

CHAPTER 10

Transition to adulthood

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Key points

- The process of transition to adulthood involves changes in both the law and service provision for disabled young people.
- This process can be mismanaged and transition to adult services has been described as a 'cliff edge' or 'black hole'.
- The Care Act 2014, the Children and Families Act (CFA) 2014 and the Children Act (CA) 1989 (as amended) contain specific provisions designed to ensure that appropriate transition arrangements are put in place for disabled children.
- Government guidance requires a multi-agency approach to effective transition planning for disabled young people.
- Unless there has been significant social care or health input in the life of a disabled young person, education should generally take the lead in transition planning.
- The education duties are to produce a transition plan following the annual review of a child's education, health and care (EHC) plan or Statement of Special Educational Needs (SEN) at 14 and every review thereafter;
- Disabled young people can continue to receive social care services under the Children Act 1989 and the Chronically Sick and Disabled Persons Act (CSDPA) 1970 s2 even after they have become 18.
- Disabled young people who are accommodated by local authorities as children are entitled to a personal adviser and pathway plan under the leaving care legislation.
- The duties on health bodies generally remain the same when a disabled child becomes an adult. However, the move from paediatric to adult services can be disruptive. Government guidance expects a health transition plan to be developed for every disabled young person with health needs.
- Specific provisions exist to ensure that health and social services authorities manage the transition process for young people eligible (or who may be eligible) for NHS 'continuing healthcare' funding.
- There are a number of accommodation options available for disabled young people outside the family home as they transition into adulthood, including supported living and residential care.
- Disabled young people can access support for higher education through disabled students allowances (DSAs), although the government intends to reduce the scope of these allowances by reference to the reasonable adjustments duties on higher education institutions.

Introduction

10.1 This chapter deals with the law relating to young disabled people as they move into adulthood.¹ The process is frequently referred to simply as 'transition'. It is often an extremely difficult time for disabled people and their families, as all too frequently the services and supports they may have fought for as children fall away while adult services are not ready to step in: see paras 1.72–1.75 for more on disabled young people's experiences at this life stage. However, as disabled young people move into adulthood, the fundamental duties owed to them by public bodies remain the same – to assess their needs and to use person-centred planning to secure mainstream and specialist services and support that meet these needs.

10.2 At the point of transition to adulthood, legal and organisational arrangements change, new information needs to be accessed and new plans have to be made.² System failures in this important stage contribute to negative outcomes and poor quality of life for disabled young people.³ The report from the parliamentary hearings which informed the 2006 Aiming High for Disabled Children review described transition to adulthood as 'the black hole', meaning 'a time when young people have few options, become more isolated and families experience a drop in levels of support'.⁴ This language was echoed in a 2007 report from the (then) social care inspectorate, which described the transition process for some disabled young people as a 'nightmare'.⁵

10.3 As we note below at paras 10.22–10.37, the Care Act 2014 contains major provisions, designed to ensure that the transition process is properly planned in relation to disabled young people's social care needs. It is to be hoped that these reforms will materially improve the experiences of those in the transition process. Equally, it is to be hoped that the extension of education, health and care (EHC) plans from birth to 25 will assist in a more effective transition to adult services for those young people who benefit from them, being young people with significant levels of special educational needs; see further para 10.8 below. The emphasis on the need for effective early preparation for transition to adulthood is made clear by the title of the relevant chapter of the SEND Code (chapter 8): Preparing for adulthood from the earliest years. The benefits of effective transition planning for

¹ As the Children and Families Act (CFA) 2014 creates a single SEN and disability scheme for children and young people aged 0–25 (see chapter 4), this chapter focuses on social care and health duties.

² J Read, L Clements and D Ruebain, *Disabled children and the law – research and good practice*, Jessica Kingsley Publishers, 2006, p166.

³ J Read, L Clements and D Ruebain, *Disabled children and the law – research and good practice*, Jessica Kingsley Publishers, 2006, pp168–171.

⁴ *Report of the Parliamentary Hearings on Services for Disabled Children*, 2006, p53.

