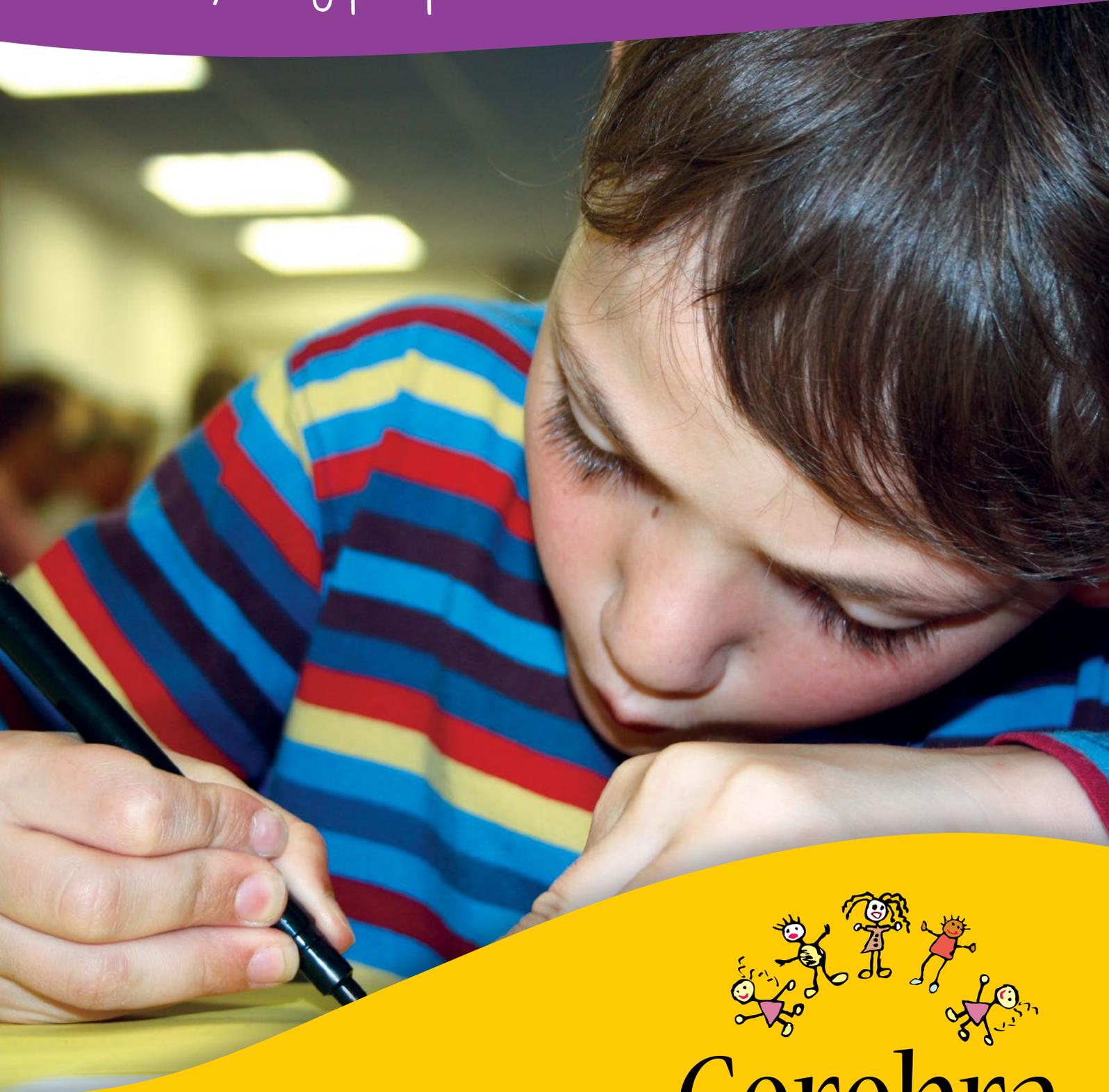


# Transition to Adulthood

A guide for practitioners working with disabled young people and their families



# Cerebra

Positively Different

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# Transition to Adulthood: A guide for practitioners working with disabled young people and their families

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# Chapter 1

## Introduction

*This guide is for practitioners working with disabled young people and their families, focusing on those young people aged between 16 and 25. It explains the legal and policy frameworks, for England and Wales, that are relevant to areas in which these young people and their families are likely to need support and advice as the young person enters adulthood. Its purpose is to help practitioners understand the relevant law and policy so that they can guide young disabled people through this transition to adulthood.*

### Transition to Adulthood: A crucial time for disabled young people

- 1.1 Entering into adulthood is a very significant time for all young people and their parents but it can be a particularly stressful time for young people who have disabilities and/or special educational needs (referred to in this guide as 'disabled young people') and their families. This is because they will need to move from services and supports that focus on children and families to those addressing the needs of adults. This process, known as 'transition', may be difficult due to a range of factors such as the numbers of agencies and professionals involved (for example education, social care and health) and the different approaches between those working in services for children and those working in adult services.
- 1.2 This guide focuses on the various aspects of transition for disabled young people aged between 16 and 25 (and unless otherwise indicated this guide will use the term 'young people' to refer to this age group). Within this transition stage there will be various different, but significant steps. For example, a disabled young person will move from children's health care services to adult services when they are 18, whereas young people who have been looked after by the local authority may continue to receive social care from the children's services into their early, and sometimes mid-twenties.<sup>1</sup> Such changes may give rise to difficulties for young disabled people and

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<sup>1</sup>The Children (Leaving Care) Act 2000 amended the Children Act 1989, setting out the circumstances in which local authorities must provide support to care leavers from the age of 16 to 21. In some circumstances the provision of support is extended to the age of 24 or beyond.

their families. For example, they may find it hard to move from professionals with whom they have established a good relationship, to new professionals whom they do not know. Young people with complex disabilities and/or serious health conditions and their families may be concerned that this transition period will lead to major changes such as moving from one form of residential accommodation to another.

- 1.3 Other, more significant changes than the re-organisation of service provision, are likely to be needed as young disabled people move into adulthood. Their needs, aspirations and close relationships are likely to change. Some will wish to live independently from their parents or other carers, others may wish to focus on getting a job.

### Understanding the roles and responsibilities of relevant agencies

- 1.4 The areas of law and policy relevant to disabled young people's transition to adult services and support are wide-ranging and in many cases, complex and overlapping. While practitioners will be clear on their own powers and duties, they may be less sure of the responsibilities of other agencies in the planning and delivery of support for disabled young people. By gaining a good understanding of each other's roles and responsibilities, practitioners will be able to work together to ensure that the young person's transition into adulthood is as smooth and stress-free as possible.
- 1.5 Accordingly this guide highlights the key areas of law and policy in England and Wales<sup>2</sup> relevant to transition, namely: education, social care, housing, health, employment and financial matters. These areas will include a wide range of different agencies, such as local authorities (education, children's services, adult social care and housing) and NHS bodies, as well as the voluntary sector.<sup>3</sup> Practitioners will be aware that some aspects of law and guidance will differ between England and Wales – such differences will be highlighted where these occur.

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<sup>2</sup>The law relating to Scotland and Northern Ireland differ in significant areas from that of England and Wales and is not covered in this guide.

<sup>3</sup>In some cases youth justice agencies may be involved with the care and support of a disabled young people but the issues relating to youth justice are beyond the scope of this guide.

1.6 Given the breadth of the areas covered, this guide can only provide an overview of the relevant law and policy. It is not a substitute for referring to relevant legislation, guidance or policies or seeking legal advice. However, throughout the text, reference is made to resources which provide a more detailed analysis of specific issues and Annexes A and B provide further information on relevant legislation and guidance. Furthermore, some areas considered in this guide are subject to legal reform, such as health and education. Wherever possible this guide has highlighted areas in which reform is proposed and where updates can be found. A Glossary at the end of this guide provides an explanation of commonly used terms – these are highlighted in bold in the text.

### Transition to Adulthood: Key Points for Young Disabled People

- > It is important that practitioners in both children's services and adult services are able to help young disabled people and their families as they move through the transition process, so that this causes the least possible stress and disruption and that they receive appropriate support. This requires an understanding of their roles and responsibilities and those of other agencies.
- > Key to all transitions in the areas covered by this guide is the need to plan and ensure that the young person and their parents/carers are prepared, in that they know what to expect, and that they have the support that they need, when they need it.
- > Successful transitions depend upon practitioners taking responsibility; acting as support / key workers for the young person and their families; keeping promises; keeping to agreed timescales; addressing problems head on; keeping sight of the transition plan's objectives and keeping good records.



# Chapter 2

## Transition: An Overview of the Legal and Policy Context

*This chapter provides a brief overview of the transition process, considering which agencies should be involved in the various stages of transition and when. It also considers general principles of law and policy that will be relevant to different aspects of the transition process. Subsequent chapters will provide more detail on the responsibilities these agencies have towards disabled young people and their families.*

The areas covered in this chapter are as follows:

- Key stages of the transition planning process
- General duties of NHS agencies, local authorities and other public bodies
- Working with young people

### Key stages of the transition planning process

2.1 This guide uses the term 'transition' to describe a process of change over a period of time as young people move from children's services to services for adults. This is likely to entail not one, but many significant stages. For example, during the years from 16 to 25 young disabled people will leave school, some will move from children's services to adult health and/or social care, some will leave local authority care, some will go into further or higher education and some will get a job. Such changes will require the relevant agencies and professionals to work together to ensure that the young person is supported during these life-changing events.

### Emphasis on Early Planning for Transition

2.2 Planning for transition should start well in advance. For those young people with a Statement of Special Educational Needs (SEN), planning for transition should have started by the age of 13 or 14 (Year 9 in school). The expectation is that during the Year 9 annual review of the young person's statement of special educational needs is reviewed, the transition planning starts and a Transition Plan is prepared in the light of these discussions. Year 9 is also a significant year for young people with complex health needs or disabilities as this is when a health plan, focusing on the young person's needs and aspirations as they move into adulthood, should be prepared.

- 2.3 The following chapters consider issues relevant to the areas of education (Chapter 3), social care (Chapter 4), health (Chapter 5), housing (Chapter 6) employment (Chapter 7) and financial issues ('Money Matters' – Chapter 8). They seek to identify the core issues for the agencies concerned with these different aspects of young people's lives. All these areas will be relevant whether or not young person has a Statement of SEN.

### **Importance of joint working**

- 2.4 Given this multi-faceted aspect of transition, it is vital that agencies work together when supporting young disabled people into adulthood. The importance of such joint working is emphasised by guidance for health practitioners in England, *Transition: moving on well*:

*"During the transition process, various plans will be made in relation to different aspects of the young person's life – further/higher education, vocation and training, leisure and independence, where they wish to live and ongoing healthcare. Health professionals working with a young person with complex health needs or a disability can prepare them for adulthood by developing a health transition plan, which takes an approach that is much broader than the medical diagnosis and helps the young person to address other lifestyle issues that may be concerning them. This needs to form an integral part of the broader transition plan, linking closely with education and social care."<sup>4</sup>*

- 2.5 Table 1 (see next page) identifies key transition stages during this period and highlights the responsibilities of the three main agencies – education, health and social services. The numbers in brackets refer to the paragraph numbers of this guide.

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<sup>4</sup>Department of Children Schools and Families and Department of Health, *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 ('Moving on Well')*, 2008, page 10

**Table 1: Key Transition Stages: Responsibilities of Education, Health & Social Services**

<b>Age</b>	<b>Education</b> (Duty to cooperate with social services and health – s27 CA 1989, s322 EA 1996, s82 NHS Act 2006 (2.6))	<b>Health</b> (Duty to cooperate with social services and education – s27 CA 1989, s322 EA 1996 NHS Act 2006 (2.6))	<b>Social Services</b> (Duty to cooperate with health and education – s27 CA 1989, s322 EA 1996 NHS Act 2006 (2.6))
<b>13</b>	<p><b>Wales NSF:</b> inter-organisation system should identify young person ('YP') requiring transition into adult services in Year 8 annual review ('AR') (5.11–5.12)</p> <p><b>YP with SEN Statement:</b> Preparation for Year 9 AR to start early (2.2)</p>	<p><b>Wales NSF:</b> inter-organisation system should identify YP requiring transition into adult services in Year 8 AR (5.11–5.12)</p> <p><b>YP with SEN Statement:</b> Preparation for Year 9 AR to start early (2.2)</p>	<p><b>Wales NSF:</b> inter-organisation system should identify YP requiring transition into adult services in Year 8 AR (5.11–5.12)</p> <p><b>YP with SEN Statement:</b> Preparation for Year 9 AR to start early (2.2)</p> <p><b>YP is a 'child in need':</b> determine support required (4.16– 4.21)</p> <p><b>Looked after child:</b> transition planning integral to care (4.41)</p>
<b>14</b>	<p><b>Wales NSF:</b> key transition worker appointed (5.12)</p> <p><b>YP with SEN Statement:</b> Year 9 AR &amp; preparation of Transition Plan; careers advice service MUST be invited and attend, MUST invite social services, MUST inform other agencies, such as health (3.14– 3.22)</p>	<p><b>Wales NSF:</b> key transition worker appointed (5.12)</p> <p><b>YP with SEN Statement:</b> MUST be informed of Yr 9 AR; should discuss move to adult services with YP, parents and GP; GP to be involved (5.5– 5.7); duty to cooperate s27 CA 1989, s322 EA 1996 (2.6, 4.20)</p> <p><b>YP with complex health needs:</b> Preparation of health care plan (5.15)</p> <p><b>YP &amp; continuing care:</b> identify if YP likely to need continuing care as an adult (5.34)</p>	<p><b>Wales NSF:</b> key transition worker appointed (5.12)</p> <p><b>YP with SEN Statement:</b> MUST be invited to Yr 9 review; MUST consider if YP is disabled (child in need) – s5 DP(SCR)A 1996, duty to cooperate s27 CA 1989, s322 EA 1996 (2.6, 4.20)</p> <p><b>YP is a 'child in need':</b> determine support required (4.16– 4.21)</p> <p><b>Looked after child:</b> Link with SEN Annual Review (4.37 – 4.41)</p>
<b>16</b>	<p><b>All YP:</b> stay in school?</p> <p><b>Wales NSF:</b> Transition Plan reviewed (5.12)</p> <p><b>YP with SEN Statement:</b> Year 11 AR (Statement &amp; Transition Plan) &amp; LDA if last year of school (3.23–3.29); Statement ceases if YP moves to FE. (3.14–3.22)</p>	<p><b>Wales NSF:</b> Transition Plan reviewed (5.12)</p> <p><b>YP with complex health needs:</b> health care plan reviewed regularly &amp; linked to SEN statement review (5.15)</p> <p><b>YP with SEN Statement:</b> Should be involved (3.21 – 3.22)</p> <p><b>YP &amp; continuing care:</b> referral for screening for adult continuing care (5.34–5.35)</p>	<p><b>Wales NSF:</b> Transition Plan reviewed (5.12)</p> <p><b>YP with SEN Statement:</b> Should be involved (3.21– 3.22)</p> <p><b>YP is a 'child in need':</b> determine support required (4.16– 4.21)</p> <p><b>Looked after child:</b> Prepare pathway plan (4.37 – 4.41)</p>

## Key to Table

CA 1989 – Children Act 1989  
 CPA – care programme approach  
 DP(SCR)A 1996 – Disabled Persons (Services, Consultation & Representation) Act 1986  
 EA 1996 – Education Act 1996  
 FE – further education

HE – higher education  
 LDA – learning difficulty assessment  
 NHTA 2006 – National Health Service Act 2006  
 Wales NSF – National Service Framework for Children, Young People and Maternity Services, Wales

<p><b>17</b></p>	<p><b>Wales NSF:</b> Transition Plan reviewed – year before 18th birthday each term (5.12)  <b>YP with SEN Statement:</b> Year 12 AR (Statement &amp; Transition Plan) (3.14–3.22)</p>	<p><b>Wales NSF:</b> Transition Plan reviewed – year before 18th birthday each term (5.12)  <b>YP with SEN Statement:</b> Should be involved (3.21 – 3.22)  <b>YP with complex health needs:</b> health care plan reviewed regularly &amp; linked to SEN statement review (5.15)  <b>YP &amp; continuing care:</b> Eligibility for adult NHS continuing care decided (5.34–5.35)</p>	<p><b>Wales NSF:</b> Transition Plan reviewed– year before 18th birthday each term (5.12)  <b>YP with SEN Statement:</b> Should be involved (3.21 – 3.22)  <b>YP in need of social care support?:</b> assess needs (4.22 – 4.29)  <b>Looked after child:</b> keep pathway plan under review (4.37)</p>
<p><b>18</b></p>	<p><b>All YP:</b> go into HE?  <b>YP with SEN Statement:</b> Year 13 at school (Statement &amp; Transition Plan); LDA (3.14 to 3.29) (statement can stay in force until end of academic year in which young person turns 19 – see 3.14)</p>	<p><b>YP with SEN Statement:</b> Should be involved (3.21 – 3.22)  <b>YP with complex health needs:</b> health plan reviewed regularly; linked to SEN statement review (if applicable) (5.15)  <b>YP &amp; continuing care:</b> Adult continuing care commissioned (unless later date agreed) (5.34–5.35)  <b>YP &amp; mental health care:</b> apply CPA and transition protocols (5.17–5.19)</p>	<p><b>YP with SEN Statement:</b> Should be involved (3.21 – 3.22)  <b>YP in need of social care support?:</b> assess needs (4.22 – 4.29)  <b>Looked after child:</b> keep pathway plan under review (4.37)</p>
<p><b>19</b></p>	<p>Statement can stay in force until end of academic year in which young person turns 19 (3.14) &amp; ceases automatically when YP moves into FE / HE provision or Apprenticeship (3.30–3.47)</p>		
<p><b>20/25</b></p>	<p>FE/Apprenticeship/HE (3.30 to 3.47)</p>		

## General duties of public bodies

2.6 NHS agencies, local authorities and other public bodies are subject to a range of responsibilities when exercising their statutory functions, including decisions concerning the planning, commissioning and provision of services and support to disabled young people. This means that those individuals working for these public bodies, who undertake functions on behalf of such public bodies, must:

- **Act reasonably and within their legal powers:** practitioners must be able to demonstrate that when making decisions on behalf of a public body, they have lawful and sound reasons for the decisions that they take. (Such reasons should be recorded in writing so that the action taken can be justified if challenged.) Practitioners must be aware of the relevant guidance – which (amongst other things) emphasises how important it is that they take responsibility, keep undertakings and avoid delay when implementing a transition plan.
- **Comply with the 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 or 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. (See Annex A for sources of further information.)
- **Comply with the Equality Act 2010:** service providers, employers and education providers must not discriminate against or harass service users, employees and pupils/ students on the basis of their '**protected characteristics**'. In addition, public bodies such as local authorities, NHS bodies, local authority maintained schools and Academies and many further and higher education providers must comply with the **public sector equality duty** which seeks to eliminate discrimination from within an organisation. The key employment provisions of the Equality Act 2010 are covered in Chapter 7 and Annex A provides sources of information in relation to other areas.

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<sup>5</sup>See for example, Department of Health, Transition: Moving on Well, 2008

- **Comply with their duties to co-operate:** joint working between the relevant agencies is not only encouraged by the various policies and guidance on transition<sup>5</sup> but is also required by legislation, such as the Children Acts 1989 and 2004, the Education Act 1996 and the NHS Act 2006. Specifically:
  - *Section 27 of the Children Act 1989:* places a specific duty on local authorities and other authorities (including local education authorities, housing authorities and NHS bodies) to co-operate in the interests of **children in need** (see paragraph 4.20).
  - *Section 322 of the Education Act 1996:* places a duty on health authorities and local authorities to assist another local authority that requests help in the exercise of their functions in relation to children with special educational needs.
  - *Section 10 of the Children Act 2004:* requires local authorities and key partner agencies (including those Strategic Health Authorities and PCTs that are responsible for any area falling within the local authority's boundaries) to co-operate in order to improve the well-being of children in that area.
  - *Section 82 of the NHS Act 2006:* requires that NHS bodies and local authorities 'co-operate with one another in order to secure and advance the health and welfare of the people of England and Wales'.
- **Be aware of their safeguarding responsibilities:** this applies to both children and young people,<sup>6</sup> as well as to 'vulnerable adults'.<sup>7</sup>

2.7 Furthermore practitioners should be aware that:

- **Statutory duties are unaffected by local arrangements:** local arrangements for the provision of health and social care by the various agencies may differ across the country, with a wide variety of policies, protocols, assessment arrangements and eligibility criteria, these do not affect the statutory duties of the relevant agencies.
- **Disputes over responsibility for funding should not affect the delivery of care:** the care provide to young people should not be adversely affected by such disputes, nor should they be allowed to cause any other detriment to the young person's welfare (by, for example delaying the commissioning of a suitable placement or the provision of necessary support services).

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<sup>6</sup>Duty to make arrangements to safeguard and promote the welfare of children: section 11  
Children Act 2004

<sup>6</sup>See Department of Health and Home Office (2000) No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse (England) and National Assembly for Wales (2000) In Safe hands (Wales) and other resources in  
Annex B

## Working with young people

2.8 In supporting disabled young people, practitioners will need to pay particular attention to the following:

- **Involving disabled young people in the planning and delivery of their care:** this is reiterated in policies and guidance on transition. It is also underpinned by legislation, for example the Children Act 1989 requires that before providing services or accommodation to a 'child in need' (explained below at paragraph 4.4), the local authority must ascertain, so far as reasonably practicable and consistent with the child's welfare, the wishes and feelings of the child and must give due consideration to such wishes and feelings.<sup>8</sup> This duty is replicated in relation to the adult care law – where the relevant English and Welsh guidance requires that assessment and care planning be 'person-centred throughout and also consider the wider family context'.<sup>9</sup>
- **Confidentiality and sharing information:** Young people aged 16 and over will have the right to make decisions about who they want to be informed about their care and other matters of a personal nature. However, where the young person (or indeed an adult) lacks sufficient mental capacity to make this decision, then the question about the extent to which information should be shared, is essentially a 'best interests' decision.
- **Decision-making:** Individuals aged 16 and over are presumed to have capacity to make their own decisions unless evidence shows otherwise.<sup>10</sup> Accordingly, the starting point for young people who are 16 or older is that they are to be assumed to be able to make decision for themselves, for example, where they want to live and decisions about their health and social care, unless there are reasons to doubt this.
- **The Mental Capacity Act 2005:** If there are concerns that the young person 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 ('the MCA 2005') and the Code of Practice to the 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. (See Annex A for resources on this Act.)

