good relations between people who share a protected characteristic and those who do not.

The specific duties in England require NHS bodies and Local Authorities to publish sufficient information to demonstrate compliance with the three aims of the general equality duty no later than 31 January 2012 and publish equality objectives by 6th April 2012 and then at least every four years.

The specific duties in Wales require NHS bodies and Local Authorities to publish equality objectives and strategic equality plans by 2 April 2012 and review these objectives every four years and to have engaged with interested people as part of gathering relevant information to assess their activities against the general duty by 2 April 2012; relevant information must be published as appropriate.

Q.49. Am I protected from discrimination because of my relationship with my disabled child?

You are protected from direct discrimination if you are treated less favourably because of your association with your disabled child by, for example, your child's service provider, education provider or your employer.

Complaints: summary of potential remedies

This section provides a general overview on how you can make a complaint in relation to the services received from, or decisions made by, Local Authority children social care services, Local Authority housing departments or NHS bodies. The Resources section (pages 41-46) provides details on where to obtain further information and assistance.

Q.50. Can I make a complaint if I am not happy with aspects of my child's care and treatment?

If you are concerned about any aspect of your child's care and treatment you have the right to complain. Such concerns might relate to the manner in which services are provided, the level of services offered to your child or your family, or a decision not to provide a particular (or any) service or not to respond to a request for an assessment of your child's needs or a failure to assess your needs.

Q.51. What do I need to think about when deciding on whether, and how, to pursue a complaint?

The various complaints procedures that might be available to you are listed below (Q.52). In addition you may find it helpful to consider informal routes to raise your concerns. Often the most effective way of resolving such disputes will be through informal contacts with representatives of the relevant NHS body or Local Authority. Involving your local MP, local councillor or even the local media, may add weight to your arguments. In general it is important to make complaints without delay (and if court proceedings are contemplated, these may need to be made very quickly indeed – in which case expert advice needs to be taken urgently).

The best course of action to take is likely to depend on a range of factors, including the basis of your complaint and costs. For example, while taking legal action by way of judicial review proceedings can lead to an early resolution, it is likely to be very expensive unless legal aid is available and may not be appropriate if there are significant factual disputes.

Q.52. How can I pursue my complaint?

The following complaints mechanisms may be relevant, depending on whether your complaint concerns a Local Authority or NHS body in England or Wales:

- **Children's social services provision – England:** You (as a person with **parental responsibility**) or your child can make a complaint to your Local Authority in relation to the discharge of its duties in relation to children in need and their families. The complaint should be made as soon as possible and in any event within 1 year from the time the matter complained of arose.
- **Local Authority and NHS complaints – England:** Since 2009 there has been a joint complaints procedure for complaints about NHS bodies and Local Authorities' social services functions (for example adult social care). Complaints should be made within 1 year of the incident which gave rise to the complaint (or when you first became aware of it). Your child can make the complaint and you can make a complaint on behalf of your child unless the body that you complain to is not satisfied that there are reasonable grounds for you representing the child, in which case it would need to give reasons for its decision.
- **Social Care Complaints – Wales:** The complaints process in Wales is similar to that in England, although the relevant procedures are streamlined to cover both complaints about children's services and about adult social care.
- **NHS Complaints – Wales:** You or your child can make a complaint (complainants can be anyone who has received a service or 'any person affected or likely to be affected' by the action giving rise to the complaint).

- **Complaint to the Ombudsman:** There are four Ombudsmen in England and Wales that investigate complaints of 'maladministration' (for example, complaints about the way in which a service is delivered, or where it is not delivered at all) in areas relevant to social care, housing and health. They are the Local Government Ombudsman (dealing with complaints against Local Authorities), the Parliamentary and Health Services Ombudsman (can investigate complaints concerning GPs, NHS Trusts and other health bodies), the Housing Ombudsman Service (covers complaints against social housing providers) and the Public Service Ombudsman for Wales (covers complaints against Local Authorities and NHS bodies in Wales).