⁵ Commission for Social Care Inspection (CSCI), *Growing up matters: better transition planning for young people with complex needs*, 2007.

disabled young people are summarised in the SEND Code.⁶ Local authorities now have a duty⁷ to offer information and advice which supports children and young people to prepare for adult life.⁸ Every 'local offer' (see paras 3.8, 4.72–4.78 and 5.27–5.29) must include provision which will help children and young people prepare for adulthood and independent living.⁹

10.4 This chapter makes many references to court and ombudsman findings concerning serious management failings by health and social care authorities of the transitional process. Such failings cause significant and sometimes long-term hardship to disabled young people and their families. Frequently, the disabled young person is vulnerable and the harm is to their emotional well-being and education/social development,¹⁰ although on occasions it is even more profound, as was the finding of the ombudsmen in a complaint concerning 'Mr W'. In this sad and extreme case, the local government ombudsman¹¹ found that arrangements by the local authority for this young man's transition into adult accommodation fell significantly below a reasonable standard: indeed Mr W died after a period of deteriorating health.

10.5 The failure of local authorities and health bodies to ensure continuity of care for disabled people moving into adulthood is not a new concern. The problem is primarily organisational, in that at this stage the people responsible for the care planning and commissioning arrangements for the young person generally change: from children's services to adult services; from paediatric services to general adult healthcare, and so on. The creation of separate social services departments in England for children and adults by the Children Act (CA) 2004 has almost certainly exacerbated this profound and long-standing problem.¹² This danger was acknowledged by the statutory guidance concerning the role of

⁶ SEND Code, para 8.2. The evidence cited suggests that supporting one person with a learning disability into employment could, in addition to improving their independence and self-esteem, increase that person's income by between 55 and 95 per cent and that equipping a young person with the skills to live in semi-independent rather than fully supported housing could, in addition to quality of life improvements, reduce lifetime support costs to the public purse by around £1 million.

⁷ Under CFA 2014 s32 and the SEND Code at para 8.3.

⁸ In addition a wide range of schools are required to ensure pupils from **Year 8** until year 13 are provided with independent careers guidance; see SEND Code at para 8.27.

⁹ See CFA 2014 s30 and SEND Regs 2014 SI No 1530 Sch 2 para 10.

¹⁰ See for example, a case summarised in Local Government Ombudsman, digest of cases 2007/8, H1, which concerned a young person who had been accommodated by a local authority in a series of inappropriate residential placements for almost two years and in respect of which the ombudsman recommended a compensation payment of over £12,000.

¹¹ Local Government Ombudsman and Parliamentary and Health Service Ombudsman, **Six lives: the provision of public services to people with learning disabilities** HC 203–201, TSO, 2009, p64.

¹² See, for example, L Clements, 'Respite and short break care and disabled children' (2008) 18 **Seen & Heard**, pp23–31.

directors of adult social services¹³ which requires that they, together with their opposite number in children's services, have in place 'adequate arrangements' to ensure 'continuity of care for young disabled people throughout their transition to becoming adults'. It is likely, however, that these long-standing difficulties and failures have been further exacerbated by local authority adult social care budgets being reduced on average by a third during the five years preceding publication of this guide.¹⁴

10.6 The courts have highlighted the public law requirement that statutory bodies' co-ordinate their actions to protect the wellbeing of individuals – even if responsibility may have transferred from one body to another. In *R (AM) v Havering LBC and Tower Hamlets LBC*,¹⁵ for example, Cobb J held:

It is trite law that once a public law duty has been engaged ... it is incumbent upon the authority on whom the duty is placed to act reasonably in discharging that duty; where the duty on the authority changes (by virtue for instance of a change of the law, or a change of specific circumstance – ie the family moves from one local authority area to another), the authority remains under a duty to act reasonably and rationally in discharging or relinquishing its duties¹⁶

10.7 In relation to the particular facts of the Havering case, the judge commented:

Even though there was no ongoing duty ... [to the family] once it had left its area, it was nonetheless ... an inexcusable failure of good social work practice to 'wash its hands' of the family in this way; continuity of social work involvement and practice best meets the obligations under statute and is indeed the most cost-efficient.¹⁷

10.8 The SEND Regs 2014¹⁸ endeavour to address the problem of transition into adulthood. Chapter 8 of the SEND Code fleshes out this obligation and states that '[t]he principles set out in this chapter apply to all young people with SEN or disabilities, except where it states they are for those with Education, Health and Care (EHC) plans only'.