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<sup>8</sup>Sections 17 (4A) and 20(6) of the Children Act 1989

<sup>9</sup>Paragraph 83, 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 see also paras 2.8 – 2.12 Welsh Assembly Government (2002) Creating a Unified and Fair System for Assessing and Managing Care.

<sup>10</sup>Section 1 of the Mental Capacity Act 2005

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- **The role of those with parental responsibility:** For young people aged under 18, it is generally important to involve those with '**parental responsibility**' (subject to the child/young person's consent). Furthermore, there may be circumstances in which those with parental responsibility for a young person who is unable to make decisions for him or herself can make such decisions for that young person. Usually, the person with 'parental responsibility' will be the child or young person's parents. However, this is not always the case. In some cases, parental responsibility may be shared, for example when the child or young person is subject to a care order.<sup>11</sup>

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<sup>11</sup>See Department of Health, 'Reference Guide to Consent for Examination or Treatment', 2nd edition, 2009, Chapter 3, paragraphs 21–27

# Chapter 3: Education

*This chapter looks at the post 16 educational opportunities and support available to young people with special educational needs and /or disabilities*

The areas covered are as follows:

- Transition and Education: Overview
- Staying on at school
- Moving into Further Education
- Apprenticeships
- Higher education
- Transport

## Transition and Education: Overview

- 3.1 As noted in Chapter 2, transition planning for most young people should have started when they were in Year 9 (at the age of 13/14). By no later than Year 11 (at the age of 16) all young people will need to make some important decisions about their future education and training. They will need to decide whether they will stay on at school, move into Further Education (FE), start an apprenticeship or leave education altogether. Similar decisions will need to be made by young people reaching the age of 18 or 19, coming to the end of Year 13, some of whom may decide to go into Higher Education (HE).
- 3.2 Young people with 'special educational needs' ('SEN') (see Box 1 below) and/or disabilities may benefit from additional learning support through the Special Educational Needs Framework whilst at school. Local education authorities have a

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<sup>12</sup>Section 14(6)(b) Education Act 1996

general duty when securing the provision of sufficient schools, to have regard to the need to secure appropriate provision for pupils with SEN<sup>12</sup> and a more specific duty to 'identify and make a statutory assessment of those children for whom they are responsible who have SEN and who probably need a statement'.<sup>13</sup> Local authorities, school staff and other relevant professionals will all need to work with these children and their parents to ensure the child is properly supported during their school years and when making decisions about their future.

- 3.3 Professionals, including health and social care professionals, working with young people with special educational needs are required to 'have regard to' the Special Educational Needs (SEN) Code of Practice which:

*'...provides practical advice to Local Education Authorities, maintained schools, early education settings and others on carrying out their statutory duties to identify, assess and make provision for children's special educational needs.'*<sup>14</sup>

There is a separate SEN Code of Practice for Wales which mirrors the SEN Code for England.

- 3.4 In addition, all education providers have duties under the Equality Act 2010 not to discriminate against their prospective, existing and in some cases former pupils/ students on the basis of a protected characteristic.<sup>15</sup> These duties include a duty to make reasonable adjustments for disabled pupils/ students. The reasonable adjustment duty operates differently for schools than for FE and HE providers. Public authorities, (a term which includes local authority maintained schools and Academies and many further and higher education providers), are also subject to the public sector equality duty. These provisions are beyond the scope of this guide but sources of further information are provided in Annex A.<sup>16</sup>

## Disability and Special Education Needs – overlap

- 3.5 Although some young people will have 'special educational needs' under the Education Act 1996 and be disabled within the meaning of the Equality Act 2010 (see Box 2, p.17, for definitions of these terms) this is not necessarily always the case. Many young disabled people will have no 'special educational needs' but may have a disability under the Equality Act 2010 which may result in a need for reasonable adjustments to be made for them, whereas other young people may have special educational needs but are not disabled within the meaning of the Equality Act 2010.

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<sup>13</sup>SEN Code 7 and sections 321 and 323 Education Act 1996

<sup>14</sup>See paragraphs 1 and 5 SEN Code of Practice

<sup>15</sup>See Glossary section.

<sup>16</sup>See Glossary section

- 3.6 Different learning support frameworks operate in FE and HE settings and these are considered later in this chapter.

### Future Reform

- 3.7 2012 is a time of great educational flux and much of this chapter will need to be revised over the next few years. The government in England has announced its plan to introduce legislation in the 2012-13 Parliamentary session to radically overhaul the SEN framework. There are plans to replace Statements of Special Educational Needs in England so that by 2014 all the support needed to meet the needs of a child or young person will be set out in one Education, Health and Care plan which will have a single assessment process and follow a young person from birth to 25; other key reforms include personal budgets and a local offer of services. Pilot schemes testing key reforms are already underway with more being planned. In Wales SEN reforms are also being considered: pilot schemes testing an Individual Development Plan (the equivalent of the Education, Health and Care Plan) are underway and the Welsh Assembly has said it will introduce legislation to implement the changes in its 2012-13 session. The participation age in some form of education or training is to be extended to 17 in 2013 and to 18 in 2015 in England which will also have a significant impact on the educational landscape.

### Children and young people with Statements of Special Educational Needs

- 3.8 The SEN Code of Practice anticipates that 'the SEN of the great majority of children' will be met by either Early Years Action/ School Action or Early Years Action Plus/ School Action Plus (see Box 2 opposite) without the need to consider a statutory assessment of the child's SEN, which may result in a Statement being made.<sup>17</sup>
- 3.9 However, there will be children for whom a Statement is necessary. Box 1 explains this term.

#### Box 1: Statement of Special Educational Needs ('Statement')

A Statement is a document which sets out the child's special educational and other non-educational needs, and how and where these are to be met. The LEA is legally responsible for ensuring the special educational provision set out in Part 3 is made (even though some therapies such as speech and language therapy or physiotherapy set out in Part 3 may be provided by the local health authority for example). If the provision is not put in place, this can be challenged by way of judicial review.

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<sup>17</sup>SEN Code 7.1

3.10 A child's parents or their school make a written request to the LEA to carry out a statutory assessment of the child's SEN at the end of which the LEA must decide whether or not it considers it is necessary to issue a Statement. Another agency such as social services or the health service can also make a referral to the LEA for a statutory assessment to be carried out.

3.11 The box below sets out definitions of some other key terms used in education.

### Box 2: Definitions of Key Terms

- Disabled within the meaning of the Equality Act 2010: A person is disabled under the Act if they have a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day to day activities.
- Early Years Action / School Action: Learning support that is different from or additional to the support provided to the child's peer group.
- Early Years Action Plus / School Action Plus: Learning support that is additional to that provided at Early Years Action / School Action and for which support from external support agencies is usually sought.
- Special educational needs: A child (for this purpose a person under the age of 19 who is a registered pupil at a school) has special educational needs if they have a 'learning difficulty' which requires special educational provision to be made for them.<sup>18</sup>
- A child has a learning difficulty in an SEN context if s/he:
  - a) has a significantly greater degree in learning than the majority of children of the same age; or
  - b) has a disability which prevents or hinders him / her from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local authority
  - c) is under compulsory school age and falls within the definition at (a) or (b) above or would do so if special educational provision were not made for him/her.

Simply speaking a different language at home does not mean a child has a learning difficulty.

- Special educational provision:
  - a) For children aged two and over, this is educational provision which is additional to or otherwise different from, the educational provision made generally for children of their age in schools maintained by the local authority, other than special schools, in the area
  - b) For children under 2, this is educational provision of any kind.

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<sup>18</sup>See section 312 of the Education Act 1996. See also para. 1.3 of the SEN Code.

## Staying on at School

*This section focuses on the support available to young people with 'special educational needs' who have decided to stay on at their school or another school for Years 12 and 13.<sup>19</sup>*

- 3.12 Some young people with SEN may not have a Statement of Special Educational Needs (see Box 1 above). Some may be supported by their school through "School Action" or "School Action Plus" (see Box 2 above). In some cases, however, the young person's SEN may not yet have been identified.
- 3.13 Some children with SEN will be 'educated otherwise' than at school such as at home and LEAs have the power to fund home education where they consider it is inappropriate to deliver some or all of the required provision in a school. The Annual Review procedure for such children with statements is essentially the same as that for children with statements who are educated at school (discussed below) but it is the LEA and not a Head teacher who convenes the review which will take place in the most appropriate location.

## Annual Reviews of Statements

- 3.14 Young people with Statements of SEN will have annual reviews of their Statements until they leave school or until they cease to have a Statement, whichever is the earlier; a Statement can last until the end of the academic year in which a young person turns 19.<sup>20</sup> They will also have a 'learning difficulty assessment' (explained below at paragraphs 3.23 to 3.29) in their last year of school.
- 3.15 The Year 11 annual review for young people aged 16 will also review the Transition Plan that should have been prepared following the Year 9 annual review. The Year 9 annual review is significant because this is when the transition planning for young people with statements of SEN starts. The Year 9 annual review and the subsequent annual reviews, until the young person leaves school, are therefore of crucial importance to each young person's transition planning.
- 3.16 A Head teacher is responsible for convening these Annual Review meetings and will invite professionals involved in the young person's care (such as health and social care professionals) to consider the young person's needs and aspirations.

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<sup>19</sup>As noted in the introduction to this chapter schools will have specific duties towards young disabled people under the Equality Act 2010, such as the duty to provide reasonable adjustments.

<sup>20</sup>Although this is currently the subject of a legal challenge.

3.17 The Transition Plan should be based on, and draw together, information from all those individuals involved in the young person's education and care so that it plans coherently for the young person's transition from childhood to adult life

### **Purpose of the Annual Review**

3.18 The purpose of the annual review is to:

- review the Statement of SEN to ensure its continuing appropriateness
- to draw up a Transition Plan (in Year 9) and at subsequent annual review meetings to review the Transition Plan.

### **The purpose of the Transition Plan**

3.19 The purpose of the Transition Plan is to plan for the young person's transition to adult life. It includes a plan for on-going school provision under their Statement, at least until the end of compulsory school age is reached. Information from individuals both within and outside school should feed into the plan.

### **Involving the young person**

3.20 The SEN Code of Practice states that a young person's views 'should be sought and recorded wherever possible in any assessment, reassessment or review from year 9 onward.'<sup>21</sup> Chapter 3 of the SEN Code of Practice (see Annex A) provides advice on how young people can be involved in this process.

### **Summary of actions for the Annual Review**

3.21 A range of professionals and agencies are expected to be involved in the Annual Review, in particular:

- The Head teacher (who can delegate this role to a qualified teacher at the school)
- Local authority (education)
- Local authority (children's services/ social services)
- Health professions involved in the young person's care
- Careers professionals

3.22 The main responsibilities of each of these individuals/agencies are set out below.<sup>22</sup>

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<sup>21</sup>Paragraph 9.55

<sup>22</sup>See also the SEN Code, Chapter 9. Chapter 10 of the Code highlights the importance of joint working.

### The Head teacher must:

- Seek advice from the child's parents, anyone specified by the local education authority and anyone else the Head teacher considers appropriate
- Convene annual review meetings until such time as the pupil leaves school
- Circulate copies of all written advice reports at least 2 weeks before the meeting
- Invite to the Annual Review meeting the child's parents, (or social worker, residential care worker or foster parents if a looked after child), a relevant teacher, a representative from the LEA, any person whom the LEA has specified in a notice and any other person the Head teacher considers appropriate
- Prepare a written report and submit it to the LEA no later than 10 school days after the Annual Review meeting or the end of that school term (whichever is the earlier) which includes a summary of the outcome of the meeting.

In relation to the **Annual Review in Year 9**, the Head teacher:

- Should ensure that other agencies, such as health, are aware of the special Year 9 procedures
- Must invite a representative from the relevant careers advice service<sup>23</sup> (in Wales this is Careers Wales) to provide written advice and attend the meeting
- Must invite social services to attend the Annual Review to ensure that any parallel assessments under the Disabled Persons (Services, Consultation and Representation) Act 1986<sup>24</sup> the NHS and Community Care Act 1990; and the Chronically Sick and Disabled Persons Act 1970 can feed into and inform the review process.
- Must ensure the Transition Plan is drawn up, in consultation with the representative from the careers service (England) or from Careers Wales.

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<sup>23</sup>In England, local authorities are identifying a replacement service for Connexions to provide career advice role for children with statements and draft their Transition Plans. The responsibility for providing general careers advice is moving from local authorities to schools while a new National Careers Service was launched in April 2012 and will focus mainly on career support for adults.

<sup>24</sup>Under section 5 of this Act LEAs must seek information as to whether a young person with a SEN statement is disabled and so may require services from the local authority when leaving school. See the SEN Code of Practice 9.58–9.59 and 10.34–10.36

### **Local authority (education):**

- Must write to all head teachers at least 2 weeks before the start of each term with a list of all pupils on roll at their school who require an annual review that term (England). In Wales a term's notice must be given.
- Must provide similar lists covering all their schools to the health authority and social services, including details of those pupils with Statements who are not educated at school (England). In Wales the Code of Practice advises that LEAs may find it helpful to do so.
- Must decide whether or not to accept a head teacher's recommendations following the Annual Review meeting and decide whether or not to amend or cease to amend the Statement, informing the Head teacher, the child's parents and anyone else they think appropriate of their decision
- In relation to the **Year 9 Annual Review**
  - must send the careers service / Careers Wales a list of all pupils in their area who will require a Year 9 review no later than 2 weeks before the start of the school year (England) or prior to the end of Year 8 (Wales).
  - must obtain information from the social services department as to whether a young person with a statement is disabled and may require services from them on leaving school)
- In relation to young people subject to a care order or accommodated by a local authority on their 16th birthday:
  - appoint a personal adviser for such young people and prepare a pathway plan.

### **Local authority (children services/social services):**

- must respond to a head teacher's request (on behalf of the LEA) for written advice for an Annual Review meeting:
  - unless they consider the help is not necessary for the exercise of the LEA's functions and
  - provided the request is compatible with their duties and does not unduly prejudice the discharge of any of their functions.
- In relation to young people subject to a care order, accommodated by the local authority or 'children in need': should ensure that a social worker attends the Year 9 Annual Review meeting and contributes to the Transition Plan.

### **Health professionals involved with the young person:**

- Must respond to a head teacher's request (on behalf of the LEA) for written advice for an Annual Review meeting unless they consider that the help is not necessary for the exercise of the LEA's functions and provided the request is reasonable in light of the resources available to them.
- Should attend the Year 9 review wherever possible and provide written advice on the services the young person is likely to need and transition arrangements from child to adult services.<sup>25</sup>
- Where a child is 'educated otherwise' because of major difficulties arising from a health condition or a disability, the views of the designated medical officer for SEN should be sought and professional advisers from the relevant child health services should attend the meeting.

### **The careers service/Careers Wales representative:**

- Must attend the Year 9 annual review
- Is responsible for helping the young person and their parents to decide on the most-appropriate post-16 provision for them
- Should be invited to and should attend the annual review meeting in Year 11 in order to ensure that the Transition Plan is updated appropriately

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<sup>25</sup>See SEN Code of Practice which states that health professionals should discuss arrangements for the transfer to adult health care services with the young person, their parents and their GP.

## Learning Difficulty Assessments

### General

- 3.23 Local authorities in England must arrange for a Learning Difficulty Assessment ('LDA') (sometimes called a 'section 139A assessment')<sup>26</sup> in the last year of school for all young people for whom they maintain a Statement and who they expect to leave school to receive post 16 education (e.g. in a sixth form college or specialist college but not at a school), training (e.g. an apprenticeship) or higher education. In Wales this is known as a s140 assessment. The purpose of such an assessment is to identify the needs of the young person as well as suitable provision to meet these needs
- 3.24 Local authorities have the power to undertake a LDA for those young people who do not have Statements but who appear to have **learning difficulties** and are receiving or are likely to receive post 16 education (see paragraph 3.29 below). The LDA statutory guidance for England<sup>27</sup> ('the LDA statutory guidance') at paragraph 9.1 states that local authorities '*should have a transparent process setting out the circumstances in which they will use the power to undertake a LDA and they should ensure that young people and/or their parents and carers are aware of this policy*'.
- 3.25 Once a local authority has decided a LDA is necessary it must continue to support that young person up to the age of 25 if they stay in further education or training and continue to have learning difficulties.

### Box 3: What is a learning difficulty in a LDA context?<sup>28</sup>

A person has a learning difficulty if they have:

- a) a significantly greater difficulty in learning than the majority of persons of their age, or
- b) a disability which either prevents or hinders them from making use of facilities of a kind generally provided by institutions providing post-16 education or training.

Simply speaking another language at home will not amount to a learning difficulty.

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<sup>26</sup>Under s139A Learning and Skills Act 2000 (England) and s140 Learning and Skills Act 2000 (Wales)

<sup>27</sup>Section 139A Learning Difficulty Assessments Guidance for Local Authorities, updated in February 2012.

<sup>28</sup>Sections 15ZA(6) and (7) of the Education Act 1996 (inserted by section 41 of the Apprenticeship, Skills Children and Learners Act 2009).

- 3.26 Where a young person attends a residential school, their home local authority arranges for the LDA to be carried out with support from the hosting authority (i.e. the one in which the school is located) as necessary.
- 3.27 LDAs are important, in that they not only identify a young person's continuing educational needs – they can also unlock funding – including funding for specialist residential placements (see below).
- 3.28 In England however, there are plans to amend legislation to replace current LDAs as well as Statements with an Education, Health and Care Plan; similar proposals are being considered in Wales (see paragraph 3.7). The LDA Statutory guidance will remain in force until these plans are in force and is due to be reviewed in March 2013.

### **The Power to undertake a LDA**

- 3.29 The LDA statutory guidance explains that local authorities should have a transparent policy setting out when they should use their power to undertake a LDA in respect of:
- young people with a learning difficulty but without a Statement in their last year of compulsory schooling who the local authority believes are likely to require additional support as part of their future education or training and who would benefit from a LDA so that their learning needs and the provision necessary to meet those needs can be identified.
  - young people with a learning difficulty but without a Statement who are over compulsory school age but under 25 and receiving (or the local authority believes are likely to receive) post 16 education or training if they:
    - are likely to leave school during or at the end of the current school year, likely to need additional support as part of their future education or training and who the local authority believes would benefit from a LDA to identify their learning needs and the provision necessary to meet those needs
    - are currently in or about to start post 16 education or training who have not previously had a Statement or a LDA but who the local authority now thinks should have such an assessment
    - have previously had a LDA but whose circumstances have now changed to such an extent that the local authority considers a further assessment is necessary
    - have previously had a Statement but did not have a LDA as they did not go straight from school into education or training.
  - young people who acquire a learning difficulty or disability as a result of a disease or injury for whom the local authority thinks a LDA will be beneficial
  - young people who carry on learning after they are 19 and the local authority believes need to have a reassessment to ensure the provision and support remains appropriate.

## Box 4: Learning Difficulty Assessment: Key Points<sup>29</sup>

### *Links to the Annual Review of SEN Statements:*

- The SEN Code of Practice at paragraph 9.62 states that 'every effort should be made to link [the] final annual review of the statement and to consider the Transition Plan together with this [LDA] so that a holistic approach is maintained'.
- The LDA statutory guidance at paragraph 13.1 states 'The assessment should be a seamless transition from previous assessments and any SEN statement and must allow time for the commissioning of any necessary provision and support to take place'.

### *LDAs must:*

- consider the young person's wider needs
- result in a clear, written report which covers:
  - the young person's educational and training needs and
  - the learning provision to meet those needs and be specific about both.
- take account of the young person's views and wishes

### *LDAs should:*

- be supported by an appropriately trained workforce who are independent of any learning provider and have an advice or related qualification to at least level 4
- have a person centred approach focusing on progression
- adopt a multi-agency approach with local authorities ensuring relevant links are in place across all relevant services such as travel, health, medical and social care.
- take into account value for money considerations when making placement decisions
- have a clear complaints process
- be reviewed regularly.

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<sup>29</sup>See the SEN Code and the LDA statutory guidance

## Moving into Further Education

### Handover from school

3.30 Transition planning for young people with Statements will have started with their Year 9 review (see paragraph 3.15 above).

3.31 If young people are leaving school, the transition planning may have identified that they should attend a general FE provision such as a sixth form college or FE college or that their needs would best met at a residential specialist college. Whatever the decision, it is good practice to invite a representative from the new provision to the Annual Review in Year 11 or Year 13 (depending on when the young person leaves school) so that there can be effective liaison between the young person's school and their new provision to ensure a smooth transition.

3.32 A LDA must be carried out for pupils with statements in their last year of school and may be carried out for pupils with SEN but without Statements (see the Learning Difficulty Assessment section above). Local authorities in England have a duty to secure sufficient education and training opportunities to meet the reasonable needs of young people in their areas who have had a learning difficulty assessment and are aged 19 or over but under 25.

### Funding for students

3.33 Once a young person leaves school and moves into Further or Higher Education their Statement will cease. There are various forms of general funding as well as funding specifically for students with learning difficulties and disabilities. Wales is currently consulting on its proposals for reform of further and higher education which will impact on future funding and student support arrangements.<sup>30</sup>

3.34 Under the Equality Act 2010 FE and HE institutions are under a duty to make reasonable adjustments for their prospective, existing and in some cases, former disabled students.

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<sup>30</sup>See <http://wales.gov.uk/consultations/education/feandhebill/?lang=en>

## General funding

### *16–19 Bursary Fund (England)*

3.35 This new fund consists of a payment of £1200 and a discretionary fund. It replaces the Education Maintenance Allowance and aims to help the most vulnerable 16-19 year olds in full time education, namely:

- young people in care,
- care leavers,
- those in receipt of Income Support and
- those in receipt of both Disability Living Allowance and Employment Support allowance (see paragraph 8.7 below).

### *Education Maintenance Allowance (Wales)*

3.36 The Education Maintenance Allowance is still in existence in Wales (although a new planning and funding system will be introduced from 2014 / 2015). It provides financial support to 16–18 year olds whose household income is below a certain amount and who are studying at a participating school or college on an eligible course which is:

- an academic or vocational course up to and including Level 3; and
- full-time at school; or
- a minimum of 12 guided hours at college.

## Funding for students with learning difficulties and disabilities

### *Additional Learner Support (England and Wales)*

3.37 Additional learner support funding (non-means tested) is allocated to FE colleges and independent providers for support of students with learning difficulties and disabilities as a whole.