Information on how to complain to these bodies is given on their respective websites – see the Resources section, pages 41-42 for further information. In most cases the complainant will be expected to have used the NHS body or Local Authority's complaints procedure first.

- **Legal action – England and Wales:** You, on behalf of your child can make an application to the High Court for judicial review, an application to the Secretary of State for Health or the Welsh Assembly to use their default powers or an ordinary application under section 7 of the Human Rights Act 1998.

In relation to issues arising under the Equality Act 2010 (see Q.43 – Q.49): discrimination claims are made to the County Court. Claims in relation to the public sector equality duty are brought by way of judicial review in the High Court. These can be brought by individuals, interested parties and/or the Equality and Human Rights Commission. For more information about the procedure, see the Resources section pages 41-43.

Please note: If you are considering taking legal action you should seek legal advice immediately as the time limits are very strict and short.

Glossary

Carers (Equal Opportunities) Act 2004: 'seeks, through section 1, to give carers more choice and better opportunities to lead a more fulfilling life by ensuring that carers receive information about their rights to an assessment under the 2000 Act. Section 2 ensures that those assessments now consider the carer's wishes in relation to leisure, education, training and work activities. Section 3 provides for co-operation between Local Authorities and other public authorities, including housing, education and health, in relation to the planning and provision of services that may help support the carer in their caring role.' See Carers and Disabled Children Act 2000 & Carers (Equal Opportunities) Act 2004 Combined Policy Guidance, Department of Health, 2005).

Carers (Recognition & Services) Act 1995 requires Local Authorities to carry out an assessment of a carer's needs in certain circumstances where:

- (i) the disabled child is being assessed by the Local Authority under the Children Act 1989;
- (ii) the carers are providing a substantial amount of care on a regular basis;
- (iii) the carers are providing the care on an unpaid basis; and
- (iv) the carers request such an assessment.

Care Programme Approach: A system of care and support for individuals with complex mental health needs which includes an assessment, a care plan, and a care co-ordinator. It is used mainly for adults in England who receive specialist mental healthcare and in some **CAMHS** services. Separate guidance has been issued in Wales (see Resources section page 43). The Department of Health's Refocusing the Care Programme Approach: Policy and Positive Practice Guidance Department of Health, published in March 2008 provides guidance on whether an individual requires the support of the CPA. This includes those people who are:

- at risk of suicide or self harm or causing harm to others, relapse history requiring urgent response;
- in need of multiple service provision from different agencies, including: housing, physical care, employment, criminal justice, voluntary agencies;
- currently/recently detained under Mental Health Act or referred to crisis/home treatment team;
- reliant (significantly) on carer(s).

Children and Adolescent Mental Health Services (CAMHS): Specialist mental health services for children and adolescents covering all types of provision and intervention – from mental health promotion and primary prevention and specialist community-based services through to very specialist care, as provided by in-patient units for children and young people with mental illness. They are mainly composed of a multi-disciplinary workforce with specialist training in child and adolescent mental health.

Common Assessment Framework (CAF): helps practitioners working with children, young people and families, to assess children and young people's additional needs and identify what action needs to be taken to address those needs. It is a 'basic assessment tool' that can be used as a 'gateway' to other more specialist assessments such as the Assessment Framework used to assess a child in need (discussed in the section on Social Care above).

Children Act 1989: covers a wide range of areas concerning children. Part 3 of the Children Act 1989 concerns children 'in need' and their families: Local Authorities must safeguard and promote the welfare of those children in need living in the Local Authority area by providing services appropriate to their needs. So far as is consistent with their duty to safeguard and promote the welfare of children in need, Local Authorities must also provide services appropriate to those children's needs to promote their upbringing by their families. The definition of a 'child in need' is given below. For the purposes of this Act a child is a person under the age of 18.

Child in need: under the Children Act 1989 (Section 17(10)), a child is in need, for the purpose 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 disabled child).

Chronically Sick and Disabled Persons Act 1970: sets out duties of Local Authorities to provide services to both disabled adults and disabled children.

Disabled child is, for the purpose of 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).

Eligibility criteria: these are the criteria used by children's services and local social services authorities to assess the level of need of a person and determine whether s/he qualifies for a service. Guidance issued in England and Wales has standardised Local Authority eligibility criteria for community care services (thus in general, adult services) but no guidance has been issued in relation to children's services. (The guidance on community care services: Department of Health (2010) Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England 2010 and Welsh Assembly Government (2002) Creating a Unified and Fair System for Assessing and Managing Care.)

Harassment under the Equality Act 2010 in a services context: The Act prohibits three different types of harassment:

- a) Harassment related to a 'relevant protected characteristic' (not pregnancy and maternity, religion or belief or sexual orientation in a services context);
- b) Sexual harassment, and
- c) Less favourable treatment because of submission to or rejection of sexual harassment and harassment related to sex.

Clearly in relation to sexual harassment of a child, there is other relevant legislation including that which covers criminal behaviour.

Human Rights Act 1998: this Act places an obligation on public bodies such as Local Authorities and NHS bodies to work in accordance with the rights set out under the European Convention on Human Rights ('ECHR'). This means that individuals working for public authorities, whether in the delivery of services to the public or devising policies and procedures, must ensure that they take the ECHR into account when carrying out their day to day work.

Looked after child: A child is looked after by a Local Authority if s/he is in their care by reason of a care order or is being provided with accommodation under section 20 of the 1989 Act for more than 24 hours with the agreement of the parents, or of the child if s/he is aged 16 or over (section 22(1) and (2) of the 1989 Act).

Local Authority children's social care services: this term is used 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 people 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.

Mental Capacity Act 2005: The MCA 2005 provides the legal framework for making decisions on behalf of individuals aged 16 or over who lack capacity to make such decisions for themselves. Anything done for, and any decision made on behalf of, a person without capacity should be done or made in the 'best interests' of that person. For individuals aged 16 and over who lack capacity to make decisions for themselves, the Mental Capacity Act 2005 provides that 'acts in connection' with the person's care and treatment can be taken in the person's 'best interests'. In order to determine what might be in the person's best interests those involved in caring for the person (such as the parents) should be consulted.

NHS bodies: this term is used to describe the range of organisations that are involved in the planning, commissioning and delivery of health services (covering a wide range of services such as community health services, mental health services, in-patient provision and specialist services for those with rare conditions). In England NHS Trusts and NHS Foundation Trusts deliver health services such as running hospitals and ambulance services and Primary Care Trusts (PCTs) are responsible for commissioning health care services in their area such as primary care (e.g. doctors and dentists) as well as other health care services such as hospital care. However the role of PCTs is due to be taken over by 'Clinical Commissioning Groups' as part of the reforms to be introduced by the Health and Social Care Act 2012. These groups, known as CCGs, are due to be established across England by April 2013.

In Wales the commissioning of local health services is discharged by local health boards (LHBs) and hospitals, a range of services are provided by District General Hospitals (outpatient, inpatient and day case basis) and a network of community hospitals across Wales.

Non-statutory guidance: practical guidance aimed at helping people understand their rights and obligations under the relevant Act but it has no legal standing. Nevertheless it is something to which the Local Authority / NHS body must have regard when carrying out their functions, and if they intend not to follow the guidance, they will have to be able to provide good reasons for so deciding.

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'. Those working with children will need to ascertain who has 'parental responsibility'. This will be particularly important when the child is not able to make decisions about his or her care or treatment as in those circumstances a person with parental responsibility may be able to make that decision on behalf of the child.

Usually both your child's parents will have parental responsibility, but this will not always be the case. In some cases, parental responsibility may be shared, for example when the child or young person is subject to a care order. Details of where to find further information on parental responsibility is given in the Resources section below. (See Decision-making, sharing information and confidentiality.)

Section 7 Guidance: This refers to guidance that has been issued under section 7 of the Local Authority Social Services Act 1970. This section requires Local Authorities in exercising their social services functions to act under the general guidance of the Secretary of State; unless there are exceptional reasons in individual cases authorities are expected to comply with this guidance.