- In England, FE colleges receive funding for Additional Learning Support from the Education Funding Agency and the Skills Funding Agency which funds adult learners over 19 to 25 if they have a LDA.
- In Wales the Additional Learning Support funding comes from the department of the Minister for Education and Skills which is part of the Welsh Assembly.
- Private colleges in England and Wales do not receive such funding but have a duty to make reasonable adjustments for disabled students under the Equality Act 2010.
- Most FE providers will have a range of student support services which should be set out in their prospectuses and on their websites.

3.38 The types of Additional support provided in general FE colleges or sixth form colleges are:

- specialist teaching for students with specific learning difficulties such as dyslexia
- sign language interpreters
- materials in accessible formats
- specialist equipment (which will remain the property of the college; charities may provide grants for students to purchase their own items).

### *Residential specialist colleges (England and Wales)*

3.39 If a young person's LDA has identified that their needs cannot be met in a local college, they may receive funding to attend a residential specialist college which are for disabled students only. Before 'out of county' funding is unlocked for such a specialist college, the LDA assessor will have to provide evidence that local provision is not possible (by, for example, obtaining letters from local colleges stating that they are unable to meet the young person's educational needs). If a young person has significant care needs, social services may fund those social care support services that are needed whilst he or she is in the placement (the funding being provided under s2(1)(c) Chronically Sick and Disabled Persons Act 1970).

## Apprenticeships

3.40 Apprenticeships are open to all people aged over 16 and not in full time education. There are three different levels of apprenticeship:

- Intermediate, Advanced and Higher (England)
- Foundation Apprenticeships, Apprenticeships and Higher Apprenticeships (Wales)

3.41 These levels of apprenticeship combine a work based qualification such as an NVQ, key transferable skills and a Technical certificate. Learning providers focus on knowledge and key transferable skills while the employer offers practical on-site training.

3.42 Applications for apprenticeships are made through the National Apprenticeship Service, which is housed in the Skills Funding Agency and is responsible for apprenticeships from start to finish (England) and through Careers Wales in Wales. The National Apprenticeship Service is under a duty to work with local authorities to do everything reasonable to find someone an Apprenticeship. Apprentices are paid a salary by their employer. In addition, the National Apprenticeship Service will pay a percentage of an apprentice's training costs which varies depending on their age.

3.43 The Chief Executive of Skills Funding, who manages the National Apprenticeship Service, has the following duties:

- to ensure an apprenticeship place is available to all suitably qualified young people aged 16-18 who want one
- to secure suitable apprenticeship provision for young people aged 19 or over but under 25 and leaving care or subject to an LDA (local authorities will be responsible for their education and training (see paragraph 3.25 above).

## Higher Education

### Support Services for Disabled Students

3.44 As with FE providers, HE providers have a range of student support services covering all aspects of student life which should be set out in their prospectuses and on their websites. Most will have a service specifically supporting disabled students and will encourage students to declare their disability so that the necessary support can be put in place in time for the start of the student's course.

3.45 Under the Equality Act 2010 HE providers are under a duty to make reasonable adjustments for their prospective, existing and in some cases former, disabled students.

### Financial support

3.46 There is a wide variety of financial support available to higher education students including: student grants, student loans, bursaries, scholarships and awards and access to learning funds.<sup>31</sup>

3.47 In addition, Disabled Students Allowances ('DSAs') provide funds to students to help pay for the additional costs they incur in studying as a result of their disability, mental-health condition or learning difficulty. The DSAs help students buy equipment, pay for support workers and other disability related study items. Further information on DSAs, such as eligibility for these allowances and what they cover, is provided in Annex C.

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<sup>31</sup>Those students with childcare responsibilities may be eligible for childcare support and there is a grant for students who have dependent adults.

## Transport

3.48 This section considers the transport provisions relevant to 16–18 year olds followed by those relevant to 19–24 year olds. There are different rules for children and young people of compulsory school age<sup>32</sup> or below.<sup>33</sup> Authorities should consider their transport responsibilities when commissioning education and training.

### 16–18 year olds (England)

3.49 In England, local authorities must publish their agreed Transport Policy Statement by 31 May each year which sets out the transport arrangements and provision of financial assistance in relation to reasonable travelling expenses:

- they consider necessary to assist the attendance of all persons aged 16–18 and those continuing learners who started their learning programme before their 19th birthday
- in place to help young people of the same age as above with learning difficulties and /or disabilities to access education and training.<sup>34</sup> The statutory guidance highlights that it is good practice to extend transport arrangements until a learner has completed their programme of study, even if this is after they have reached the age of 19.<sup>35</sup>

3.50 The intention behind this duty is to enable learners of sixth form age to access their choice of education or training where reasonable and to be assessed and provided with support for access where required. A reasonable choice for students might be a provider situated outside their local authority boundaries.<sup>36</sup>

3.51 Young people of sixth form age and their parents are now included on the list of named stakeholders who local authorities must consult when drawing up their Transport Policy Statement.<sup>37</sup> This statement must specify the arrangements that governing bodies of schools and further education colleges propose to make, which could include help with transport costs or other transport provision. Essentially the statement must give sufficient information about transport options, fares and how to apply for support so as to enable students to make informed choices about their Post 16 provision.

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<sup>32</sup>See Glossary section

<sup>33</sup>Department of Education, *Home to School Travel and Transport Guidance* 2007

<sup>34</sup>s509 AA, s509 AB and s509AC Education Act 1996

<sup>35</sup>Paragraph 29, 2010 Post 16 Transport Guidance; Department of Education

<sup>36</sup>Paragraph 2 2010 Post 16 Transport Guidance; Department of Education

<sup>37</sup>Section 509AB(6)(ca) Education Act 1996 as inserted by s54 ASCL Act 2009

### *16–18 year olds (Wales)*

3.52 Local authorities in Wales must assess each academic year for the following year, the travel needs of learners who are under the age of 19 and are in education or training, or learners who are 19 and who started a course of education or training when under 19 and continue to attend that course, and who are ordinarily resident in the authority's area.<sup>38</sup> When making an assessment, a local authority is required to have regard to certain matters including the needs of disabled learners or learners with learning difficulties and any particular needs of learners who are children 'looked after' or formerly looked after by a local authority. There is currently no duty to provide transport arrangements for these learners but there is provision for Welsh Ministers to make regulations in the future concerning travel arrangements for those learners who live in Wales and attend courses funded by the Welsh Ministers in Wales or elsewhere. Local authorities have a discretion to make travel arrangements (for which a charge can be made) to facilitate the attendance of a learner at their place of education or training for learners living or studying in the Local Authority's area.

### *19–24 year olds (England and Wales)*

3.53 In England, local authorities must make such arrangements for the provision of free transport as they consider necessary (or as directed by the Secretary of State) to:

- aid the attendance of adults receiving education at any institution assisted or maintained by the authority which provides FE or HE or both or at any FE institution;
- aid the attendance of adults under the age of 25 who have had a Learning Difficulty Assessment for whom education or training at an institution outside the FE and HE sectors and boarding accommodation has been secured by the local authority.<sup>39</sup>

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<sup>38</sup>Section 2 Learner Travel (Wales) Measure 2008 (2008No 2)

<sup>39</sup>Section 508F and s509G Education Act 1996 as inserted by s57 ASCL Act (re-enacts the then existing transport duty in relation to adult learners)

In addition local authorities are also required to publish an annual Transport Policy Statement setting out the transport or other arrangements in place for young people with learning difficulties and/or disabilities aged 19–24 for whom they have carried out, or are about to carry out, a Learning Difficulty Assessment.<sup>40</sup> This can be produced together with the Transport Policy Statement for young people of sixth form age (see paragraph 3.49 above). Again, the intention behind this duty is to ensure that these young people and their parents can access information about the transport available and then make an informed decision about the educational institutions to apply for. In Wales there is currently no duty to make travel arrangements for this group of learners but local provision may be in place. A young person's LDA should address their learner transport needs.<sup>41</sup>

*Specialist HE provisions for disabled students (England and Wales)*

3.54 Students who are eligible for the Disabled Students Allowances or equivalent (see Annex C and paragraph 3.47), may be able to claim the travel allowance component. This is designed to help with any extra travel costs a student has to pay to attend their HE course, for example if the student needs to take a taxi because their disability prevents them from taking public transport. The travel allowance does not cover every day travel costs which a student would be expected to pay. The amount payable will be determined by the DSA needs assessment and is not income related.

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<sup>40</sup>Section 508G Education Act 1996 as inserted by s57 ASCL Act

<sup>41</sup>s7 Learner Travel (Wales) Measure 2008 (2008 No 2)

# Chapter 4: Social Care

*This chapter considers local authorities' responsibilities for the provision of social care and support to young disabled people aged between 16 and 25.*

It covers the following areas:

- Social Care: Overview
- Scope of duties to young people and their families
- Assessments of need for support
- Care Plans
- Carers
- Looked After Children
- Charging for Services
- Direct Payments and personal budgets

## Social Care: Overview

### Organisation of social services

4.1 Local authorities are responsible for the provision of social care to disabled people of all ages. In England and Wales responsibility for the social care needs of disabled children and adults lies with the same authority.

- In England, the authorities divide this responsibility between a children's services directorate<sup>42</sup> and an adult social services department. Adult social care falls within the responsibility of the Director of Adult Social Services<sup>43</sup> and the responsibility for children's social services (and education) falls within the responsibility of the Director of Children's Services.<sup>44</sup>

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<sup>42</sup>The Children Act 2004 required local social services authorities in England to split their functions between children's services and adult services (and have directors for each of these departments).

<sup>43</sup>Section 6 of the Local Authority Social Services Act 1970

<sup>44</sup>Section 18 of the Children Act 2004

- This is a divide that the young person must cross when he or she reaches the age of 18 (although where the young person is a 'care leaver', children's services will continue to be involved beyond that age).
- The Director of Adult Social Services is responsible for the 'transition of service users... between children's and adult's services'.<sup>45</sup>
- In Wales authorities are not required to have separate departments for adults and children services.

### **Wide range of legislation, policy and guidance**

4.2 The legislation governing social care is wide-ranging, complex and in some areas overlapping. Different legislation will apply depending on the person's age or circumstances, for example some legislation is relevant to only those aged under 18, some applies to those aged 18 or older, while other legislation applies to people of all ages. In many areas young people of 16 and 17 will be considered to be 'children' for the purpose of key legislation, such as the Children Act 1989 but will be treated as adults once they have reached the age of 18.

### *Scope of duties to young disabled people and their families*

4.3 The table below summarises the key duties of local authorities to provide social care and support to young disabled people and their families. The relevant legislation is abbreviated in the table, and the text below, as follows:

- Children Act 1989 – CA 1989
- Chronically Sick and Disabled Persons Act 1970 – CSPDA 1970
- Mental Health Act 1983 – MHA 1983
- National Assistance Act 1948 – NAA 1948
- National Health Service Act 2006 – NHSA 2006
- National Health Service and Community Care Act 1990 – NHSCCA 1990

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<sup>45</sup>Department of Health, *Best Practice Guidance on the role of the Director of Adult Social Services*, May 2006, paragraph 40

**Table 2: Local Authorities' Responsibilities: Children's Services & Social Care**

Individuals	Legislation	Services that may/must be provided
<p>Children in need – this includes disabled children (i.e. those under 18 years). (See Box 5 for explanations of these terms)</p>	<p><b>Part 3 CA 1989, in particular:</b>            Section 17: LAs must safeguard and promote the welfare of children in need in their area by providing services appropriate to those children's needs.            Section 20 (provision of accommodation to children in need)            Services subject to <b>eligibility criteria</b></p>	<ul style="list-style-type: none"> <li>• Accommodation</li> <li>• Assistance 'in kind, or in cash'</li> <li>• 'Provision for children living with their families'<sup>46</sup>:               <ul style="list-style-type: none"> <li>&gt; advice, guidance and counselling;</li> <li>&gt; occupational, social, cultural or recreational activities;</li> <li>&gt; home help (which may include laundry facilities);</li> <li>&gt; facilities for, or assistance with, travelling to and from home for the purpose of taking advantage of any other service provided under this Act or of any similar service;</li> <li>&gt; assistance to enable the child and family to have a holiday</li> </ul> </li> </ul>
<p>Disabled children (i.e. those under 18 years – see Box 5)</p>	<p>Part 3 CA 1989. Section 17 CA 1989 (see above)            Services subject to <b>eligibility criteria</b></p>	<ul style="list-style-type: none"> <li>• Services designed to:               <ul style="list-style-type: none"> <li>&gt; minimise the effect on disabled children of their disabilities,</li> <li>&gt; give such children the opportunity to lead lives which are as normal as possible, and</li> <li>&gt; 'assist individuals who provide care to continue to do so, or to do so more effectively, by giving them breaks from caring' (i.e. short term breaks)</li> </ul> </li> </ul>
<p>Disabled people (ie disabled children and disabled adults – see Box 5) of any age if they are 'ordinarily resident' (see Box 5) in the LA's area</p>	<p>Section 2 of the CSPDA 1970:            Services subject to <b>eligibility criteria</b></p>	<ul style="list-style-type: none"> <li>• Practical assistance in the home</li> <li>• Providing, or helping the person to obtain, 'wireless, television, library or similar recreational facilities;</li> <li>• 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</li> <li>• Provision of travel and other assistance to enable the person to participate in services provided under section 2 CSPDA 1970</li> <li>• Home adaptations and 'additional facilities designed to secure the person's greater safety, comfort or convenience'</li> <li>• Facilitating holidays</li> <li>• Provision of meals, whether in the person's home or elsewhere</li> <li>• Providing, or helping the person to obtain, 'a telephone and any special equipment necessary to enable him to use a telephone'.</li> </ul>

<sup>46</sup>Schedule 2, Part 1, paragraph 8 CA 1989

**Table 2: Local Authorities' Responsibilities: Children's Services & Social Care (continued)**

Disabled adults	Section 21 NAA 1948	<ul style="list-style-type: none"> <li>Accommodation in a registered care home</li> </ul>
Individuals who may be in need of 'community care services' (in general 18 & over – see Box 5 for definition)	Section 47 NHSCCA 1990: duty to carry out a 'community care assessment' <b>Services subject to eligibility criteria.</b>	<ul style="list-style-type: none"> <li>A range of services fall within the definition of 'community care services',<sup>47</sup> including: <ul style="list-style-type: none"> <li>&gt; accommodation in a registered care home</li> <li>&gt; social work service advice and support,</li> <li>&gt; day centres and other facilities,</li> <li>&gt; assistance in finding accommodation,</li> <li>&gt; home help and laundry services,</li> <li>&gt; domiciliary and care services to people living in their own homes and elsewhere,</li> <li>&gt; home adaptations and residential accommodation.</li> </ul> </li> </ul>
Looked after children leaving care (aged 16 – 25)	Leaving care provisions of the CA 1989	The type of 'leaving care' support that the LA must provide will depend on the age of the young person and whether s/he continued to be a looked after child. (See paragraphs 4.37–4.41)
Individuals receiving aftercare services under the MHA 1983 (all ages) – see Box 5)	Section 117 MHA 1983: duty on health and local social services authorities to provide 'aftercare services'	No definition of 'aftercare services' is included in the MHA 1983 but can include social work, support in helping the person into employment, accommodation and domiciliary services. <sup>48</sup>
Households for whom help is required due to illness/disability	Sch. 20 paragraph 3 NHTA 2006	Home help and laundry facilities (when someone in the household is suffering from illness, is pregnant or has recently given birth, is aged, or is 'handicapped as a result of having suffered from illness or by congenital deformity')

<sup>47</sup>See section 46(3) NHS and Community Care Act 1990

<sup>48</sup>R (K) v Camden and Islington Health Authority [2001] EWCA Civ 240

4.4 Box 5 below defines some common terms used in relation to assessments of individuals' needs for support.

*Box 5: Common terms used in assessment of need for support*

- > Aftercare services under Section 117 MHA 1983: this requires the relevant health and local social services authorities to provide 'aftercare services' to patients (of any age) who have been detained for treatment for their mental disorder,<sup>49</sup> until such time as they 'are satisfied that the person concerned is no longer in need of such services'.<sup>50</sup>
- > Child in need: for the purpose of the CA 1989 a child is in need, 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).<sup>51</sup>
- > Community care services: these are 'services which a local authority may provide or arrange to be provided under provisions set out in the NHSCCA 1990.<sup>52</sup> These include a wide range of services such as social work service advice and support, day centres and other facilities, home help and laundry services, home adaptations and residential care.
- > Disabled child: is defined under the CA 1989 as being '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'.<sup>53</sup>
- > Disabled adult: a person aged 18 or over will be considered to be disabled for the purpose of the NAA 1948 and the CSDPA 1970 if they: 'are blind, deaf or dumb', 'suffer from mental disorder of any description' or 'are substantially and permanently handicapped by illness, injury or congenital deformity or such other disabilities as may be prescribed'.

<sup>49</sup>Under section 3 MHA 1983 or admitted, or transferred to hospital under Part 3 of that Act, and then cease to be so detained (see sections 37, 45A, 47 and 48 MHA 1983).

<sup>50</sup>Section 117(2) MHA 1983.

<sup>51</sup>Section 17(10)

<sup>52</sup>Section 46(3) NHS and Community Care Act 1990

<sup>53</sup>Section 17(11)

### Box 5: Common terms used in assessment of need for support (continued)

- > 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<sup>54</sup> (thus in general, adult services) but no guidance has been issued in relation to children's services.<sup>55</sup>
- > Ordinary residence: There is no statutory definition of 'ordinary residence'. Department of Health guidance Ordinary residence: Guidance on the identification of the ordinary residence of people in need of community care services, England London, March 2010 (paragraphs 18–37) replacing earlier guidance, (LAC(93)7) advises that it should be given its ordinary and natural meaning, subject to interpretation by the courts. It suggests that the determination of a person's place of ordinary residence involves questions of fact such as time, intention and continuity.<sup>56</sup> In general, the ordinary residence of a child is the local authority area in which their parents are based. Adults are generally 'ordinary resident' where their 'base' is – which is the place they have chosen to live voluntarily and for settled purposes (although they may travel away from this place – but to which they tend to return).

4.5 As Table 2 (p.35-36) shows, a wide range of services can be provided to young disabled people and their families. Some of the commonly provided services are listed in the box opposite:

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<sup>54</sup>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*.

<sup>55</sup>See discussion in Clements and Thompson, *Community Care and the Law*, 5th Edition 23.36–23.40

<sup>56</sup>For a detailed discussion on establishing 'Ordinary residence' and resolving disputes see Clements and Thompson, *Community Care and the Law*, 5th Edition, Chapter 6

## Box 6: Services that can be provided by local authorities

- > Accommodation
- > 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 short term breaks ('respite care)
- > Direct payments and personal budgets (see 4.44–4.46 below)

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<sup>57</sup>Schedule 2, Part 1, para. 1 Children Act 1989

## Duty to publish information about services

- 4.6 Under the CA 1989, local authorities are required to 'take reasonable steps to identify the extent to which there are children in need within their area'. They must also:
- Publish information about:
    - the services that they provide under their general duty to provide for children in need (section 17), day care services for children (section 18) accommodation (section 20) and in relation to their duties to children leaving care (sections 23B – 23D, 24A and 24B), and
    - (where the local authority considers it appropriate) the provision of similar services by others, such as voluntary organisations.
  - Take 'such steps as are reasonably practicable to ensure that those who might benefit from the services receive the information relevant to them'.
- 4.7 Local authorities' responsibilities to provide accommodation are considered in Chapter 6 below. The process for assessing an individual's social care needs, and what if any services must be provided to meet such needs are considered in the section below.

## Assessments of need for support

- 4.8 This section considers the duties on local authorities to carry out an assessment of a young person's needs for social care and support and how such assessments are carried out.
- 4.9 In many cases, the young person will be receiving services from local authority social services (in England from children's services department) already.
- The services and support that the young person is receiving should be set out in a care plan, agreed with the young person and generally their parents/carers). However, they or their parent's/carer's on their behalf, can request a review of the care plan at any stage.
  - In addition, as the young person nears their eighteenth birthday, preparations will need to be made for the transfer from children's services to adult services. This is particularly important in England where children's services will need to transfer their care to adult services.

4.10 In England, the two key documents for the assessment of children in need are the Department of Health's policy and practice guidance Framework for the Assessment of Children in Need and their Families ('the Assessment Framework').<sup>58</sup> Similar policy and practice guidance has been issued in Wales.<sup>59</sup>

4.11 The Assessment Framework policy guidance for both England and Wales identifies young people in transition as requiring particular care and attention during assessment, including 'a high degree of co-operation and co-ordination between staff in different agencies, in planning or preparing for assessments, in undertaking and completing them' and that 'extra care must be taken to ensure that there is an holistic view of the child and that the child does not become lost between the agencies involved and their different systems and procedures'. It advises:

- responsibility for action and providing services must be clearly identified and recorded, with specific timescales;
- overall responsibility for ensuring the welfare of the child in need must be clearly allocated.<sup>60</sup>

4.12 As Table 2 (p.35-36) shows, there is a wide range of legislation that may apply to a young disabled person and the relevant legislation will depend on the young person's age and particular circumstances. However this should not impact upon the young person's care and support.

### Ensuring Continuity of Care

- > Professions must assess the young person's needs – and in so doing must decide which is the appropriate legal framework to base a young person's assessment and the subsequent decision on the service to be provided.
- > However this should never be a reason for not providing appropriate support whilst young people are in transition.
- > It is irrelevant whether the assessment is undertaken under the CA 1989 or the NHS&CCA 1990 – if properly conducted, the assessment should ensure that the young person's welfare is safeguarded and promoted (and appropriate services are available).

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<sup>58</sup>These documents can be found at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4003256](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003256) Note that the Department of Education has issued a 'Consultation on statutory guidance to safeguard and promote the welfare of children', the consultation period ending 4th September 2012. This includes the Assessment Framework. See: [www.education.gov.uk/childrenandyoungpeople/strategy/laupdates/a00210252/consultation-guidance-welfare06-12](http://www.education.gov.uk/childrenandyoungpeople/strategy/laupdates/a00210252/consultation-guidance-welfare06-12)

<sup>59</sup>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/110323/frameworken.pdf>

<sup>60</sup>Paragraph 3.58 (England) paragraph 3.62 (Wales)

4.13 Table 3 summarises the relevant legislation and guidance on the assessment of young people’s needs and the decisions on what services should be provided to meet those needs. This is followed by additional information on the relevant issues.

<b>Table 3: Assessment of needs and service provision decision<sup>61</sup></b>		
<b>Questions</b>	<b>Under 18</b>	<b>18 and over</b>
<b>Relevant legislation</b>	Section 17 CA 1989	Section 47 NHSCCA 1990
<b>Is there a duty to assess?</b>	Yes – If YP is a ‘child in need’ (defined in section 17(11) CA 1989, see Box 5 above)	Yes – If person ‘may be in need of community care services’
<b>Who has the responsibility to assess?</b>	England: Local Children’s Services Authority (LCSA) Wales: Local Social Services Authority (LSSA)	England: Adult Social Services Authority Wales: LSSA
<b>How to assess: what is the relevant guidance?</b>	<ul style="list-style-type: none"> <li>• Assessment Framework</li> <li>• CAF for initial assessment</li> <li>• CPA may also be relevant</li> </ul>	<ul style="list-style-type: none"> <li>• Putting People First</li> <li>• CPA may also be relevant</li> </ul>
<b>How long should the assessment take?</b>	See Assessment Framework (initial assessment 10 (England)/ 7(Wales) days; core assessment within 35 days) <sup>62</sup>	No statutory timescale but the the Ombudsman ‘normally considers that it is reasonable for this to take between four and six weeks from the date of the initial request’ <sup>63</sup>
<b>Will services be provided?</b>	Depends on whether eligibility criteria met	Depends on whether eligibility criteria met
<b>Will other agencies be involved? (Co-operation between agencies)</b>	LCSA may request the help of agencies including NHS agencies and local housing authority who must respond unless good reason for not doing so (section 27 CA 1989)	LSSA may request the help of NHS agencies and local housing authority who should respond (s47(3) NHSCCA 1990)
<b>Do carers have a right to an assessment?</b>	Yes, see section on Carers’ assessments below (4.32–4.36)	Yes, see section on Carers’ assessments below (4.32–4.36)

<sup>61</sup>Abbreviations used: CPA – Care Programme Approach; CAF – Common Assessment Framework – see Glossary

<sup>62</sup>Note that in England this is subject to consultation – see footnote 68 below.

<sup>63</sup>Local Government Ombudsman (2011) Fact Sheet Complaints about councils that conduct community care assessments at [www.lgo.org.uk/publications/fact-sheets/complaints-about-community-care-assessments/](http://www.lgo.org.uk/publications/fact-sheets/complaints-about-community-care-assessments/)

- 4.14 Assessments under the CA 1989 and the NHSCCA 1990 are considered below. Assessments undertaken under both these Acts will consider whether or not the local authority should provide support services. Such services can be provided under a range of statutes (including section 2 of the CSDP Act 1970<sup>64</sup>).
- 4.15 Local authorities will have additional responsibilities to those young disabled people who are, or have been, looked after children. The definition of a 'looked after child' includes young people under the age of 18 who have been accommodated under section 20 of the CA 1989 for a continuous period of more than 24 hours. This will be relevant to young people in residential care and in some cases those who are placed in residential accommodation for respite care. Local authorities' duties to looked after children in transition are summarised below (paragraphs 4.37–4.41).

### Assessments and service provision decisions: the Children Act 1989

- 4.16 *Duty to assess*: Local authorities are required to assess the needs of disabled children and their families.
- Local authorities must take reasonable steps to carry out an assessment of the needs of a disabled child or young person under the age of 18.<sup>65</sup>
  - The assessment should consider whether there is a need for provision of support under both the CA 1989 and section 2 of the CSDPA 1970. (The assessments can be carried out together.)
- 4.17 *Framework for the Assessment of Children in Need and their Families (the Assessment Framework)*: as discussed above this guidance (similar guidance being issued in England and Wales) sets out the process to be followed for the assessment of children in need under the CA 1989. It has been issued under section 7 of the Local Authority Social Services Act 1970 (LASSA 1970), which in essence means that local authorities must comply with this guidance unless there are exceptional reasons for not doing so.

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<sup>64</sup>See Clements and Thompson, *Community Care and the Law*, 5th Edition, 3.177 and 9.76

<sup>65</sup>This is necessary in order to fulfil their statutory duties under section 17 of the CA 1989 and section 2 of the CSPDA 1970. See Clements and Thompson, *Community Care and the Law*, 5th Edition 23.12-23.14

4.18 Examples of key points from the Assessment Framework are as follows:

- The assessment should be needs-led and involve the whole family, covering three main areas: the developmental needs of the child or young person; the capacities of parents or caregivers to respond appropriately to those needs and the impact of wider family and environmental factors on parenting capacity and children.<sup>66</sup>
- It should be led by social services but the input of any other agency providing care and/or support to the young person, for example health and education professionals will also be important.
- Agencies and individuals involved in the assessment should be informed of the decisions, with reasons for these made clear.<sup>67</sup>
- Save for exceptional circumstances the initial assessment should be undertaken within a maximum of [10 (England)<sup>68</sup> or 7 (Wales)<sup>69</sup>] days and the 'Core Assessment' (in-depth assessment) must be completed within a maximum of 35 working days.

4.19 *Involving young people*: The young person's wishes and feelings must be ascertained and given due consideration by the local authority before determining what, if any, services to provide.<sup>70</sup> The Assessment Framework (England and Wales) states that at the conclusion of either an initial or core assessment, they (and, where appropriate, their parents) should be informed in writing, and/or in another more appropriate medium, of the decisions made and offered the opportunity to record their views, disagreements and to ask for corrections to recorded information.<sup>71</sup>

4.20 *Joint working*: Section 27 CA 1989: places a duty on a range of authorities including local housing authorities and NHS agencies to cooperate with a local authority that requests their assistance in relation to children in need (unless complying with this request would be incompatible with the authorities own duties).

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<sup>66</sup>See the Assessment Framework, Chapter 2

<sup>67</sup>Assessment Framework (England and Wales) 3.13

<sup>68</sup>This was originally 7 working days but in England this has been changed to 10 working days – see *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children*, 2010. The Department of Education's 'Consultation on the statutory guidance to safeguard and promote the welfare of children' proposes to replace these timescales for assessment 'with a more flexible approach'. The consultation period ended on 4th September 2012: [www.education.gov.uk/childrenandyoungpeople/strategy/laupdates/a00210252/consultation-guidance-welfare06-12](http://www.education.gov.uk/childrenandyoungpeople/strategy/laupdates/a00210252/consultation-guidance-welfare06-12)

<sup>69</sup>Paragraph 3.9 Assessment Framework (Wales)

<sup>70</sup>See: sections 17(4A) and 20(6) (and in relation to care leavers, 22(5)) of the CA 1989.

<sup>71</sup>Assessment Framework (England and Wales) 3.13

4.21 *Eligibility criteria*: The assessment process requires (regardless of the Act) that the children's social care services have 'eligibility criteria' to determine what, if any services to provide ('the service provision decision'), to a young person who has been assessed to be in need. This decision:

- Must be consistent with the information obtained through the assessment.
- Recognise explicitly, and take account of, the consequences of not providing the services, both in relation to the potential harm or impaired development of the child/young person and in terms of the impact on the child/young person's family (such as work, training or education) or their ability to sustain the caring relationship.<sup>72</sup>

### Assessments and service provide decisions: NHS & Community Care Act 1990

4.22 *Duty to assess*: Local authorities must carry out an assessment of the needs of individuals who may be in need of 'community care services' (see section 47 NHSCCA1990).

- The duty to carry out a community care assessment arises when the social services authority is made aware that a person may be in need of such services. This may be because:
  - A person has requested an assessment for themselves or for the person they care for; or
  - Another agency makes a referral to social services.
- An assessment under section 47 can also incorporate an assessment under section 2 of the CSPDA 1970.

4.23 *Community care assessments for young people under 18*: Even though they are not yet 18, young people will be entitled to a community care assessment if:

- They are entitled to services referred to in the NHSCCA 1990<sup>73</sup> namely:
  - section 117 of the MHA 1983, or
  - schedule 20 of NHA 2006 or schedule 15 of NHS (Wales) Act 2006.

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<sup>72</sup>Clements and Thompson, *Community Care and the Law*, 5th Edition 23.41

<sup>73</sup>See section 46 NHS & Community Act 1990

- They are likely to need community services as an adult and are about to become 18 – in such cases they should be treated as a ‘person who may be in need’ of community care services.<sup>74</sup>
  - Such an assessment will be a crucial stage of a young person’s transition to adult services as it will be the mechanism by which the young person’s needs for social care are assessed.
  - It can also assist in other needs being identified, for example if the young person appears to have health or housing needs they can be referred to the relevant health or housing authority.

4.24 *Guidance for Assessments*: the main guidance as to how community care assessments should be undertaken in both England and Wales has been issued under section 7 of the LASSA 1970.<sup>75</sup> The relevant guidance being:

- *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* (2010) (England)
- *Creating an Unified and Fair System for Assessing and Managing Care* (2002) (Wales).

4.25 Both guidance adopt a very similar approach to the assessment process, the purpose of which is described in the English guidance as being to identify and evaluate an individual’s presenting needs (defined as ‘the issues and support needs that are identified when individuals approach, or are referred to, councils seeking social care support’) and how these needs impose barriers to that person’s independence and/or well-being.<sup>76</sup>

4.26 *Involving young people*: In England, *Prioritising Need* states that the assessments should explore with individuals their presenting needs and identify what outcomes they would like to be able to achieve so that they can evaluate how the individual’s presenting needs might pose risks to their independence and/or well-being, both in the immediate and longer-term.<sup>77</sup>

4.27 *Joint working*: local authorities are required to inform the relevant health or housing agencies if the person being assessed appears to have a health or housing need (section 47(3) of the NHS & Community Care Act 1990).

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<sup>74</sup>See for example *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*, 51

<sup>75</sup>See paragraph 4.17 for an explanation of the relevance of s. 7 LASSA 1970

<sup>76</sup>*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*, para. 78

<sup>77</sup>In England the *Prioritising Need* guidance paragraph 59 and in Wales the *Creating a Unified and Fair System for Assessing and Managing Care* guidance at para 5.8.

4.28 *Decision on services to be delivered:* Once the community care assessment has been completed local authorities must decide whether the person's needs call for the provision of any community care services by the authority. It will do this by:

- Considering the information from the community care assessment and the carers assessment (the local authority must have 'regard' to the results of the assessment and where a carer's assessment has been undertaken, take account of the sustainability of the caring role when deciding what community care services it is necessary to provide;<sup>78</sup> and
- Using its 'eligibility criteria' to identify the needs which call for the provision of services (eligible needs),<sup>79</sup> according to the risks to independence and well-being both in the immediate and longer-term.
- The eligible needs should be recorded and agreed wherever possible, by the individual or their representatives.
- Where eligible needs have been identified, an appropriate support plan can then be put together in collaboration with the individual, describing the support they will draw upon to overcome barriers to independence and well-being, both immediately and over the longer term.

4.29 Once a local authority is satisfied that it is necessary to provide a person with a service under the community care legislation, then it must do so.<sup>80</sup>

## Care plans

4.30 Whichever legislation has formed the basis of the young person's assessment, where it is decided that support is required a care plan must be prepared.<sup>81</sup> The plan must set out the young person's needs, how they are going to be met, by whom and by when. All of the above need to be set out clearly so it is possible to check whether the objectives of the plan are being met.<sup>82</sup>

4.31 Guidance on community care assessments for both England and Wales emphasise the importance of setting out clear arrangements for a person's care. The eight key requirements from *Prioritising Need* are set out below. A similar list is included in the guidance for Wales (*Unified and Fair System for Assessing and Managing Care*). These are set out in the box below.

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<sup>78</sup>Carers (Recognition and Services) Act 1995

<sup>79</sup>See '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* para 78 Eligibility criteria are graded into four bands: critical, substantial, moderate and low

<sup>80</sup>See Clements and Thompson, *Community Care and the Law*, 5th Edition para 3.175

<sup>81</sup>For further information see *Prioritising Need* (DH 2010) 121 and *Unified and Fair System for Assessing and Managing Care Wales* 2002 2.66

<sup>82</sup>See discussion in Clements and Thompson, *Community Care and the Law*, 5th Edition, 4.20–4.30 and 23.23

### Box 7: Key aspects of the care plan<sup>83</sup>

Councils should agree a written record of the support plan with the individual which should include the following:

- > A note of the eligible needs identified during assessment;
- > Agreed outcomes and how support will be organised to meet those outcomes;
- > A risk assessment including any actions to be taken to manage identified risks;
- > Contingency plans to manage emergency changes;
- > Any financial contributions the individual is assessed to pay;
- > Support which carers and others are willing and able to provide;
- > Support to be provided to address needs identified through the carers assessment, where appropriate; and
- > A review date.

## Carers

4.32 Parents and other carers (including young carers) of disabled young people are also entitled to assessments of their needs.

4.33 *Parents:* Assessments for a disabled child under the Children Act 1989 should always take into account the needs of parents and other family members (and 'significant others'). All those who provide 'substantial amounts of care' (which self evidently includes almost all parents) are also entitled to a Carers Assessment under the **Carers (Recognition & Services) Act 1995**. The local authority must take into account the results of this assessment when deciding what services, if any, to provide.

4.34 The Local Authority must take into account whether the carer works or wishes to work and whether s/he has undertaken, or wishes to undertake, any education, training or regular leisure activities (under the **Carers (Equal Opportunities) Act 2004**).

4.35 *Other carers:* If the young person has a carer who is providing 'a substantial amount of care on a regular basis', that carer can request an assessment under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000.

4.36 *Services to carers:* although in general local authorities provide support to carers by making sure the disabled person's care needs are fully met – they also have a power to provide services to carers (aged 16 or over caring for an adult) under the Carers and Disabled Children Act 2000. For younger carers or people caring for children or young people, 'carer specific' support services can be provided under section 17 of the CA 1989.

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<sup>83</sup>See *Prioritising Need*, para 121. See also *Unified and Fair System for Assessing and Managing Care Wales 2002 2.66*

## Looked After Children

- 4.37 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.<sup>84</sup> The type of 'leaving care' support that local authorities must provide will vary depending on the age of the young person and whether s/he continues to be a looked after child (referred to as an 'eligible child'), is aged 16 or 17 and is no longer a looked after child (referred to as a 'relevant child') or is 18 or over and is a 'former relevant child'. 'Pathway plans' will be developed and must be kept under review.<sup>85</sup>
- 4.38 *The Children Act 1989 Guidance and Regulations, Volume 3: Planning Transition to Adulthood for Care Leavers*, provides a summary of the definitions of these different categories of looked after children and the level of support that must be provided to them.<sup>86</sup> Guidance in relation to young people entitled to support on leaving care but who remain looked after children is provided in Volume 2 of the Children Act 1989 Guidance, *Care Planning, Placement and Case Review, regulations and statutory guidance*.
- 4.39 The definition of a 'looked after child' includes young people under the age of 18 who have been accommodated under section 20 of the CA 1989 for a continuous period of more than 24 hours as well as those who are subject to a care order under section 31 of the CA 1989 or interim care order under section 31 of the CA 1989.
- 4.40 *Support for care leavers*: Local authorities are responsible for planning and continuing support to all care leavers until they reach the age of 21, and beyond this age, if the young person remains in an approved programme of education or training. (Support will continue if the young person is 'being helped with education or training, to the end of the agreed programme of education or training (which can take them beyond their 25th birthday)').<sup>87</sup>

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<sup>84</sup>These provisions were introduced by the (principally by the Children (Leaving Care) Act 2000, the Adoption and Children Act 2002 and the Children and Young Persons Act 2008), amending the Children Act 1989

<sup>85</sup>See the Care Leavers (England) Regulations 2010 No. 2571, reg 7 and Children (Leaving care) (Wales) Regulations 2001, No. 2189, regulation 9

<sup>86</sup>Chapter 2, Department of Education, October 2010. See also Table 22 Young Persons entitled to care leaving support, Clements and Thompson *Community Care and the Law*, 5th edition pp 789–791

<sup>87</sup>Department of Education, 'Planning Transition to Adulthood for Care Leavers' Volume 3 of the Children Act 1989 Guidance and Regulations, October 2010, paragraph 2.4,

4.41 Box 8 includes some key points on planning for transition.<sup>88</sup>

### Box 8: Planning for transition

- > Transition to adulthood should not just start at 16, preparation for a time when they will no longer be looked after should be integral to the care planning process throughout the care of the child/young person.
- > Planning for transition must take place for every looked after child regardless of any other status that a child or young person may have.
- > *'Where it is likely that a care leaver will require continuing support from adult services, it will be good practice to make a formal referral as early as possible from the age of 16 so that eligibility is established in time for their 18th birthday. Protocols should clarify roles and funding responsibilities of different agencies.'*<sup>89</sup>
- > *'Where it is likely that a young person leaving care will need services into adulthood, an adult services worker should contribute to pathway planning from age 16 onwards, and the change of lead worker from one service to the other should be determined within the planning process taking account of the young person's wishes and assessed needs.'*<sup>90</sup>
- > A "pathway plan" setting out how the local authority will prepare and support the young person for transition to adulthood must be in place for all looked after children aged 16 and 17 who have been looked after for at least 13 weeks after they reached the age of 14.
- > The pathway plan must include an explicit assessment of the support the young person needs to develop the skills that s/he will require to be ready for transition to adulthood.
- > While local authority responsibilities towards disabled care leavers are the same as for all other care leavers, due to their additional needs, some young disabled people may draw on a number of other services, receive support from several professionals and have multiple plans. *'The local authority must ensure that these processes are streamlined as much as possible and roles and responsibilities discussed with the young person and their carers.'*<sup>91</sup>
- > Good pathway planning is critical and local authorities should prepare, in full consultation with young person, a pathway plan at the time the young person approaches 16. The pathway plan should map out the needs, aims and ambitions of the young person as they approach adulthood
- > This is so that that the transition is positive and, so that where the young person remains entitled to care leaving support, there is a continuing focus on working with the young person and other agencies to achieve the best possible outcomes.

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<sup>88</sup>See Department of Education's guidance 'Planning Transition to Adulthood for Care Leavers' Volume 3 of the Children Act 1989 Guidance and Regulations, October 2010 21.–2.5, 3.4 and 3.9; and Volume 2 of the Children Act 1989 Guidance, *Care Planning, Placement and Case Review, regulations and statutory guidance*, March 2010, 5.3

<sup>89</sup>*Planning Transition to Adulthood for Care Leavers* 6.9. See generally 6.1–6.19

<sup>90</sup>*Planning Transition to Adulthood for Care Leavers* 6.17

<sup>91</sup>*Planning Transition to Adulthood for Care Leavers* 6.3

## Charging for services

- 4.42 **Services to disabled children and young people:** Local authorities may charge for the services that they provide subject to various restrictions relating to the person's financial means. Whereas the parents of children under 16 may be charged, it is only the young person aged 16 or over who can be charged for the services provided.<sup>92</sup>
- 4.43 **Community care services following a community care assessment:** The assessment of the 'individual's ability to pay charges should be carried out promptly, and written information about any charges or contributions payable, and how they have been calculated, should be communicated to the individual.'<sup>93</sup> Local authorities must also provide information to the person, and if appropriate any carers, about any charges that are going to be made in respect of the community care services to be provided.<sup>94</sup>

## Direct Payments and Personal Budgets<sup>95</sup>

### Direct payments

- 4.44 Instead of providing or arranging the services that a disabled person needs, local authorities can be required to give the disabled person (or the parents of a disabled child) a cash payment sufficient to enable that person to purchase the services themselves. Direct payment of this kind 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 are paid to parents of disabled children up to the age of 18 but 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. (See section 17A Children Act 1989.)
  - Disabled adults are entitled to direct payments under section 57 of the Health and Social Care Act 2001.
  - If Direct Payments are used by the recipient to employ someone (such as a carer or personal assistant), the amount of the payment should be sufficient to top up all additional costs – such as Employer's NI contributions, holiday pay, employers liability insurance and so on.

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<sup>92</sup>For further information, see Clements and Thompson, *Community Care and the Law*, 5th Edition, 23.41.

<sup>93</sup>Paragraph 71.

<sup>94</sup>Community Care Assessment Directions 2004

<sup>95</sup>For more information on direct payments see: [www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Introductiontofinancialsupport/DG\\_10016128](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Introductiontofinancialsupport/DG_10016128)

## **Direct payments and care leavers**

4.45 Where local authorities have set up a Personal Assistance Support Scheme which includes a direct payment, the disabled care leaver's personal adviser will need to work with this scheme in order to support the young person to use these payments. Until the age of 18, these will be provided under section 17A of the CA 1989, and after the age of 18 direct payments can continue under section 57 of the Health and Social Care Act 2001.<sup>96</sup>

## **Personal budgets in social care**

4.46 Personal budgets are local authority money apportioned to individuals to manage their care costs in line with an agreed support plan, following a full community care 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.

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<sup>96</sup>Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009 SI No 1887

# Chapter 5: Health

*This chapter considers the responsibilities of NHS bodies in relation to disabled young people and their transition to adult services.*

It covers the following areas:

- Overview of NHS responsibilities
- NHS bodies' duty to assess
- Role of GPs
- Local authorities duties to children in hospital
- Policy guidance
- Disputes about funding
- Continuing NHS health care

## Overview of NHS responsibilities

5.1 Whereas there is a range of specific statutory duties in relation to local authorities' assessment of individuals' needs for social care and housing and determining how such needs should be met (if at all), the corresponding statutory duties on NHS bodies in relation to health care are 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 services is provided. Such services are to include 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'.<sup>97</sup>
- 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 2012 Primary Care

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<sup>97</sup>See sections 1 and 3 National Health Service Act 2006

Trusts (PCTs) have the primary responsibility for commissioning health care services in England.<sup>98</sup> In Wales, this responsibility is discharged by local health boards (LHBs).

- Detailed regulations set out the basis for establishing the responsible commissioner for NHS treatment of an individual patient i.e. which PCT / LHB will be responsible for funding an individual's NHS care and guidance explains how these regulations apply in particular situations such as when arrangements are made to place certain groups of children and young people 'in accommodation in the area of another PCT/ LHB for secondary healthcare type services'<sup>99</sup>
- Comply with general public law: All NHS bodies must '...comply with the law, respect fundamental human rights and ensure that their decisions are reached in accordance with established public law principles. They must not, for instance: ignore circular guidance, violate European Union law, operate an irrational or perverse policy, fetter their discretion to fund the treatment, fail to consult before reaching certain decisions or refuse funding due to the patient's financial circumstances.'<sup>100</sup>

## NHS bodies' duties to assess

5.2 *General:* Although there is no statute that places an explicit duty on NHS bodies to carry out an assessment of an individuals' health care needs:

- In many cases a duty is implied, in that carrying out an assessment (i.e. gathering the relevant information about the person and determining whether it is necessary to provide services to meet such needs) is an essential part of a process that must be followed by NHS bodies in order to exercise their statutory duties.<sup>101</sup>

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<sup>98</sup>As part of the reforms to be introduced by the Health and Social Care Act 2012, the role of PCTs will be taken over by 'Clinical Commissioning Groups' (due to be established across England by April 2013).