Statutory guidance: guidance that has been approved by the Secretary of State / Welsh Government and laid before Parliament / the Assembly. It is not an authoritative statement of the law. However,

it can be used as evidence in court or tribunal proceedings connected with the relevant legislation and the court / tribunal must take into account any part of the guidance it considers relevant when determining the questions arising.

Victimisation under the Equality Act 2010 in a services context: If a service provider subjects a service user or a person seeking to access a service to a detriment because they have carried out or may carry out a 'protected act' this amounts to victimisation of the service user or the person seeking to access the service.

A 'protected act' is:

- Bringing proceedings under the Equality Act 2010 (the Act)
- Giving evidence or information in connection with proceedings brought under the Act
- Doing anything else for the purposes of or in connection with the Act
- Making an express or implicit allegation that another person has done something in breach of the Act (whether or not an allegation is later dropped).

Resources

Useful Organisations

- **Advisory Centre for Education (ACE)** - publishes the Special Education Handbook with detailed information about the operation of the SEN framework. Provides general helplines and specific exclusion helpline: www.ace-ed.org.uk/
- **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/
- **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
- **Housing Ombudsman Service**: looks at complaints about registered providers of social housing, for example housing associations, and other landlords, managers, and agents: www.housing-ombudsman.org.uk/
- **IPSEA (Independent Parental Special Education Advice)** - a registered charity offering free and independent advice to parents of children with special educational needs in England and Wales on: Local Authorities’ legal duties to assess and provide for children with special educational needs; exclusions of children with special needs/ disabilities; actions or inaction by Local Authorities and/or schools which discriminate against children with disabilities. - www.ipsea.org.uk/
- **Local Government Ombudsman** - looks at complaints about councils (Local Authorities) and some other authorities and organisations, including education admissions appeal panels and adult social care providers (such as care homes and home care providers). It is a free service: www.lgo.org.uk/

- **Parliamentary and Health Service 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 their carers. <http://www.pals.nhs.uk/default.aspx>
- **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

Accommodation – adaptations

- Disabled facilities grant Department for Communities and Local Government and the Welsh Assembly Government 2009
www.communities.gov.uk/documents/housing/pdf/138592.pdf
- Department for Communities and Local Government Delivering Housing Adaptations for Disabled People: A Good Practice Guide, June 2006

Assessments

- Carers and Disabled Children Act 2000 & Carers (Equal Opportunities) Act 2004 Combined Policy Guidance, Department of Health, (2005)
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4118023
- Framework for the Assessment of Children in Need and their Families (Department of Health, April 2000):
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003256
- 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>

- Refocusing the Care Programme Approach (Department of Health, March 2008): www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083647
- Delivering the Care Programme Approach in Wales: Interim Policy Implementation Guidance, Welsh Assembly Government, July 2010: <http://wales.gov.uk/docs/dhss/publications/100803cpaguidanceen.pdf>

Care planning for looked after children and care leavers

- A range of information, including The Children Act 1989 Guidance and Regulations Volume 2 Volume 2: Care Planning, Placement and Case Review (England) Regulations 2010 and statutory guidance, March 2010 and Volume 3 Planning transition to adulthood for care leavers - including guidance on the Care Leavers (England) Regulations 2010 is available at: www.education.gov.uk/childrenandyoungpeople/families/a0065502/care-planning-for-looked-after-children-and-care-leavers

Complaints

- How do I make a complaint about an NHS service? <http://www.nhs.uk/chq/Pages/1084.aspx?CategoryID=68&SubCategoryID=162>
- Information provided by the Home Office on the process for complaints under the Equality Act 2010: <http://www.homeoffice.gov.uk/publications/equalities/equality-act-publications/complaints-Equality-Act/>
- Information is also available on the EHRC's website: <http://www.equalityhumanrights.com/advice-and-guidance/new-equality-act-guidance/taking-a-discrimination-case/>

Continuing Care

- National Framework for Children and Young People's Continuing Care (Department of Health, 25 March 2010): www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114784