<sup>99</sup>The rules are complex – and outlined in Luke Clements and Pauline Thompson, *Community Care and the Law*, 5th Edition, LAG, para 6.71 – 6.99 and see also Department of Health, *Who Pays? Establishing the responsible commissioner*, September 2007

<sup>100</sup>Luke Clements and Pauline Thompson, *Community Care and the Law*, 5th Edition, LAG, 13.19

<sup>101</sup>Steve Broach, Luke Clements and Janet Read, *Disabled Children, A Legal Handbook*, Council for Disabled Children, LAG, 2010, at 178. The authors also suggest that the duty to assess can be implied by section 11 of the CA 2004 which requires NHS bodies and other organisations, including local authorities, to make arrangements to ensure that they safeguard and promote the welfare of children

- It is the view of the Department of Health and the Welsh Government that such a duty exists. For example, guidance concerning looked after children states: 'In general, PCTs have a duty to comply with requests by local authorities for assistance to make sure that the assessment happens'.<sup>102</sup>

5.3 *Responding to requests from local authorities:* As discussed above, local authorities must notify the PCT (England) or LHB (Wales) if during the community care assessment under section 47 NHS & CC Act 1990 it appears that the person has a health need. Although these health bodies are not under a statutory duty to respond to this request a 'failure to respond – or failure to respond within a reasonable time or in a reasonable manner – would, however, be vulnerable to challenge as maladministration'.<sup>103</sup> A duty also exists on both bodies to cooperate with each other (section 82 NHS Act 2006).

5.4 *Referrals to local authorities:* If an NHS body is assessing a person's needs (whether or not potential eligibility for NHS continuing healthcare has been identified) and the assessment indicates a potential need for community care services that may fall within a local authority's responsibilities, it should notify the local authority of this and consider inviting it to participate in the assessment process.

## Role of GPs

5.5 Disabled young people will be entitled to be registered with a GP based in the area in which they live, if not already registered (children under 16 years of age should have been registered with a GP by their parents).

5.6 *A Transition Guide for all Services: key information for professionals about the transition process for disabled young people* explains that GPs are 'an initial point of access to all primary health services' but that for many disabled young people, 'contact with their GP is minimal and most contact is with their paediatrician' and then the 'change to adult health services often involves multiple specialists rather than one person overseeing their medical needs' with each of these specialists needing to get to know the young person and carry out separate assessments. However, the guide emphasises the importance of the GP:

- The GP or school doctor needs to be involved in the transition planning process, as they become the first point of contact for young people on leaving school for any therapies which may have been provided via the school.

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<sup>102</sup>HM Government, *The Children Act 1989 Guidance and Regulations, Volume 2: Care Planning, Placement and Case Review (England) Regulations 2010 and statutory guidance*, March 2010, paragraph 2.51

<sup>103</sup>See Luke Clements and Pauline Thompson *Community Care and the Law* 5th edition para. 3.128

- Where there are continuing needs and an adult service exists, involved health professionals, including therapists, can refer on directly, however the GP needs to be kept informed as the ongoing medical link.<sup>104</sup>

5.7 GPs are also obliged to make appropriate referrals to social services where the person appears to be in need of community care services.<sup>105</sup>

### Local Authorities duties to young people in hospital

5.8 Where a child or young person under the age of 18 is likely to be accommodated in hospital for three months or more, the relevant local authority is required to take steps to ensure that the child or young person's welfare is adequately safeguarded and promoted.<sup>106</sup> Local authorities should arrange for visits for children or young people in hospital who are being looked after by the local authority.<sup>107</sup>

### Policy guidance

5.9 There is a wealth of policy guidance that highlights the importance of planning for transition. The *National Service Framework for Children, Young People and Maternity Services for England*<sup>108</sup> and Wales highlight the importance of ensuring an effective transition from children's services to services for adults. A key document for health professionals is *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 ('Moving on Well')*. In addition policies specific to the areas of mental health and palliative care include guidance on transition planning. Key aspects of these documents are summarised below.

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<sup>104</sup>Department of Children, Schools and Families and Department of Health, 2007, at page 41

<sup>105</sup>See Clements and Thompson *Community Care and the Law* 5th edition para. 13.46

<sup>106</sup>Section 85(4) Children Act 1989. The relevant local authority will be the authority in which the child or young person was ordinarily resident prior to being admitted to hospital.

<sup>107</sup>They are required to make such visits in relation to children and young people subject to a care order – see section 116 MHA 1983 (which applies to all such patients, whether or not they are receiving treatment for mental disorder). The Code of Practice to the Mental Health Act 1983 (August 2008) states that local authorities should arrange visits for looked after children and young people, whether or not they are subject to a care order (paragraph 36.80).

<sup>108</sup>Although the National Service Framework no longer forms part of the Government's health policy (England), the aspirations set out in the NSF remain part of its overall policy objectives.

## National Service Framework for Children, Young People & Maternity Services

5.10 In England, Standard 4 of the National Service Framework for Children, Young People and Maternity Services ('the NSF for Children, (England)') states: 'All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood.' It sets out a range of actions that need to be taken by NHS bodies and partner organisations. These include:

- All transition processes are planned and focussed around preparation of the young person rather than the service organisation.
- Young People and their families are actively involved in transition planning.
- Policies on health services for young people are developed between agencies as appropriate, and ensure that:
  - Young people are not transferred fully to adult services until the supports are in place to enable them to function in an adult service;
  - Individual disciplines have clear good practice protocols for the management of young people's health during transfer to adult care;
  - General Practitioners are fully involved; and
  - Joint audit of local transitional arrangements is undertaken.

5.11 In Wales, the National Service Framework for Children, Young People and Maternity Services Wales<sup>109</sup> includes a Transitions Standard,<sup>110</sup> which states:

*'Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families and carers, and care leavers, are offered a range of co-ordinated multi-agency services, according to assessed need, in order to make effective transitions from childhood to adulthood.'*

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<sup>109</sup><http://wales.gov.uk/docs/caecd/publications/090414nsfchildrenyoungpeoplematernityen.pdf>

<sup>110</sup>NSF for Children (Wales) Page 54

5.12 This standard includes the following key actions:

- There is an inter-organisation system to identify children who will require transition into adult services in the year before their 14th birthday (in Year 8). This informs the strategic planning for all organisations.
- A key transition worker is appointed to all disabled young people at age 14 (to co-ordinate the planning and delivery of services before, during and after the process of transition, to monitor and have contact with the young person until the age of 25 years and to ensure that the young people, their families and all relevant agencies are appropriately involved in the planning process).
- Information about how to gain access to services and facilities is available to disabled young people.
- There is one joint organisations' transition plan produced for each disabled young person which forms the basis of the Unified Assessment within adult services and specifies arrangements for continuing support and services.
- The joint organisations' transition plan is reviewed at least annually or, in the case of young people who are looked after, every six months in accordance with statutory regulations Children (Leaving Care) Act 2000. During the year before their 18th birthday the plan is reviewed each term.

## Moving on Well

5.13 Although this guidance is directed to English health bodies, it is clearly of relevance to Welsh NHS bodies (where no equivalent guidance exists).

5.14 *Moving on Well* provides guidance for health professionals and their partners in both children's and adult health services, including GPs and commissioners of services. Its focus is on young people with conditions such as such as cerebral palsy, muscular dystrophy and spina bifida, learning disabilities, autism spectrum disorders and acquired brain injury but the general points will be relevant to all health needs. The Department of Health considers that all transition planning for young people 'should take full account'<sup>111</sup> of the approaches set out in *Moving on Well and A transition guide for all services*<sup>112</sup> (which explains how all relevant services should work together in transition planning). Both these policies emphasise the need for the relevant agencies to work together to plan for the transition of young people from children's services to adult services and to start the planning process at an early stage.

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<sup>111</sup>National Framework for Children and Young People's Continuing Care at para. 80.

<sup>112</sup>Departments of Children Schools and Families and Department of Health, 2007 <http://media.education.gov.uk/assets/files/pdf/a/a%20transition%20guide%20for%20all%20services.pdf>

5.15 In *Moving on Well*, the young person's needs and aspirations are placed firmly at the centre of the planning process, which is intended to prepare the young person and their family for the move to adulthood and transfer to adult healthcare. The planning process should start at the latest when the child is aged 13 or 14 (Year 9 in school) and recognise that the young person's needs will change over time. The guidance stresses that *'early engagement with adult health services and continuing links with the GP reduces the risk of overdependence as young people and families move on from comprehensive children's services'*. It includes a very detailed self-assessment form for young people to complete which will then inform the health care team's preparation of a transition plan which meets the young person's needs and helps them take responsibilities for managing their own health care. This health transition plan should be regularly reviewed and incorporated into the young person's broader transition plan (such as the SEN statement review process).<sup>113</sup>

5.16 *Moving on Well* provides advice on areas such as key principles for transition planning, areas to be covered by the health care plan, engaging with the young person, the roles of the core professionals, sharing information and confidentiality and the role of key worker in co-ordinating the health plan. It also stresses that all agencies have a responsibility to work together, while non-statutory and voluntary agencies should also be involved as appropriate. Health professionals, with school staff, the careers adviser and the transition social worker should *'work in partnership with the young person and family to agree how they prepare for the process of transition and how the young person will be supported to have a lead voice in planning and reviews'*. In addition: *'Health services should support the vocational and employment needs of young people beyond traditional health settings'*.<sup>114</sup>

## Mental Health

5.17 In England, the government's strategy for mental health, *No health without mental health* published in February 2011 states that services can improve transitions, including from child and adolescent mental health services (CAMHS) into adult mental health services, or back to primary care, by:

- planning for transition early, listening to young people and improving their self-efficacy;
- providing appropriate and accessible information and advice so that young people can exercise choice effectively and participate in decisions about which adult and other services they receive; and
- focusing on outcomes and improving joint commissioning, to promote flexible services based on developmental needs.<sup>115</sup>

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<sup>113</sup>See pages 11, 14 and 21

<sup>114</sup>*Moving on Well* pages 22–23

<sup>115</sup>See para. 3.38

5.18 The National Service Framework for Children, Young People and Maternity Services (England) highlights the importance of 'ensuring the smooth transition of care for young people from child and adolescent mental health services to services for adults'. *Standard 9 of the Children's NSF – The Mental Health and Psychological Well-being of Children and Young People* ('the CAMHS Standard') states:

*'Services ensure that young people experience a smooth transition of care between child and adult services and protocols are in place to ensure a flexible and organised approach is taken and that a developmental perspective is incorporated into staff training.'*<sup>116</sup>

5.19 The CAMHS standard states that in order to ensure the continuity of care, the Care Programme Approach (CPA) should be used for individuals under the age of 18 when such young people are being transferred from child to adult services.<sup>117</sup> The care coordinator should follow the transition protocols at their Trust for CAMHS to adult services.<sup>118</sup>

### Implementing Fulfilling and Rewarding Lives

5.20 In England, *Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*<sup>119</sup> aims to help local authorities, NHS bodies and NHS Foundation Trusts to develop services that support and meet the locally identified needs of people with autism and their families and carers. In relation to transition planning for young people with autism the guidance states:

- Professionals working with a young person with autism approaching transition, including CAMHS professionals, special educational needs co-ordinators (SENCOs) and social workers should inform:
  - the parent and young person of their right to a community care assessment
  - carers of the right to a carer's assessment.
- NHS bodies and NHS Foundation Trusts should ensure that protocols are in place in every local area for the transition of clinical mental health care for children with autism in receipt of CAMHS.
- Where individuals do not fulfil referral criteria for adult mental health teams, it would be good practice for local authorities and NHS bodies to signpost on to other sources of support and information available locally and nationally.<sup>120</sup>

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<sup>116</sup>Page 22

<sup>117</sup>Page 22

<sup>118</sup>*Refocusing the Care Programme Approach* page 48

<sup>119</sup>Department of Health, 17th December 2010 issued to local authorities, NHS bodies and NHS Foundation Trusts under section 2 Autism Act 2009

<sup>120</sup>Page 21

## Palliative Care

5.21 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 and young people.

5.22 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*<sup>121</sup> 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'.

5.23 In relation to transition the guidance emphasises the importance of 'ensuring that services are properly planned so that the young person can move seamlessly into adult care at a time appropriate to them and their family'. The transition process must begin early, be planned and regularly reviewed, and be age and developmentally appropriate. Thus:

*'successful transition process should include education, social services and voluntary agencies as active partners. In addition it will:*

- *Start early*
- *Be flexible*
- *be individually tailored to meet the needs of the young person and family; and*
- *continue, if necessary, following the transfer to adult care.*<sup>122</sup>

5.24 Noting that co-ordination of transition care is critical, the guidance states 'if this does not already exist, a transition support worker/named key or lead worker should ideally be identified for each young person to oversee their transition, ensuring links with a counterpart within the receiving adult service.' It recommends the Association for Children's Palliative Care ('ACT') Transition Care Pathway 2007,<sup>123</sup> as providing a good framework for planning transitional care for life-limited young people, ensuring that their needs are central to the process.

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<sup>121</sup> Department of Health 2008 [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_083108.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_083108.pdf)

<sup>122</sup>Page 40

<sup>123</sup>Page 40. The ACT publication can be found at: [www.act.org.uk/page.asp?section=115&sectionTitle=ACT%27s+transition+care+pathway](http://www.act.org.uk/page.asp?section=115&sectionTitle=ACT%27s+transition+care+pathway)

5.25 Standard 4 of the All Wales Palliative Care Standards for Children and Young People's Specialised Healthcare Services<sup>124</sup> identifies a key action point as: 'Transitional arrangements are in place to plan for seamless transition to adult services.' It also notes that:

*'The age for transition to adult services must be flexible to ensure that all young people are treated by the most appropriate professional and in the most appropriate setting. This will depend on the young person's mental, emotional and physical development.'*<sup>125</sup>

### Continuing NHS health care

5.26 Some young people's health care needs are so significant that the primary obligation for meeting their health and social care needs falls on the NHS rather than social services department. Such persons are described as being 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. Accordingly, the transition arrangements for this group of young people will require particular attention.

### Young People under 18

5.27 In England, the *National Framework for Children and Young People's Continuing Care*<sup>126</sup> 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'.

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<sup>124</sup>2008 Welsh Assembly Government, available at: <http://wales.gov.uk/docs/caecd/publications/090908palliativecarestandardsen.pdf>

<sup>125</sup>Page 4

<sup>126</sup>Department of Health, (25 March 2010): [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_114784](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114784)

5.28 To date no equivalent guidance has been issued in Wales although in December 2011 the Welsh Government issued draft guidance for consultation<sup>127</sup> (closing March 2012). The draft is silent as to when implementation is proposed.

5.29 *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.'*<sup>128</sup>

### Young People aged 18 or over

5.30 Whereas the English guidance on continuing care for children and young people under the age of 18 expects other agencies to be involved in the planning and delivery (and by implication funding) of the young person's care, this is not the case for continuing health care for adults.

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<sup>127</sup>*Children and Young People's Continuing Care Guidance* at: <http://wales.gov.uk/docs/dhss/consultation/111220-careen.pdf>

<sup>128</sup>Pages 10–11

5.31 In both England and Wales the continuing healthcare package is comprised of all the persons' eligible health and social care needs and is funded solely by the NHS.<sup>129</sup> Each country has guidance on NHS continuing care for adults which sets out the eligibility for continuing care. In England this guidance notes that the term 'continuing care' has different meanings in child and adult services and that it 'is important that young people and their families are helped to understand this and its implications right from the start of transition planning'.<sup>130</sup>

5.32 If a person does not qualify for full NHS continuing healthcare, the NHS may still have a responsibility to contribute to that person's health needs – either by directly providing services or by part-funding the package of support.<sup>131</sup> Furthermore:

- Where a package of support is provided or funded by both a local authority and an NHS body, this is known as a 'joint package' of continuing care.
- A joint package of care could include NHS-funded nursing care and other NHS services that are beyond the powers of a local authority to meet.
- The joint package could also involve both the PCT/LHB and the local authority contributing to the cost of the care package, or the PCT/LHB commissioning and/or providing part of the package.
- Full NHS Continuing Healthcare (or joint packages) can be funded in any setting – including a nursing or residential care home, or in a person's own home.

5.33 Where a young person is receiving support via a placement outside of the PCT's area, the adult National Framework (for England)<sup>132</sup> emphasises that:

- There should be clear agreement between all relevant PCTs at an early stage in the transition planning process as to who the responsible commissioner presently is, and to any potential future changes to the arrangement. (This should be determined by applying the principles set out in the *Who Pays? Establishing the responsible commissioner* ('the Responsible Commissioner guidance'), which is discussed below.)
- All PCTs with present or future responsibilities should be actively represented in the transition planning process.
- A dispute or lack of clarity over commissioner responsibilities should not lead to a lack of appropriate input in the transition process.

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<sup>129</sup>For England, see *The NHS Continuing Healthcare (Responsibilities) Directions 2009*, 1(2); for Wales, see *Continuing NHS Healthcare The National Framework for Implementation in Wales* May 2010 EH/ML/018/10 Welsh Assembly Government Circular: 015/2010, K1

<sup>130</sup>Paragraph 119

<sup>131</sup>See page 36 of Department of Health *The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* July 2009 (revised)

<sup>132</sup>Paragraph 128

## Specific points on transition

5.34 Both the (English) guides on continuing care (children and adults) include the following points about transition from children's services to adult's services.

- Children's continuing care teams should identify those young people for whom it is likely that adult NHS continuing healthcare will be necessary and notify the relevant PCT who will hold adult responsibility for them.
- Such young people should be identified when they reach the age of 14.
- This should be followed up by a formal referral for screening at age 16 to the adult NHS continuing healthcare team at the relevant PCT.
- By the age of 17, an individual's eligibility for adult NHS continuing healthcare should be decided in principle by the relevant PCT in order that, where applicable, effective packages of care can be commissioned in time for the individual's 18th birthday (or a later date if it is jointly agreed that it is more appropriate for responsibility to transfer at that time).
- Where needs may change, it may be appropriate to make a provisional decision and then re-check it through repeating the process as adulthood approaches.
- Entitlement for adult NHS continuing healthcare should initially be established through use of the decision-making process set out in the **adult** National Framework.<sup>133</sup>
- The health plans and other assessments and plans developed as part of the transition process will provide key evidence to be considered in the decision-making process. Any entitlement that is identified by means of these processes before a young person reaches adulthood will come into effect on their 18th birthday, subject to any change in their needs.
- No services or funding should be withdrawn unless a full assessment has been carried out in respect of need for adult health and social care services, including funding responsibilities.

5.35 Even if a young person is not entitled to adult NHS continuing healthcare, their health needs will still be the responsibility of the NHS. In such circumstances, PCTs/LHBs should continue to play a full role in transition planning for the young person, and should ensure that appropriate arrangements are in place for services that meet these needs to be commissioned or provided. The focus should always be on the individual's desired outcomes and the support needed to achieve these.<sup>134</sup>

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<sup>133</sup>Department of Health, *The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* revised 22nd July 2009

<sup>134</sup>Department of Health *The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* July 2009 (revised) paragraph 129

## Disputes about funding

- 5.36 In some cases there may be disagreements over who has the responsibility to fund an individual's care. Guidance makes clear that disputes between agencies should not affect the provision of care. For example Principle 2 of the Department of Health's, *Who Pays? Establishing the responsible commissioner* states that no treatment should be refused or delayed due to uncertainty or ambiguity as to which PCT is responsible for funding an individual's healthcare provision.
- 5.37 If the young person suffers as a result of a such a dispute, this will amount to maladministration and subject to challenge on grounds such as the failure of the relevant bodies to work together to improve the well being of such young people (see for example section 10 of the CA 2004 and section 82 of the NHS Act 2006).

### Health Care: Key Points

- > All disabled young people, like everyone else, are entitled to general health care and should be registered with a GP.
- > NHS bodies must act reasonably and within their legal powers: practitioners must be able to demonstrate that when making decisions on behalf of a public body, they have lawful and sound reasons for the decisions that they take. (Such reasons should be recorded in writing so that the action taken can be justified if challenged).
- > The transition from paediatric services to adult services for young people with significant health conditions should be in accordance with the best practice guide *Moving on Well*.
- > There are specific issues to consider for the transition of those disabled young people who are receiving continuing health care.

# Chapter 6: Housing

*Disabled young people will require suitable accommodation for themselves, whether they continue to live with their families or wish to live more independently. For some disabled young people this will require adaptations to be made to their home.*

The following areas are covered in this section:

- Accommodation under the Children Act 1989 ('the CA 1989')
- Accommodation under the National Assistance Act 1948 ('the NAA 1948')
- Respite and short breaks
- Supported living arrangements
- Disabled Facilities Grant
- Homelessness

## Accommodation under the Children Act 1989

6.1 The wide range of services that local authorities can provide to children in need under the CA 1989 includes the provision of accommodation. This can be under section 17 or section 20 of the CA 1989.

6.2 *Section 20 of the CA 1989*: places a duty on local authorities to provide accommodation to a child in need who presents themselves as requiring assistance. The local authority:

- **Must** provide 'accommodation for any child in need within their area who appears to them to require accommodation' as a result of
  - a) there being no person who has parental responsibility for him;
  - b) his being lost or having been abandoned; or
  - c) the person who has been caring for him being prevented (whether or not permanently, and for whatever reason) from providing him with suitable accommodation or care.<sup>135</sup>

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<sup>135</sup>Section 20(1) Children Act 1989

- **Must** 'provide accommodation for any child in need within their area who has reached the age of sixteen and whose welfare the authority consider is likely to be seriously prejudiced if they do not provide him with accommodation.'<sup>136</sup>

6.3 *Section 17(6) of the CA 1989: permits* local authorities to provide accommodation. Such accommodation will 'almost always' concern children and young people 'needing to be accommodated with their families'.<sup>137</sup>

6.4 In *G(FC) v Southwark*, the House of Lords stated that local authorities must 'look after the children in their area irrespective of where they are habitually resident' and '*...there should be no more passing the child from pillar to post while the authorities argue about where he comes from.*'<sup>138</sup>

6.5 As discussed in Chapter 4 above, young people who are accommodated under section 20 of the CA 1989 may in certain circumstances become entitled to the benefit of the 'children leaving care' provisions. However, these rights are not available to those who are accommodated under section 17 of the CA 1989. Reflecting recent case-law,<sup>139</sup> guidance on this issue makes clear that local authorities cannot avoid their obligations by determining that the accommodation is provided under section 17 rather than section 20. *Provision of accommodation for 16- and 17-year-old young people who may be homeless and/or require accommodation* states that in relation to homeless 16 and 17 year olds who are assessed as being 'children in need':

*'The powers of local authorities to provide accommodation under section 17 cannot be used to substitute for their duty to provide accommodation under section 20(1) of the 1989 Act...'*<sup>140</sup>

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<sup>136</sup>Section 20(3) Children Act 1989

<sup>137</sup>*Provision of accommodation for 16- and 17-year-old young people who may be homeless and/or require accommodation* Department Children Schools and Families and Communities and Local Government, April 2010, 2.54 <http://www.education.gov.uk/childrenandyoungpeople/families/childrenincare/news/a0065647/children-in-care-news>

<sup>138</sup>*R on the application of G(FC) v Southwark LBC*, 12 CCLR 437 at 447

<sup>139</sup>*R (M) v Hammersmith and Fulham LBC* [2008] UKHL 14.

<sup>140</sup>Department of Children Schools and Families and Communities and Local Government, April 2010, 2.55. See also Clements and Thompson *Community Care and the Law* 5th edition, 23.58–23.60

## Residential accommodation

6.6 The responsibilities of social services authorities to provide residential accommodation to disabled adults and others are dealt with primarily under Part 3 of the the NAA 1948, in particular section 21.<sup>141</sup> The key provisions are summarised below:

- **Section 21 NAA 1948:** local authorities must provide accommodation to individuals age 18 or over who by reason of age, illness, disability or other circumstances are in need of care and attention. This applies to people who are ordinarily resident in the local authority's area and other persons who are in urgent need of residential accommodation. Usually the accommodation will be provided in a care home, but other accommodation, such as ordinary housing can also be provided.<sup>142</sup>
- **Additional provisions:** Accommodation can be provided to individuals receiving aftercare services under section 117 of the Mental Health Act 1983 (see paragraph 4.4. above) – note this provision can apply to individuals of any age. Where local authorities are providing workshops under section 29 NAA 1948 to disabled people aged 18, they can also provide hostel accommodation.

## Respite care and short breaks

6.7 Most respite care will be provided under section 2 Chronically Sick and Disabled Persons Act 1970 in the form of a 'sitting service, an overnight 'in home' service or, as a community-based day service'.<sup>143</sup> This duty is reinforced by a duty under the CA 1989 – to provide respite care (when assessed as needed) – it requires local authorities 'to assist individuals who provide care for such children to continue to do so, or to do so more effectively, by giving them breaks from caring',<sup>144</sup> by providing a range of services such as day-time care and overnight care in their own homes or elsewhere, educational or leisure activities for disabled children outside their own homes and services to assist carers in the evenings, at weekends and during the school holiday.<sup>145</sup>

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<sup>141</sup>See also section 29 NAA 1948 which provides that local authorities can provide hostel accommodation for disabled people engaged in workshops

<sup>142</sup>See discussion in Clements and Thompson *Community Care and the Law* 5th edition, 7.44–7.53

<sup>143</sup>Clements and Thompson *Community Care and the Law* 5th edition 23.55

<sup>144</sup>Part 1, Schedule 2, para 6 CA 1989

<sup>145</sup>Breaks for Carers of Disabled Children Regulations 2011 SI No 707

## Residential respite care<sup>146</sup>

6.8 There may be times when a young person needs to have some time away from the family home. Such short breaks can be provided under section 17(6) of the CA 1989 or section 20(4) of the CA 1989. In some circumstances this will mean that the young person is a 'looked after child', depending on whether the young person is accommodated under section 17 CA of the 1989 or section 20 of the CA 1989.<sup>147</sup> (More information on 'looked after children' is given below.) In summary:

- If the young person is being provided with accommodation under section 20 of the CA 1989 s/he will be a looked after child if the placements lasts for a continuous period of more than 24 hours.
- If the young person 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 CA 1989.
- If the young person is provided with accommodation under section 17 of the CA 1989 s/he will not be a looked after child.

6.9 Chapter 2 of the Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks, provides guidance to assist in determining whether the accommodation provided as part of the arrangements for short breaks or respite care is provided under section 17(6) of the CA 1989 or under section 20(4) of the CA 1989.<sup>148</sup> The guidance states:

*'If the accommodation is provided under section 20(4) for a continuous period of more than 24 hours, then the child is looked after by the local authority for the period in which the child is accommodated...*

*...If the child is looked after, then the placement must be a placement with local authority foster parents, in a registered children's home; or in other appropriate arrangements under section 22C of the 1989 Act. In these circumstances the placement must comply with the Regulations, which require the local authority to make short and long term arrangements for the child's care (i.e. have a care plan) amongst other matters.'*<sup>149</sup>

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<sup>146</sup>See Clements and Thompson *Community Care and the Law* 5th edition 23.57

<sup>147</sup>See LAC (2003)13. In relation to short term breaks, LAC (2003)13 is amended by *Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks*, Department of Children, Schools and Families, 2010, see para 2.6

<sup>148</sup>Department of Children, Schools and Families, 2010.

<sup>149</sup>Para. 2.14 – 2.15

6.10 In both England and Wales the regulations concerning the care planning, placement and review of looked after children are modified in relation to some disabled children who are looked after due to the level of short-term breaks provided to them. The modifications apply where children and young people under the age of 18 are attending successive and pre-planned respite care away from their home and aim to lessen the administrative burden on local authorities. They allow such placements to be treated as a single placement 'so that they are more appropriate for situations where the child's parents are effectively planning for their child's future, and the child is provided with a series of short breaks as a measure of family support'.<sup>150</sup> In such cases the focus is on the preparation of a 'short term break plan' which seeks to ensure that the child or young person's needs are met while they are away from their parents.<sup>151</sup>

6.11 The modified arrangements apply:

- In England: if the child/young person receives the short break:
  - in the same setting; and
  - no single placement lasts for more than 17 days; and
  - the total of the short breaks in one year is 75 days or less.<sup>152</sup>
- In Wales: if the child/young person receives the short break:
  - in the same setting; and
  - if no single placement lasts for more than 4 weeks and
  - the total duration of the placement does not exceed 120 days in any 12 month period.<sup>153</sup>

### Adaptations: Disabled facilities grants<sup>154</sup>

6.12 Disabled facilities grants (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<sup>155</sup> and £36,000 in Wales,<sup>156</sup> although local authorities are empowered to make higher awards.

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<sup>150</sup>Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks, para 2.17

<sup>151</sup>See paragraphs 2.19 – 2.28 and Table 1 on page 16 of the guidance for further information.

<sup>152</sup>Care Planning, Placement and Case Review (England) Regulations 2010 SI no 959, para 48

<sup>153</sup>The Placement of Children (Wales) Regulations 2007 SI No 310 (W27) regulation 14

<sup>154</sup>For more information on Disabled Facilities Grants see Clements and Thompson *Community Care and the Law* 5th edition, 15.27–15.118

<sup>155</sup>Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008 SI No 1189, order 2.

<sup>156</sup>Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (Wales) Order 2008 SI No 2370 (W 205), order 2.

## Legislation, guidance and potential reform

6.13 The availability and administration of DFGs are governed by the Housing Grants, Construction and Regeneration Act (HGCR) 1996<sup>157</sup> and regulations.<sup>158</sup> Detailed 'non-statutory' good practice guidance on the scheme has been issued:

- England: Delivering Housing Adaptations for Disabled People: A Good Practice Guide (June 2006). It states that the underlying purpose of DFGs is 'to modify disabling environments in order to restore or enable independent living, privacy, confidence and dignity for individuals and their families'.<sup>159</sup>
- Wales: relatively brief guidance was issued in 2002 (Housing Renewal Guidance NAFWC 20/02 Annex D).<sup>160</sup>

6.14 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.

## The role of the housing authority

6.15 The housing authority is responsible for the administration of the DFG through all stages from initial enquiry to post-completion approval,<sup>161</sup> although the original application may be instigated (and referred to it) by a social services authority as part of the community care or Children Act assessment process.

- The housing authority must decide whether it is reasonable and practicable to carry out the proposed adaptation works. In making its assessment, a housing authority must have regard to the age and condition of the dwelling or building.<sup>162</sup>
- It must also decide whether the proposed works are necessary and appropriate to meet the needs of the disabled occupant.

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<sup>157</sup>See Part I, section 23

<sup>158</sup>Principally the Housing Renewal Grants Regulations 1996 (regularly updated in both England and Wales).

<sup>159</sup>*Delivering Housing Adaptations for Disabled People: A Good Practice Guide*, June 2006, jointly issued by the Department for Communities and Local Government, Department for Education and Skills and the Department of Health, at para 1.

<sup>160</sup>National Assembly for Wales (2002): contains only relatively brief advice concerning DFGs

<sup>161</sup>See Clements and Thompson *Community Care and the Law* 5th edition for discussion on concerns about the delays in the processing of DGF applications, priority cases and interim arrangements – 15.108-15.118

<sup>162</sup>Section 24(3)

- Housing authorities, which are not themselves social services authorities, must consult the relevant social services authority on the adaptation needs of disabled people. A similar level of cooperation is required in unitary authorities.<sup>163</sup> The consideration of what 'meets' the assessed needs of a disabled person may include consideration of any alternative way of meeting the need.
- When undertaking their assessment, the social services authority will generally rely on an assessment by an Occupational Therapist. Such assessments should, as a general rule, look at all the relevant needs of the disabled person not just matters that can be funded by a DFG.<sup>164</sup>

## Eligibility

6.16 DGGs are only available to disabled people<sup>165</sup> who live (or intend to live) in the accommodation as their only or main residence<sup>166</sup> (this includes people living in rented accommodation as well as well as owner-occupiers). This is subject to:

- *Five years occupancy*: the requirement that the person intends that the accommodation will be his or her only or main residence for a period of five years<sup>167</sup> 'or for such shorter period as his health and other relevant circumstances permit'.<sup>168</sup>
- *Means test*: for disabled adults<sup>169</sup> – only the financial circumstances of the disabled occupant,<sup>170</sup> his or her spouse or civil partner or co-habiting partner are assessed and not other members of the household. Applications for a disabled person under the age of 19 no longer require a means test.
- Where a disabled child has parents who are separated and the child lives for part of the time with both parents, arrangements may need to be made to provide for adaptations at both locations. However, a mandatory DFG (see below) is only available at the 'main residence' of the disabled occupant.<sup>171</sup> Accordingly, if a community care assessment determines that adaptations are required at the other location, this may trigger a duty under the Chronically Sick and Disabled Persons Act 1970 to facilitate those adaptations – see paragraph 6.18 below).

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<sup>163</sup>Complaint no 07C03887 against Bury MBC 14th October 2009, para 38.

<sup>164</sup>Complaint no 07/A/11108 against Surrey County Council 11 November 2008.

<sup>165</sup>Persons who are 'substantially and permanently handicapped' within the meaning of NAA 1948 s29

<sup>166</sup>Annex B paras 42–47 of the practice guidance and Annex D para 42 of the Welsh guidance.

<sup>167</sup>See section 44 (3) HGCRA 1996 and the Housing Renewal Grants Regulations which are subject to annual amendment in England and separately in Wales.

<sup>168</sup>HGCRA 1996 ss21(2)(b) and 22(2)(b). See also the Practice Guidance Paragraph 5.22 and para 29 of annex B

<sup>169</sup>Section 30 HGCRA 1996

<sup>170</sup>The disabled occupant may or may not be the applicant.

<sup>171</sup>See annex B para 50 of the practice guidance

## Grants

6.17 Mandatory and discretionary grants are available. The main purposes for which mandatory grants are made are to facilitate access and provision.<sup>172</sup> Box 9 sets out the primary purpose of such grants. Housing authorities have a wide ranging power to give discretionary assistance, in any form, for adaptations or other housing purposes.<sup>173</sup>

### Box 9: 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.

## Responsibilities of other agencies

6.18 Both the NHS and local social service authorities have responsibilities in relation to adaptations:

- NHS bodies: have extensive statutory powers to transfer monies to social services and the guidance advises<sup>174</sup> 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.

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<sup>172</sup>See Section 23(1) of the 1996 Act

<sup>173</sup>Article 3 of the Regulatory Reform (Housing Assistance) (England and Wales) Order 2002 (RRO) See for England: Office of Deputy Prime Minister circular 05/2003 Housing Renewal and for Wales: National Assembly for Wales (2002) Housing Renewal Guidance NAFWC 20/02.

<sup>174</sup>Department for Communities and Local Government (2006) *Delivering Housing Adaptations for Disabled People: A Good Practice Guide*, June 2006 para 5.26 and 5.24 and National Assembly for Wales (2002) Housing Renewal Guidance NAFWC 20/02 paras 30 and 34.

- Social services authorities: the fact that a housing authority refuses or is unable to approve the grant (for example because the works in question do not come under the mandatory scheme, or because the applicant fails the means test) does not absolve the social services authority of its duty to meet an assessed need under section 2 of the CSDPA 1970.<sup>175</sup> It is maladministration for a local authority to fail to appreciate that it has a duty under section 2 of the 1970 Act to provide adaptations.<sup>176</sup>

## Supported housing

6.19 There are various accommodation arrangements that might be applicable to a young disabled person wishing to live independently. Two significant (non-care home) arrangements are:

### Adult placements or shared lives schemes

6.20 Adult placements or 'shared lives schemes' are frequently likened to fostering arrangements. They involve a provider (often, but not always, a local authority) placing a vulnerable and disabled adult in the care (and frequently the home) of an approved adult placement carer.

- Most commonly the disabled person has learning disabilities but the scheme is not limited in this respect and can provide for people with physical disabilities, mental health issues, or drug/alcohol problems.
- The purpose of such an arrangement is to enable the person to live as independently and to have as normal a life in the community as is possible. Placements may be long term or as a transitional arrangement. Before any placement the disabled person must have been assessed under the community care legislation and the placement must be deemed an appropriate care plan to meet the person's assessed needs.
- Disabled people in an adult placement can be charged for their accommodation in the normal way – and apply for housing benefit to help with such costs.<sup>177</sup> Their care support services are subject to the standard charging rules applying to all non-domiciliary care services (see 4.42–4.43 above).

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<sup>175</sup>See para 2.6 of the practice guidance

<sup>176</sup>Complaint no 05/C/13157 against Leeds City Council 20 November 2007, and see also complaint no 10 008 979 about Liverpool City Council 4 April 2011.

<sup>177</sup>Almost invariably, such schemes will not however qualify as exempt accommodation for housing benefit purposes – see Upper Tribunal decision [2009] UKUT 12 (AAC)

## Supported living

6.21 Supported living is a generic term that has come to describe arrangements whereby a local authority secures a package of care together with accommodation (which is not a residential care home) for a disabled, elderly or ill person. However, because of the way the arrangements are made (the delivery of care being separated at an organisational level, from the provision of accommodation<sup>178</sup>), the accommodation is not deemed to be a registered care home and so does not have to be registered as such under the relevant legislation. Because of this, the disabled person in such a supported living arrangement can benefit from a variety of funding streams (depending upon the particular scheme) including enhanced rates of housing benefits, 'supporting peoples' monies and various other social security payments.

- While the goal is to maximise user independence, 'supported living' packages do not necessarily promote independent living. There are concerns that supported living may result in less security and an inferior support package.<sup>179</sup>
- Disabled people in supported living schemes can be charged for their care support in the normal way – i.e. subject to the standard charging rules applying to all non-domiciliary care services (see paragraphs 4.42–4.43 above). Guidance has been issued (jointly with the Department of Health) concerning charges for such schemes.<sup>180</sup>

## Homelessness

6.22 The duties of local authorities to provide accommodation to homeless people under part 7 of the Housing Act 1996 may apply to disabled children and young people and their families. This is because individuals are considered to be 'homeless' not only when they have no accommodation but also if they have no accommodation which it 'would be reasonable' for them to continue to occupy.<sup>181</sup> The local authority will be required to provide accommodation to such homeless disabled children/young people and their families if a member of the household is in 'priority need' and not intentionally homeless.<sup>182</sup>

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<sup>178</sup>The Care Standards Act 2000 s3(2) (which applies in Wales) requires establishments to be registered if they provide accommodation 'together with nursing or personal care'; and in England in general the provision of residential accommodation, 'together with nursing or personal care' is a regulated activity under Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 SI 781 Schedule 1 para 2

<sup>179</sup>Clements and Thompson *Community Care and the Law* 5th edition 15.35-136

<sup>180</sup>See Housing Learning & Improvement Network (2010) *Charging in extra care housing* at [www.housinglin.org.uk/Topics/type/resource/?cid=7337&](http://www.housinglin.org.uk/Topics/type/resource/?cid=7337&)

<sup>181</sup>See section 175(3) Housing Act 1996

<sup>182</sup>The groups of people who fall within the definition of 'priority need' include persons who are 'vulnerable as a result of old age, mental illness or handicap or physical disability or other special reason, or with whom such a person resides or might reasonably be expected to reside' – section 189(1)(c)

6.23 The Homelessness Code of Guidance for Local Authorities explains:

*'Under the legislation, certain categories of household, such as families with children and households that include someone who is vulnerable, for example because of pregnancy, old age, or physical or mental disability, have a priority need for accommodation. Housing authorities must ensure that suitable accommodation is available for people who have priority need, if they are eligible for assistance and unintentionally homeless (certain categories of persons from abroad are ineligible.)'*<sup>183</sup>

6.24 Specific guidance has been published in relation to young people aged 16 and 17, by the Department of Children Schools and Families and the Communities and Local Government Department in April 2010, 'Provision of Accommodation for 16 and 17 year old young people who may be homeless and/or require accommodation'.<sup>184</sup> The guidance sets out the role of housing authorities and children's services in responding to the needs of young people aged 16 and 17 who are homeless. Reflecting on recent case law<sup>185</sup> it also reiterates that:

*'the duty under section 20 of the 1989 [Children] Act takes precedence over the duties in the 1996 [Housing] Act in providing for children in need who require accommodation, and that the specific duty owed under section 20 of the 1989 Act takes precedence over the general duty owed to children in need and their families under section 17 of the 1989 Act.'*<sup>186</sup>

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<sup>183</sup>Department for Communities and Local Government: London, July 2006, para. 11 <http://www.communities.gov.uk/documents/housing/pdf/152056.pdf>

<sup>184</sup>*Guidance to children's services authorities and local housing authorities about their duties under Part 3 of the Children Act 1989 and Part 7 of the Housing Act 1996 to secure or provide accommodation for homeless 16 and 17 year old young people*, Issued April 2010

<sup>185</sup>See in particular *R on the application of G(FC) v Southwark LBC*, 12 CCLR 437 at 447

<sup>186</sup>Paragraph 1.1.

# Chapter 7: Employment

*This chapter provides information for professionals seeking to help young people into work.*

It covers the following areas:

- Assistance in finding work and support once in work
- Key employment provisions of the Equality Act 2010
- Parents'/carers' employment rights: absence from work to care for a disabled child
- Supportive employers

## Introduction

- 7.1 The Shaw Trust<sup>187</sup> which supports disabled and disadvantaged people to prepare for work, find jobs and live more independently, uses Labour Force survey statistics from January to March 2009 to highlight the concerning fact that only 50% of disabled people of working age are in work compared to 80% of non-disabled people.
- 7.2 There is clearly much work to be done to level the employment playing field. This section looks at some of the key employment support available to disabled people, explains the key duties of employers towards applicants and employees under the Equality Act 2010, discusses parents'/carers' employment rights surrounding absence from work to care for a disabled people and highlights those employers who are likely to be supportive to disabled applicants and employees.

## Assistance in finding work and support once in work

- 7.3 If a young person is still in education, be this at school or at a further or higher education institution, they should receive careers guidance from that institution. It may be that the young person has secured an apprenticeship and will find ongoing employment through that route (see Chapter 3 for further information on apprenticeships).

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<sup>187</sup>[www.shaw-trust.org.uk](http://www.shaw-trust.org.uk)

- 7.4 In its response to the consultation on the SEN Green Paper: *Support and Aspiration: A new approach to special educational needs and disability*, the Government has announced its intention to introduce supported internships in England (a programme of study which is based in the main at an employer's premises) for students aged 16-25 with either a Statement of SEN, a Learning Difficulty Assessment or, in due course, an Education, Health and Care Plan. These supported internships will be part of new study programmes for post 16 vocational education which are due to start from September 2013 although 15 colleges will be involved in trials of supported internships from September 2012. Their goal is to enable a young person to move into paid employment and the Government's wish is that the employers involved will make job offers to those interns who have met the required standard.
- 7.5 As a result of a recent Government-commissioned review into the skills, needs and practical help a disabled person requires to start or continue work, funding for disability employment services will be focussed on supporting individuals through services like Access to Work (see paragraphs 7.7 to 7.11 below) with the aim of increasing the number of disabled people working in mainstream employment. There is also a new Inter-Ministerial group on Disability Employment to lead on cross-government work on disability employment.

### **Disability Employment Advisers**

- 7.6 Disability Employment Advisers are based at local Jobcentres and are there to help disabled people of any age who need extra employment support because of their disability. They offer a range of services including:
- an employment assessment to help identify suitable work or training
  - a referral for a specialist employment assessment with a Work Psychologist
  - a job-matching and referral service
  - advice about Access to Work (see paragraphs 7.7 to 7.11 below)
  - a referral to the Work Programme
  - a referral to programmes for disabled people such as Work Choice (which helps disabled people whose needs cannot be met by Access to Work or other work programmes) or residential training. In May 2012 the Government announced that it would offer a six month subsidy for employers taking on young disabled jobseekers through the Work Choice programme which mirrors the subsidy offered through the Government's Youth Contract Scheme for jobseekers aged between 18 and 24.
  - information on local employers who have adopted the 'two ticks' disability symbol (see Annex B for additional sources of information).

### **The Access to Work Scheme**

- 7.7 Run by Jobcentre Plus, this currently provides advice and support to employers and to disabled people (16 or over and not on certain benefits), who are unemployed and about to start a job/work trial; employed; self-employed; starting a business through the New Enterprise Allowance; and starting a work trial/work experience under the Youth Contract.