Decision-making, sharing information and confidentiality

- Confidentiality: NHS Code of Practice (Department of Health, November 2003): www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPublicationsPolicyAndGuidance/DH_4069253

- Department of Health, Reference guide to consent for examination or treatment Second edition, 2009, Chapter 3 paragraphs 21 – 27
- Department of Health, Mental Health Act 1983 Code of Practice, Chapter 36, paragraphs 36.9-36.15

Education

- Cerebra's Education Guide - Disabled Children Parents' Guide: Education: available at [http:// www.cerebra.org.uk/English/getinformation/education/Pages/DisabledChildrenParents%e2%80%99GuideEducation.aspx](http://www.cerebra.org.uk/English/getinformation/education/Pages/DisabledChildrenParents%e2%80%99GuideEducation.aspx)

Equality Act 2010 and social care, housing and health services

- Services, public functions and association Statutory Code of Practice available to download from the Equality and Human Rights Commission's website at: http://www.equalityhumanrights.com/uploaded_files/EqualityAct/servicescode.pdf
- Additional guidance on the Equality Act 2010: <http://www.equalityhumanrights.com/legal-and-policy/equality-act/>
- Office for Disability Issues Guidance on matters to be taken into account in determining questions relating to the definition of disability - <http://odi.dwp.gov.uk/docs/law/ea/ea-guide-2.pdf>

Legal references

- Steve Broach, Luke Clements, and Janet Read, Disabled Children: A Legal Handbook, LAG & Council for Disabled Children, 2010 (the full text is also on line – see www.ncb.org.uk/cdc/resources/legal_handbook.aspx)
- Luke Clements and Pauline Thompson Community Care and the Law, LAG, 5th Edition 2011

National Service Frameworks for Children

- NSF Wales National Service Framework (NSF) for Children, Young People and Maternity Services: http://www.wales.nhs.uk/sites3/Documents/441/EnglishNSF_amended_final.pdf

- National Service Framework for Children, Young People and Maternity Services: Standard 8: Disabled children and young people and those with complex health needs: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4094479
- The National Service Framework for Children, Young People and Maternity Services: For Parents: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4094777

Palliative care

- Better Care, Better Lives: Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions, Department of Health, 2008 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083106

Short term breaks

- Short Breaks for Carers of Disabled Children Advice for Local Authorities, Department of Education: <http://media.education.gov.uk/assets/files/pdf/s/short%20breaks%20-%20advice%20for%20local%20authorities.pdf>

Transition

- Association for Children's Palliative Care ('ACT') Transition Care Pathway 2007: available at: www.act.org.uk
- Guide to Transition for Parents and Carers Young Minds: www.dawsonmarketing.co.uk/youngminds/shop/PDF/PARENT-TRANS.PDF
- Guidelines on the discharge from hospital of children and young people with high support needs (Council for Disabled Children, 2010) available at: www.ncb.org.uk/cdc/Guidelines_on_the_discharge_from_hospital_of_children_and_young_people_with_high_support_needs.pdf
- Managing the Transitions From Adolescent Psychiatric, In-patient Care Toolkit Sheree Kane National Children's Bureau, 2008 http://www.ncb.org.uk/resources/free_resources/in-patient_care_transitions.aspx

- Transition: moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability (Department of Health, 19 March 2008): www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592
- 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, National Mental Health Development Unit and National CAMHS Support Services, Camilla Parker with Luke Clements, Anthony Harbour and Jo Honigmann, 2010 <http://www.nmhd.org.uk/silo/files/transitions-in-mental-health-care.pdf>

Information about the Project Team

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

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).

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, in both private practice and the not for profit sector, Jo has worked as a legal and policy consultant since 2008. Her clients include the Equality and Human Rights Commission for whom she has drafted education guidance for the Equality Act 2010 as part of a small consortium. During her career, she has also been responsible for a large university's policy and provision for its disabled students whilst completing an MSc in Disability Management in Work and Rehabilitation. Jo has written, trained and presented on education and discrimination law and policy to a wide range of specialist and non-specialist areas. She 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.

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/fundraising or call 01267 244 221.

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