7.8 A disabled employee can apply for a grant to help pay for any extra employment costs which arise as a result of their disability. These include:

- support workers
- specialist equipment
- adaptations to premises
- travel to work where public transport is not practical
- awareness training for fellow employees

It does not matter whether an employee works part or full time or is on a permanent or temporary contract.

7.9 The amount of the approved support paid by the Access to Work fund depends on how long an employee has been in work, the type of support needed and whether there is any business benefit. The aim is to process applications as quickly as possible. Employers can help their employee's application by providing them with all the required employment information without delay.

7.10 An employee's needs will be assessed by an assessor who may visit the employee in the workplace. The employer then arranges the agreed support and/or buys the specialist equipment and recoups the money from the Access to Work fund.

7.11 An employer will continue to have duties towards a disabled employee under the Equality Act 2010 (see paragraphs 7.18 to 7.46 below) even if the employee is eligible for Access to Work funding. Indeed, the funding received through the Access to Work scheme might mean that the employer is required to make certain adjustments which, without the funding, it would not have done because the costs of making such adjustments would have been too high and therefore unreasonable because of cost. (See paragraphs 7.30 to 7.36 for an explanation of 'reasonable adjustments'.)

### **Skill/Disability Rights UK helpline**

7.12 Their advisers offer advice on training and employment as well as education. In addition, Disability Rights UK publishes a range of useful guides (see Annex B: Organisations Providing Information and/or Advice).

### **The Shaw Trust**

7.13 The Shaw Trust is a national charity which 'supports disabled and disadvantaged people to prepare for work, find jobs and live more independently'. Their advisers help people who are unemployed or on certain benefits to find work and continue to provide support during employment. They are one of the providers of the government supported initiatives: Work Programme and Work Choice.

7.14 The Shaw Trust's Young Peoples Services offers a tailor made programme for young people aged 14–25 which includes practical work preparation and experience to support future job applications and training and skills based around their chosen occupation.

### Support offered by charities

7.15 Many charities such as Scope, Mencap and the Down's Syndrome Association offer employment services. The Down's Syndrome Association has recently launched its Work Fit service.<sup>188</sup>

### Help for the self-employed

7.16 If a young person wants to pursue the self-employed route, they may be eligible for the Government's New Enterprise Allowance. Under this scheme the Government gives extra help to unemployed people who want to start their own business if they are on Jobseekers Allowance (see Cerebra Parents Guide on Money Matters) and are aged 18 and over. Those on the scheme will receive help from a volunteer business mentor who will help them to develop their business plan and provide support and guidance in the first months of trading. Financial support will be available once a claimant can show that they have a viable business plan with potential for future growth.

### Limited ability to work

7.17 If a young person's ability to work is limited, they may be eligible for Employment and Support Allowance (ESA) (see paragraph 8.7). For more information see the Gov. uk website and Disability Rights UK (see Annex B).

## The key employment provisions of the Equality Act 2010

### Introduction

7.18 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 in a work context are:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation

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<sup>188</sup>See <http://www.dsworkfit.org.uk/index.php>

- 7.19 The Act offers protection from discrimination throughout the employment cycle from recruitment, the terms of employment, access to benefits, facilities and services to dismissal and, in certain situations, to former employees.
- 7.20 The Act's definition of 'employment' is broader than under many other employment legislation provisions such as those relating to unfair dismissal. A wide range of workers is protected under the Act's definition of employment including those employed under a contract of employment and apprentices. Protection is also given to people who are in a work relationship other than employment such as contract workers, police officers and office holders for whom the employment provisions of the Act are largely the same, albeit with some specific provisions.
- 7.21 Apprentices (and others on work placements) are protected from discrimination from their employers under Part 5 of the Act and also from their training provider (under either the education provisions in Part 6 of the Act or under the services provisions in Part 3 of the Act, depending on the nature of the training provider).
- 7.22 Qualifications bodies and trade organisations have obligations under Part 5 of the Act not only to their employees but also separate obligations to members and prospective members and to those on whom they confer a qualification.
- 7.23 There are some specific work exceptions to the prohibition of discrimination. For example, some jobs are allowed to specify that an applicant or worker must have a particular protected characteristic if that requirement is what is known as a 'genuine occupational requirement', such as a women's refuge requiring all its employees to be female.
- 7.24 This section focuses on the protected characteristic of **disability**. (See Box 2 under paragraph 3.11 for a definition of disability under the Equality Act 2010).

### **The different forms of discrimination**

- 7.25 **Direct discrimination** – treating a person less favourably because of their protected characteristic – for example a young woman with cerebral palsy is interviewed for a position at a local business but another candidate who does not have a disability is hired. This may amount to direct disability discrimination if the reason for not employing her was because of her disability.

Generally direct discrimination cannot be justified. It is always lawful to treat disabled people more favourably for a reason relating to their disability. Direct discrimination by association (see paragraph 7.48) and by perception are also unlawful.

- 7.26 **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 this is a 'proportionate means of achieving a legitimate aim'. For example, a busy staff canteen has a policy

of allowing workers a 30 minute slot in which to buy and eat their lunch. Workers with mobility and sensory impairments are put at a disadvantage by this practice and it would be hard to see how this practice could be objectively justified.

- 7.27 **Pregnancy and maternity discrimination** – treating a woman unfavourably during the ‘protected period’ (generally from start of pregnancy to end of maternity leave or until return to work if earlier) because of her pregnancy, a related illness or in relation to exercising her right to maternity leave.
- 7.28 **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. The unfavourable treatment will not amount to discrimination arising from disability if the employer did not know and couldn’t reasonably have been expected to know the person was disabled. If the employer has failed to make a reasonable adjustment for the disabled person, it will be very difficult for them to prove the treatment was justified. For example an employer dismisses a worker because he has had 3 months sick leave. The employer is aware that the worker has epilepsy and most of the sick leave is disability-related. The reason for the dismissal is not the worker’s disability itself but the worker has been treated unfavourably for a reason related to his disability (namely, the need to take a period of disability-related sick leave). This will amount to discrimination arising from disability unless the employer can objectively justify the decision. A reasonable adjustment may have been to disregard some or all of the 3 months sick leave that is disability-related. (This example is adapted from the Equality and Human Rights Commission’s Employment Statutory Code of Practice (‘the Employment Code’) – see Annex A.)
- 7.29 **A failure to make reasonable adjustments** (for disabled people only) – see below.

### **How the reasonable adjustment duty applies in an employment context**

- 7.30 The reasonable adjustment duty applies to a particular disabled applicant (or potential applicant) or worker and requires employers to take reasonable steps to:
- avoid a substantial disadvantage where a practice, provision or criteria puts a disabled applicant or worker at a substantial disadvantage compared to those who are not disabled (Note: ‘substantial’ means more than minor or trivial).
  - remove or alter a physical feature or put in place a reasonable means of avoiding such a feature where it puts a disabled applicant or worker at a substantial disadvantage compared to those who are not disabled (but not a potential applicant).
  - provide an auxiliary aid or service where a failure to do so would put the disabled job applicant or worker at a substantial disadvantage compared to those who are not disabled.
- 7.31 If the provision, practice or criteria or the need for an auxiliary aid relates to the provision of information, the duty will encompass ensuring the information is provided in an accessible format.

- 7.32 An employer must know or reasonably be expected to know that an applicant / worker is disabled in order for the reasonable adjustment duty to arise.
- 7.33 An employer cannot justify a failure to make a reasonable adjustment; the question to consider is whether or not the adjustment is reasonable which will depend on the circumstances of each case.
- 7.34 Employers will need to ensure that where necessary reasonable adjustments are put in place during the recruitment process and in the course of a worker's employment. If an employer is considering whether or not to dismiss a disabled worker, they should first consider whether the reason for the dismissal is connected to or as a result of the worker's disability and, if it is, they will need to consider whether the dismissal can be objectively justified. If proceeding with a dismissal, an employer will need to consider whether any reasonable adjustments need to be made to the dismissal process.
- 7.35 The Employment Code (see Annex A) gives examples of possible reasonable adjustments including:
- adjustments to premises
  - allocating some of a disabled worker's duties to another worker
  - altering a disabled worker's hours of work or training
  - acquiring or modifying equipment
  - providing a reader or interpreter
  - employing a support worker to assist a disabled worker
  - modifying performance –related pay arrangements for a disabled worker
- 7.36 The Access to Work Scheme (see paragraphs 7.7 to 7.11 above) does not take the place of an employer's reasonable adjustment duty; funds from it may mean that certain steps become reasonable for an employer to take because in the light of the funding they are no longer unreasonably expensive.

### **How the Equality Act 2010 can help a young person to overcome discriminatory barriers and secure employment**

- 7.37 The Equality Act 2010 prohibits employers from discriminating at any stage of the recruitment process.
- 7.38 In terms of advertising positions, employers need to ensure that neither the arrangements for advertising or not advertising jobs, nor the content of a job advertisement, are discriminatory.
- 7.39 The application process including selection, assessment and interview must be non-discriminatory. It is generally unlawful for an employer to ask an applicant any questions about their disability or health (including as part of the application process or in an interview) until they have been offered a job on a conditional or unconditional basis or are in a pool of candidates who will be offered a job when

one becomes available. (This includes questions about sickness absence, filling in an occupational health questionnaire or being assessed by an occupational health practitioner).

7.40 The six exceptions to this are:

- to ask questions relating to whether any reasonable adjustments are needed as part of the recruitment process
- for monitoring purposes
- in order for the applicant to benefit from any positive action measures such as the guaranteed interview scheme for disabled people
- to determine that the applicant satisfies a genuine occupational requirement
- to vet applicants where necessary for national security purposes
- to check the applicant can carry out a function which is intrinsic to the job; only functions which can be justified as necessary to a job should be specified in a job description.

7.41 Once a job offer has been made or the applicant is in a pool of candidates to whom job offers will be made once a job becomes available, pre-employment health checks can be made but an employer must not discriminate on the basis of these and must always consider whether any reasonable adjustments need to be made.

### **The public sector equality duty**

7.42 If a young person is applying for a job with, or works for, a public authority (such as a local authority, maintained school, health body, police, fire or transport authority or a government department) their employer will be subject to the public sector equality duty. If their employer is not a public authority but carries out a public function as part of its work, it will be covered by the general part of the equality duty in relation to the exercise of that function.

7.43 The **general duty** has three aims. It requires public bodies 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.

7.44 The second and third aims do not apply to the protected characteristic of marriage and civil partnership.

7.45 The **specific duties** in England require public authorities to publish sufficient information annually to demonstrate compliance with the three aims of the general equality duty by 31 January 2012 (except schools which had until 6 April 2012) and

to publish equality objectives by 6th April 2012 and to review them at least every four years.

7.46 The **specific duties** in Wales requires public authorities to publish equality objectives and strategic equality plans by 2 April 2012 and to 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.

### Parents'/carers' employment rights: absence from work to care for a disabled child

7.47 Working parents of a disabled child may need to take time off from work to take their child to a medical appointment for example. If they are employees (as opposed to being self-employed or agency workers) in addition to their contractual rights concerning annual leave and sick leave, they will have various statutory rights in terms of absence from work:

- **Dependant leave/time off for emergencies:** the Employment Rights Act 1996 gives all employees the right to take a 'reasonable' amount of time off to deal with an emergency involving a dependant. The employer has a discretion as to whether or not the time off is paid.
- **Parental leave:** employees with at least one year's continuous service who are a parent, an adoptive parent or have parental responsibility for a child and give at least 21 days' notice to their employer can take up to:
  - 13 weeks unpaid leave per child to look after a child under 5 – such leave must be taken before the child's 5th birthday (or if the child is adopted, within 5 years from the date of placement or until their 18th birthday, whichever comes first).
  - 18 weeks unpaid leave per child to look after a child who is under 18 on DLA (such leave must be taken before the child's 18th birthday).
- **Flexible working** – the Work and Families Act 2006 gives employees with 26 weeks of continuous employment the right to ask for a change in their working arrangements so they can manage their caring responsibilities more easily. Examples of flexible working include part-time working, job-sharing, term-time working and compressed hours. Employers must agree to such requests unless they have good business reasons not to do so.

7.48 In addition, under the Equality Act 2010 an employer is prohibited from discriminating against or harassing a worker because of their association with their disabled child. This is illustrated in paragraph 3.19 of the Employment Statutory Code of Practice:

*A lone father caring for a disabled son has to take time off work whenever his son is sick or has medical appointments. The employer appears to resent the fact the worker needs to care for his son and eventually dismissed him. The dismissal may amount to direct disability discrimination against the worker by association with his son.*

7.49 For information about other employment rights such as such as paternity and maternity rights and in relation to disputes and conflict at work see the ACAS listing in Annex B.

### Supportive employers

7.50 There are a number of schemes that employers can sign up to indicating that they are supportive of disabled people as employees:

#### **The disability symbol**

7.51 In addition to their responsibilities towards disabled employees under the Equality Act 2010, some employers have adopted the Jobcentre Plus disability symbol made up of two ticks and the words 'positive about disabled people'. If the employer displays this symbol, they have made the following five commitments (see [www.gov.uk](http://www.gov.uk)):

- to interview all disabled applicants who meet the minimum criteria for a job vacancy and to consider them on their abilities
- to discuss with disabled employees, at any time but at least once a year, what both parties can do to make sure disabled employees can develop and use their abilities
- to make every effort when employees become disabled to make sure they stay in employment
- to take action to ensure that all employees develop the appropriate level of disability awareness needed to make these commitments work
- to review these commitments each year and assess what has been achieved, plan ways to improve on them and let employees and Jobcentre Plus know about progress and future plans.

#### **Business Disability Forum (BDF), formerly the Employers Forum on Disability (EFD), Disability Standard**

7.52 The BDF has a wide membership which currently collectively employs about 20% of the UK workforce. Member organisations can receive specialist advice and training on recruiting and retaining disabled employees.

7.53 The EFD (as then was) developed the Disability Standard in 2004. It is an online management tool to help business to measure and improve on performance not only for disabled employees but also for disabled customers, clients, service users and stakeholders. The latest version has recently been launched.

7.54 The BDF intends to publish case studies on its website.

#### **Mindful Employer**

7.55 The Mindful Employer initiative (<http://www.mindfulemployer.net/>) was launched in 2004 and aims to increase awareness of mental health at work and provide support for businesses in recruiting and retaining staff with mental health difficulties.

7.56 Any business can sign up to the charter for employers who are positive about mental health. While this is not an accreditation scheme, nor a set of quality standards, by signing the charter employers indicate that they are working towards putting the charter's principles into practice. Organisations who have signed up to the charter recognise that:

- People who have mental health issues may have experienced discrimination in recruitment and selection procedures. This may discourage them from seeking employment.
- Whilst some people will acknowledge their experience of mental health issues in a frank and open way, others fear that stigma will jeopardise their chances of getting a job.
- Given appropriate support, the vast majority of people who have experienced mental ill health continue to work successfully as do many with ongoing issues.

7.57 Organisations that have signed up to the charter aim to:

- Show a positive and enabling attitude to employees and job applicants with mental health issues. This will include positive statements in local recruitment literature.
- Ensure that all staff involved in recruitment and selection are briefed on mental health issues and the Equality Act 2010, and are given appropriate interview skills.
- Make it clear in any recruitment or occupational health check that people who have experienced mental health issues will not be discriminated against and that disclosure of a mental health problem will enable both employee and employer to assess and provide the right level of support or adjustment.
- Not make assumptions that a person with a mental health problem will be more vulnerable to workplace stress or take more time off than any other employee or job applicant.
- Provide non-judgemental and proactive support to individual staff who experience mental health issues.
- Ensure all line managers have information and training about managing mental health in the workplace.

### **Sector specific initiatives**

7.58 There are also sector specific initiatives such as the Bank Workers Charity Partnership, a collaboration between Leonard Cheshire Disability and the Bank Workers' Charity. This provides 'independent and confidential information, advice and mentoring support to disabled people and carers from the banking community, including people with mental health or long-term health conditions that affect their ability to work' (see <http://www.lcdisability.org/?lid=21494>).

# Chapter 8: Money Matters

*This chapter provides information on financial matters that are likely to affect young disabled people and their parents, covering opening bank accounts, claiming benefits, paying for care, managing income, savings and capital and making wills or trusts.*

## Overview

- 8.1 Young people reaching the age of 16 and above become entitled to benefits and financial support in their own right, even if they continue to live at home with their parents. The benefits and financial support that are available depend on whether they are still in education, looking for, or in, work and the severity of their disability. How their money is managed is a significant feature of a young person's transition into adulthood, and the arrangements that need to be put in place will depend on whether the young person has the capacity to manage their own finances or whether they need someone else to manage their affairs on their behalf.
- 8.2 In some circumstances, all that young people need to know is what to claim when and to open a bank account into which their benefits can be paid. They may also need advice about using direct payments or personal budgets to pay for care. If the young person lacks capacity to make relevant decisions about their finances or to claim benefits, arrangements must be put in place for someone else to do this on their behalf once they reach adulthood. Anyone making decisions on behalf of a young person aged 16 or above will need to comply with the principles and provisions of the Mental Capacity Act 2005 ('the MCA 2005') and in particular, to act in the young person's best interests.<sup>189</sup> In some circumstances, where the young person has savings or an award of damages, formal legal arrangements must be put in place, such as the appointment of a deputy by the Court of Protection, to look after the person's property and affairs.

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<sup>189</sup>See Annex A for sources of further information on this Act

- 8.3 Changes in a young person's finances may also have an impact on their parents or carers. Depending on the family circumstances, it may be more advantageous for a young person to claim their own benefits (or if they lack capacity, for someone (called an appointee) to do this on their behalf). But sometimes the family will be better off if parents/carers continue to claim for the young person as their dependant. The family may need help to do the 'better off' calculation.
- 8.4 Parents or carers wishing to make plans for the future, when they may no longer be around or able to help look after, or provide, for their disabled adult child or relative, should seek advice from a solicitor about making a will or setting up a trust making provision for the young person's future care.

## Working with young people

### Young people able to manage their own financial affairs

#### Opening a bank account

- 8.5 A young person receiving benefits or other payments will need their own bank account. Banks vary in the type of accounts they offer and whether they offer on-line banking. Many offer a 'basic bank account' into which benefits and other income can be paid, bills paid by Direct Debit and money withdrawn at cash machines with a cash card, but with a limit on the amount by which the account can be overdrawn (usually £10). This can be a useful first step for young people. Most banks make specific arrangements to ensure their services are accessible to disabled people – these are usually described on a bank's website.
- 8.6 To open an account, proof of identity will need to be shown to the bank, such as a passport and proof of address, for example an official letter from a government department or local authority confirming a right to state benefits. Confirmation of identity from a young person's workplace or educational institution may also be accepted.

#### Claiming benefits

- 8.7 Entitlement to benefits for disabled people is particularly complex and cannot be covered here in any detail. The following bullet points set out the main benefits that are available for disabled young people, depending on their circumstances, whether they are in education or employment and the severity of their disability. Possible future changes to benefits are set out in italics.
- **Disability Living Allowance (DLA)** – This is a benefit for children and adults who need help with personal care or being able to get around. DLA is in two parts, the care and mobility components both payable at different rates. For children under 16, DLA is paid to a parent or carer. Disabled young people can claim DLA in their own right once they turn 16, when the qualifying rules change. If the young person is already receiving DLA before they turn 16, the claim will be looked at again to see if they qualify for a higher amount. Those not entitled to DLA before they turn 16 should make a new claim on reaching 16.

**Note: Personal Independence Payment** – DLA will be abolished in the future and replaced with a benefit called a Personal Independence Payment. The earliest this will happen is in 2013.

- **Employment and Support Allowance (ESA)** – Anyone over 16 who has an illness or disability affecting their ability to work may be eligible for ESA. There are two types of ESA – contribution based and income related but the latter is more relevant to young people who have not paid sufficient National Insurance contributions. Income related ESA depends on the person's income and savings and is payable to young people not in school or equivalent education, nor in full time advanced education (what counts as full time varies for 'further education' and 'higher education' and for the type of tuition – seek advice from the course provider). However young people receiving DLA while at school or in full time advanced education may also be eligible for income related ESA. People claiming ESA have to undergo a detailed 'Work Capability Assessment' to see if they qualify, unless they are terminally ill or receiving chemotherapy. People refused ESA have the right to challenge that decision at the First-tier Tribunal (Social Entitlement) where many refusals have been overturned.

**Note:** Claiming ESA may have an effect on family finances for young people still living with parents or carers, so a 'better off' calculation may be needed to work out the most advantageous arrangements – see Annex B for details of organisations that can help with this. **Note:** See Universal Credit below.

- **Jobseeker's Allowance (JSA)** – This is payable to disabled young people aged 18 and over who are found to have 'capability for work' (they may have been refused ESA because of this) and who are looking for a job and don't have enough money to live on. Young people are unlikely to qualify for contribution based JSA because they have not been working long enough. Income related JSA is payable to young people who are not working (or are working less than 16 hours a week) and who have limited income or savings. People claiming JSA have to attend an interview at the Jobcentre and sign a 'Jobseeker's agreement' setting out the steps they will take to find work or training.

**Note:** Young people aged 16–17 won't usually qualify for JSA unless they can show 'severe hardship', for example as a result of their disability or because their parents/carers are unable to support them. **Note:** See Universal Credit below.

- **Working Tax Credit (WTC)** – Young people aged 16 and over who are working at least 16 hours a week may be entitled to WTC if they have a physical or mental disability that puts them at a disadvantage in getting a job. They must also satisfy a 'qualifying benefit' test, either by getting DLA, or by having received ESA or a similar benefit before starting work. HM Revenue and Customs have produced a 'Disability Helpsheet' to explain the conditions needed to qualify for WTC (see Annex A for details). The level of WTC will depend on their income and the degree of disability, determining whether they qualify for the disability component or severe disability component of WTC. **Note:** See Universal Credit below.

- **Universal Credit – Available after October 2013**

**Note:** Most means-tested benefits (including IS, JSA, ESA and WTC) will be replaced by a new Universal Credit. This will apply to all new claims from October 2013, with people on existing means-tested benefits being moved onto the new Universal Credit at some point between 2014 and 2017.

- **Education Maintenance Allowance (EMA)** – EMA has been abolished in England but is still available in Wales for young people who continue in education after school leaving age who live in a low income household. They must attend school or college regularly and meet the goals agreed with the course provider.
- **Disabled Students Allowance (DSA)** – Disabled students in higher education may qualify for DSA to help pay for extra support or equipment they need because of their disability. For further information, see Annex C.

#### Paying for care

- 8.8 For an explanation of direct payments and personal budgets, see Chapter 4, paragraphs 4.44 – 4.46)
- 8.9 A fund known as the Independent Living Fund (ILF) – is now permanently closed to new applicants. This means that young people not already receiving ILF funding can no longer apply for assistance from the fund. The Government has promised to consult on incorporating the ILF into a social care system based on Personal Budgets.

#### Young people lacking capacity to manage their own financial affairs

- 8.10 If there are concerns that a young person aged 16 or over lacks capacity to make certain decisions for him or herself, an assessment of their capacity should be undertaken in accordance with the MCA 2005 and the MCA Code of Practice. (See Annex A resources providing information on the MCA 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.
- 8.11 Young people who lack capacity to manage their own affairs are likely to qualify for DLA (and possibly ESA) and for the provision of care services from the local council, as set out above. However, they will need someone else, such as a parent or carer, to claim and manage the benefits and services on their behalf.

#### Claiming benefits – appointeeship

- 8.12 Parents or carers of disabled young people under 18 years may claim and receive benefits on the young person's behalf. Once the young person turns 18, new arrangements need to be put in place.

- 8.13 If a young person aged 18 and over has income only from social security benefits, and is considered to be incapable of claiming and managing those benefits, the agency paying the benefit (usually the Pension, Disability and Carers Service (PDSCS)) will appoint someone, called an 'appointee', to claim the benefits and use them on the young person's behalf. A parent can ask to be made an appointee for their child or, if they are unwilling to do this, they can suggest to the PDSCS who might be an appropriate appointee, such as another family member.
- 8.14 Anyone wishing to become an appointee will need to contact the Department for Work and Pensions (DWP) or the agency that pays the young person's benefits and explain that the young person needs their help to claim and manage their benefits. The person wishing to become the appointee will be asked to complete the application form BF56 (also available from a Post Office). A DWP officer will visit them to interview them and to assess the young person's ability to act for themselves. If the officer thinks this is a suitable arrangement, the DWP will confirm the appointee's appointment on Form BF57, which they can then use to prove that they are the young person's appointee.
- 8.15 An appointee takes on responsibility for claiming the benefits, using the money on the young person's behalf, and has a duty to report any changes in the young person's circumstances which may affect their entitlement to benefits.
- 8.16 An appointee should open a separate bank account in their own name on behalf of the young person (known as an 'appointee account') into which the benefits can be paid. Appointees have no right to deal with any savings or capital owned by the young person unless they have formal authority (see 8.25 below).

#### Paying for care

- 8.17 If a local authority is making a Direct Payment in relation to a young person who is under 18, it is able to pay this to the young person's parents. However, if the young person is aged 16 or over they have the right to manage their own direct payments so long as they have capacity to do so. If they are over 16 and lack capacity to manage such a Direct Payment, the payment can be made instead to a 'suitable person', who could be someone who already has authority to deal with the young person's affairs (such as a deputy – see below) or anyone the local council considers to be 'suitable' (such as a parent or carer). That person must then choose the services to meet the young person's needs and arrange for them to be provided and paid for using the Direct Payment.
- 8.18 Similar arrangements are available to deal with personal budgets on behalf of a young person lacking capacity to make arrangements for themselves, including for example setting up an account managed by a suitable person, or by trustees, on behalf of the young person.

## Managing other income, savings and capital

8.19 If a young person who is aged 16 or over lacks capacity to deal with their own affairs and has income other than benefits or has savings and capital, such as an inheritance or an award of damages, then someone will need to obtain formal authority to deal with the young person's property and affairs on their behalf and in their best interests. This can be done in the following ways:

- **Lasting Power of Attorney (LPA)** – If the young person is aged 18 or over, and has the capacity to understand that they need help to look after their affairs, they may be able to make an LPA appointing their chosen attorney (or attorneys) to deal with financial affairs on their behalf. However, quite a high level of understanding is needed to make an LPA and to choose an appropriate attorney, so this will be rare (but not unheard of) for many disabled young people. An LPA must be registered with the Office of the Public Guardian before it can be used.
- **Deputyship** – Where there is an on-going need for financial decisions to be made on behalf of a young person of any age, and the person's lack of capacity is likely to continue into adulthood, the Court of Protection can be asked to appoint a deputy to make financial decisions on the person's behalf. Deputies are likely to be parents or other family members, although in some cases professional deputies (such as a solicitor or accountant) may be appointed. Deputies are supervised by the Office of the Public Guardian, and the level of supervision required will depend on individual circumstances.

## Information for parents and carers

### Claiming benefits

8.20 The section above explains the main benefits that disabled young people may be entitled to. If the young person aged 18 or over lacks capacity to claim and manage benefits for themselves, a parent or carer can ask the agency paying the benefits to make them an appointee (see above). The appointee then takes on responsibility for claiming the benefits, using the money on the person's behalf, and has a duty to report any changes to the young person's circumstances which may affect their entitlement to benefits.

8.21 If a claim is made for Employment and Support Allowance (ESA) by or for a young person, it is important to be aware that this may affect parents' or carers' finances if they are themselves in receipt of Child Benefit for the young person and/or income-related benefits (such as Income Support, Housing Benefit, JSA, Child Tax Credit and Working Tax Credit). They may need help to do a 'better off' calculation to work out the most advantageous arrangements.

8.22 In addition, parents and carers may be entitled to other benefits in their own right such as:

- **Carer's allowance (CA)** – CA is payable to a carer who looks after someone for 35 weeks or more who receives the middle or higher rate Disability Living Allowance (DLA) and the carer earns less than a set amount (currently £100 per week) after deducting tax, NI, certain pension contributions and care costs. CA is not affected by any benefits claimed by the young person. Receiving CA may also help the carer to qualify for other means-tested benefits.
- **Family Fund** – This fund gives discretionary grants to families, mainly those on low incomes, who are raising a disabled child or young person (aged 17 or under) with additional complex needs or children and young people with a serious illness. To be considered for a grant, families must show evidence of their entitlement to means-tested benefits (such as Child Tax Credit, Working Tax Credit, income based Job Seekers Allowance, Income Support, Housing Benefit) but help is not limited to those on benefits so a family may still qualify if they can provide further details of their circumstances. A family can make only one application in any 12 month period unless there are exceptional circumstances such as an emergency relating to a disabled child. The fund has its own disability criteria. Grants are for things that are not provided by statutory services, such as washing machines, fridges, clothing, sensory toys, computers or family breaks.

### **Providing and paying for care**

8.23 Parents or carers are the most likely people to be found 'suitable' to help a young person to manage Direct Payments or Personal Budgets (see Chapter 4 above) to pay for their care needs.

8.24 In addition, anyone providing 'regular and substantial care' for a disabled young person is entitled to a **Carer's Assessment** from social services (which could be done at the same time as, or separately from, the young person's assessment) to see if they are entitled to services to make caring easier for them. This could include a break from caring, the provision of adaptations or equipment and occasionally Direct Payments to meet the carer's own assessed needs.

### **Managing other income, savings and capital**

8.25 As described above, parents or carers may wish to apply to the Court of Protection to be appointed as a deputy in order to have the legal authority to make on-going financial decisions for a young person lacking capacity to deal with their own affairs, including dealing with savings or investments or managing awards of damages. Without such authority, parents or carers have no right to deal with the young person's affairs, or have access to their money or savings. A deputy must always act in the young person's best interests.

## **Making wills or trusts**

- 8.26 Parents or carers may wish to make provision for a future time when they are no longer there to care for their disabled adult child or relative. This can be done by making a will, but care needs to be taken about the effect of leaving a legacy or share of the estate on the person's own finances and entitlement to services.
- 8.27 One solution may be to create a Discretionary Trust in the will to appoint Trustees to manage funds for the benefit of the disabled person. The person making the will can decide who the Trustees will be and direct what should happen to any remaining funds after the death of the disabled person. They can also leave a detailed Letter of Wishes providing guidance on how the trust should be used for the comfort, support and maintenance of the disabled person.
- 8.28 There are other possibilities, including creating a lifetime Discretionary Trust to have effect during the parent's lifetime rather than by will. Some trusts made for the sole benefit of disabled people (known as trusts for 'vulnerable beneficiaries') get special tax treatment which means they may have to pay less tax. The law relating to wills and trusts making provision for disabled people is a complex area – specialist legal advice will be needed.
- 8.29 Cerebra provide support to parents of disabled children wishing to make a will and discretionary trust to make provision for their future by offering a voucher worth £350 that can be used towards solicitors fees. For further information see: [www.cerebra.org.uk/English/gethelp/willsandtrusts/Pages/default.aspx](http://www.cerebra.org.uk/English/gethelp/willsandtrusts/Pages/default.aspx)

# Glossary

## **Carers (Equal Opportunities) Act 2004**

Guidance from the Department of Health, Carers and Disabled Children Act 2000 & Carers (Equal Opportunities) Act 2004 Combined Policy Guidance, 2005), explains that this Act '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.'

## **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 Annex A.) 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;
- require 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 cover 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 Chapter 4).

**Compulsory school age**

Currently from the start of term following a child's 5th birthday to the last Friday in June in the academic year in which the child turns 16.

**Convention on the Rights of the Child (UNCRC):**

This is an international human rights treaty to which the UK is a signatory, which grants all children and young people under the age of 18 a comprehensive set of rights

### **Early Years Setting**

Education providers covering ages 3–5 who are in receipt of government funding are covered by the SEN Framework. However only nursery schools maintained by a local authority and nurseries within a school (be it maintained or private) are covered by the schools duties under the Equality Act 2010; private nursery providers are covered by the duties on service providers under Part 3 of the Act.

### **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.

## **Protected characteristics under the Equality Act 2010**

- For service users: disability, gender reassignment, pregnancy and maternity, race, religion and belief, sex and sexual orientation. The government introduced a ban on age discrimination for service users from 1 October 2012 but this only covers people who are aged 18 or over.
- For school pupils: disability, gender reassignment, pregnancy and maternity, race, religion and belief, sex and sexual orientation.
- For FE and HE students: as for school pupils but with the additional protected characteristic of age.
- For employees: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation.

## **Public sector equality duty under the Equality Act 2010**

Public bodies such as NHS trusts, local authorities, maintained schools and Academies and many further and higher education institutions are subject to both the general and the specific duties.

### **General Duty**

In the exercise of their functions a public body or anyone exercising public functions must have due regard to the need to:

- eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act
- 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.

## Specific Duties

- stated purpose is to 'ensure better performance by the public authorities concerned of the duty to have regard to' the three aims of the general duty
- public authorities in England subject to the specific duties have to publish sufficient information annually to demonstrate compliance with the three aims of the general equality duty and publish equality objectives, reviewing them at least every four years
- public authorities in Wales subject to the specific duties are required to publish equality objectives and strategic equality plans, review these objectives every four years, to engage with interested people as part of gathering relevant information to assess their activities and to publish such relevant information as appropriate.

## Right to an Education

All children are entitled to an education. Article 2 of the First Protocol of the European Convention on Human Rights and Fundamental Freedoms holds that 'No person shall be denied the right to education'. This principle applies to disabled and non-disabled children and young people but it is an education rather than the best education.

## Section 7 Guidance

This refers to guidance that has been issued under section 7 of the Local Authority Social Services 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.

# Annex A: Further Information and resources

## 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](http://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](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4118023)

Common Assessment Framework: a range of information, including guides for managers and practitioners is available at: [www.cwdcouncil.org.uk/integrated-working/integrated-working-guidance](http://www.cwdcouncil.org.uk/integrated-working/integrated-working-guidance)

*Creating a Unified and Fair System for Assessing and Managing Care* Welsh Assembly Government (2002)

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](http://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>

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* Department of Health (2010)

## 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](http://www.education.gov.uk/childrenandyoungpeople/families/a0065502/care-planning-for-looked-after-children-and-care-leavers)

## Confidentiality and Sharing Information

*Confidentiality: NHS Code of Practice* (Department of Health, November 2003): [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4069253](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/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

*Information Sharing: Guidance for practitioners and managers*, HM Government, 2008. Reprinted 2009. Available at: [www.education.gov.uk/publications//eOrderingDownload/00807-2008BKT-EN-March09.pdf](http://www.education.gov.uk/publications//eOrderingDownload/00807-2008BKT-EN-March09.pdf)

## Continuing Care

The national framework for NHS continuing healthcare and NHS-funded nursing care (Department of Health, July 2009 (revised): [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_103162](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103162)

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](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114784)

## Education

### Special Educational Needs

Special Educational Needs Code of Practice – Statutory guidance on the SEN framework – available free from DfE Publications on 0845 60 22260, quoting reference: DfES 581/2001

Special Educational Needs Code of Practice for Wales – available to download from the Welsh Government's website at <http://wales.gov.uk/dcells/publications/publications/guidanceandinformation/codesofpractice/specialeducop/specialeducationneedse.pdf?lang=en>

## Transport

Home to School Travel and Transport Guidance 2007 – ref: DFES – 003773-2007 – [www.education.gov.uk/publications/standard/publicationDetail/Page1/DFES-00373-2007](http://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFES-00373-2007)

Learner Travel Operational Guidance – <http://wales.gov.uk/topics/transport/publications/opguidance/?lang=en>

2010 Post 16 Transport guidance – <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/LSC-P-NAT-100520>

## Further and Higher Education

Department for Education Section 139A Learning Difficulty Assessments Guidance for Local Authorities (England) – <http://www.education.gov.uk/childrenandyoungpeople/sen/g00203393/lda>

Disability Rights UK / Skill Funding guide for Adult Learners September 2011 – <http://wales.gov.uk/docs/dcells/publications/111125fundingguideen.pdf>

(England) Bridging the Gap – a guide to the Disabled Students Allowances (DSAs) in Higher Education 2012/13 – [http://www.direct.gov.uk/prod\\_consum\\_dg/groups/dg\\_digitalassets/@dg/@en/@educ/documents/digitalasset/dg\\_200484.pdf](http://www.direct.gov.uk/prod_consum_dg/groups/dg_digitalassets/@dg/@en/@educ/documents/digitalasset/dg_200484.pdf)

(Wales) Bridging the Gap – a guide to the Disabled Students Allowances (DSAs) in Higher Education 2012/13 – [http://www.studentfinancewales.co.uk/pls/portal/docs/PAGE/WPIPG001/WPIPS002/WPIPS069/WPIPS108/WPIPS111/SFW\\_BRIDGINGTHEGAP\\_ENGLISH\\_1213.PDF](http://www.studentfinancewales.co.uk/pls/portal/docs/PAGE/WPIPG001/WPIPS002/WPIPS069/WPIPS108/WPIPS111/SFW_BRIDGINGTHEGAP_ENGLISH_1213.PDF)

## Employment

### Disabled people and Work

The Disability symbol: <https://www.gov.uk/looking-for-work-if-youre-disabled/looking-for-a-job>

### Benefits and Work Schemes

Employment and support allowance – <https://www.gov.uk/employment-support-allowance/overview>

New Enterprise scheme – <http://www.dwp.gov.uk/adviser/updates/new-enterprise-allowance/#enterprise>

## Equality Act 2010

Equality and Human Rights Commission's Working Better publications at <http://www.equalityhumanrights.com/advice-and-guidance/working-better/disability-report/>

Equality Act 2010 Employment Statutory Code of Practice – [http://www.equalityhumanrights.com/uploaded\\_files/EqualityAct/employercode.pdf](http://www.equalityhumanrights.com/uploaded_files/EqualityAct/employercode.pdf)

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/wor/new/ea-guide.pdf>

## Human Rights Act 1998

General information on human rights is available at: Ministry of Justice: <http://www.justice.gov.uk/whatwedo/humanrights.htm>

## Mental Capacity Act 2005

General information: <http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act>

Mental Capacity Act 2005 – Code of Practice: <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/mca-code-practice-0509.pdf>

## Mental Health

Department of Health, *No health without mental health: a cross-government mental health outcomes strategy for people of all ages*: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_123766](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123766)

*Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*<sup>190</sup> 2010 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_122847](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122847)

Refocusing the Care Programme Approach (Department of Health, March 2008): [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_083647](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083647)

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<sup>190</sup>Department of Health, 17th December 2010 issued to local authorities, NHS bodies and NHS Foundation Trusts under section 2 Autism Act 2009

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>

Department of Health, National Service Framework for Children, Young People and Maternity Services: The mental health and psychological wellbeing of children and young people, 2004: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4089114](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089114)

## Money Matters

Department for Work and Pensions, *Agents, Appointees, Attorneys and Deputies Guide* <http://www.dwp.gov.uk/publications/specialist-guides/agents-appointees-attorneys/>

Money Advice Service, *Help with managing money if you, or someone you care for, lacks mental capacity* (2011): [www.justice.gov.uk/downloads/guidance/protecting-the-vulnerable/mca/help-managing-money.pdf](http://www.justice.gov.uk/downloads/guidance/protecting-the-vulnerable/mca/help-managing-money.pdf)

HM Revenue and Customs, *Disability Helpsheet* <http://www.hmrc.gov.uk/taxcredits/tc956.pdf>

Transition Information Network – provides links to a range of information about money matters: <http://www.transitioninfonet.org.uk/resources/money.aspx>

## 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](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](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4094479)

## 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](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083106)

## Safeguarding

In Safe hands (Wales) National Assembly for Wales (2000)

*No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse* (England) Department of Health and Home Office (2000)

Safeguarding Disabled Children: Practice Guidance (Department Children, Schools & Families, July 2009), available from the Department of Education: <http://publications.education.gov.uk/default.aspx?PageFunction=productdetails&PageMode=publications&ProductId=DCSF-00374-2009&>

Working Together to safeguard Children: A guide to interagency working to safeguard and promote the welfare of children, HM Government March 2010

## 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](http://www.act.org.uk)

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](http://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](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](http://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>

## Annex B: Organisations Providing Information and/or Advice

### **Please note that Cerebra does not endorse any particular organisation**

ACAS (Advisory, Conciliation and Arbitration Service) – helps with employment relations by supplying up-to-date information, independent advice and high quality training, and working with employers and employees to solve problems and improve performance:

[www.acas.gov.uk](http://www.acas.gov.uk)

Business Disability Forum – an organisation whose purpose is 'to build disability smart organisations to improve business performance by increasing confidence, accessibility, productivity and profitability': <http://www.businessdisabilityforum.org.uk>

Careers Wales – provides free, bilingual, careers information, advice and guidance for individuals of all ages: <http://www.careerswales.com/>

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](http://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/](http://www.citizensadvice.org.uk/)

Contact a Family: Provides support, information and advice to families of disabled children: [www.cafamily.org.uk/](http://www.cafamily.org.uk/)

Disability Rights UK / Skill – further and Higher education information leaflets available to download for free from <http://www.disabilityalliance.org/skill.htm> Also detailed benefits information available – <http://www.disabilityrightsuk.org/>

Education Law Association – this association for educationalists, lawyers and advice workers concerned with the law of education seeks to support the advancement of education for the public benefit from pre-school through primary, secondary, further, higher and adult education. It provides training and advice and assistance in matters relating to education law: <http://www.educationlawassociation.org.uk/>

Equality Challenge Unit (ECU) – works to further and support equality and diversity for staff and students in higher education across all four nations of the UK, and in further education in Scotland: [www.ecu.ac.uk](http://www.ecu.ac.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/](http://www.equalityhumanrights.com/)

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/](http://www.housing-ombudsman.org.uk/)

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

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/](http://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/](http://www.lgo.org.uk/)

National Apprenticeship Service – (NAS) supports, funds and co-ordinates the delivery of Apprenticeships throughout England: <http://www.apprenticeships.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/](http://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/](http://www.ombudsman-wales.org.uk/)

## Annex C: Disabled Students Allowances ('DSAs')

To be eligible for DSAs, students must be either:

- on a full or part-time undergraduate course, including distance learning courses and PGCE students; such courses include degrees and HND level courses which may be delivered in an FE college rather than a university or other higher education institution
- postgraduates on an eligible full or part-time course including distance learning courses

There are particular rules for Open University students and Initial Teacher Training students. Students who have received the DSAs for past study can apply again and there is no age limit.

The DSAs are not open to:

- students who receive support equivalent to the DSAs from another funding provider including:
  - students eligible for a bursary from the NHS who cannot apply for the DSAs but can access equivalent support through the NHS bursary scheme
  - postgraduate students who are eligible for research council funding, or entitled to equivalent support from a social work bursary from the NHS Business Services authority or equivalent support from their HE provider
- EU students
- sandwich course students on a full-year placement (although some students may be eligible if they are undertaking particular types of unpaid work experience in the public or voluntary sectors); ineligible students may be able to use the Access to Work scheme – see Employment chapter)

For undergraduate students the DSAs are as follows:

- > **Specialist equipment allowance:** helps students to buy equipment they need in order to be able to study and there is a maximum amount that can be paid for the whole of the course. The equipment will remain the property of the student at the end of the course unless they leave the course early.
- > **Non-medical helper allowance:** enables students to pay for support workers such as sign-language interpreters, amanuenses, readers and specialist one-to-one support. There is a maximum yearly rate. If a student leaves the course early, they may be asked to pay back some of this allowance.
- > **General allowance:** covers other disability-related study items such as printer cartridges and can be used to top up the other allowances if need be. There is a yearly maximum rate. If a student leaves the course early, they may be asked to pay back some of this allowance.
- > **Travel allowance:** (see paragraph 3.54)
- > For **postgraduate students** there is a single yearly allowance which can be used for specialist equipment, non-medical helpers, other course related costs or extra travel costs.

Application forms are available from the gov.uk website or from Student Finance England or Student Finance Wales (or from the Open University for their students). Once a decision on eligibility has been made, students will need to have a needs assessment carried out at an independent assessment centre or at a centre located at the student's HE institution. Students can apply as early as March in the year they are due to start their course (or at any stage during their course) but the sooner they apply the better as the process can be time consuming.

After the assessment, the assessor will send out a needs assessment report detailing the recommended support, how much it will cost and how to access it but any recommended support will need to be agreed with Student Finance England or the OU (or the student's local authority or the OU in Wales).

## 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

**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.

**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 5th ed 2012).

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).

As a national charity, Cerebra strives to improve the lives of children with neurological conditions through research, education and direct, on-going family support. Living with neurological conditions can make life very hard, not just for the child but for their family too. Through the generosity of our supporters we are able to make it a little easier.

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

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