10.9 The SEND Regs 2014 require that local authorities include in the planning process (from at least year 9 onwards) a focus on preparing for adulthood (a

¹³Department of Health, *Guidance on the Statutory Chief Officer Post of Director of Adult Social Services issued under s7(1) Local Authority Social Services Act 1970*, 2006.

¹⁴ADASS Annual Budget Survey June 2015.

¹⁵[2015] EWHC 1004 (Admin).

¹⁶[2015] EWHC 1004 (Admin) at [35]: the judge here cites *R v Secretary of State for the Environment ex p Shelter* 23 August 1996, unreported, and *R v Newham LBC ex p Ojuri (No 5)* [1998] 31 HLR 631 at 637.

¹⁷[2015] EWHC 1004 (Admin) at [46].

¹⁸SI No 1530 regs 6, 12, 20 and 21 and see also the SEND Code, chapter 8.

'preparing for adulthood review').¹⁹ While a period of up to four years to plan for a young person's transition into adulthood might appear a generous timescale, experience suggests that transition planning too often remains poor. Not untypically, councils simply fail to comply with their statutory responsibilities and even when the transition process is instigated, it is frequently characterised by delay, officer turnover, a lack of incisive action, broken undertakings, ignored complaints and a persistent failure to locate suitable placements (which may require a very specific and costly package of care) during which time the authority loses the ability to look at the 'whole child' and his or her spectrum of needs and becomes particularly insensitive to the impact these failures are having on the family carers.²⁰

10.10 The basic duty owed to disabled young people in transition, across all service areas, is that the responsible statutory body must assess their needs and put in place a plan to ensure that those needs are met. Whatever the type of assessment, it is crucial that the young person and her or his family are made aware of its purpose, how it will be conducted and, most importantly, the nature of the decisions that rest on it. In addition, professionals should adopt a 'person-centred planning' approach:²¹ giving disabled young people every opportunity to take decisions about their lives with the necessary support. The SEND Code states that '[I]ocal authorities must place children, young people and families at the centre of their planning, and work with them to develop co-ordinated approaches to securing better outcomes, as should clinical commissioning groups (CCGs)'.²²

10.11 Alongside the availability of appropriate provision, a successful transition to adulthood for a disabled young person will almost always depend upon proper planning in which their needs, preferences and wishes and those of their parents are central: not least because this is a legal obligation – see for example CA 1989 ss1(3) and 17(4A) in relation to social care and CFA 2014 s19(1) in relation to education. All too often, it appears that this fundamental prerequisite is overlooked. In a 2008 Report,²³ for example, the local government ombudsman found maladministration through a failure to communicate with and consult a young person who was moved to a residential educational placement, seemingly with almost no reference to his wishes and feelings. The courts have also considered similar failures. *R (CD) v Anglesey CC*²⁴ concerned a 15-year-old disabled person for whom the local authority's transition care plan was

¹⁹See also chapter 8 of the SEND Code, headed 'Preparing for adulthood from the earliest years', at paras 8.9–8.12.

²⁰There are abundant local government ombudsmen reports which highlight failures of this kind – but for a typical example, see the report on an investigation into complaint 08/001/991 against the Isle of Wight Council, 4 June 2009.

²¹Department of Health, *National service framework for children, young people and maternity services: standard 8*, 2004, p38; Department of Health, *Valuing people: a new strategy for learning disability for the 21st century: towards person centred approaches*, 2002.

²²SEND Code, para 8.1.

²³Local Government Ombudsman, digest of cases 2008/9, Case L3: in a similar vein, see also Local Government Ombudsman, digest of cases 2007/8, Case H4.

²⁴[2004] EWHC 1635 (Admin); (2004) 7 CCLR 589 at [61].

'substantially contrary' to her wishes and feelings. In a damning judgment, the court castigated the local authority for its failures, observing:

Of course a 15-year-old who does not suffer substantial disabilities and who is directed to stay at a location to which she or he has strong objection can, as is the frequent experience of the Division, vote with her or his feet. C can do no such thing; but it would, for obvious reasons, be wrong to pay any less respect to her wishes and feelings in consequence.

10.12 Young people in transition and their families should not feel that they have to limit their ambitions. *The National Service Framework for Children (England)* describes the main focus of transition planning as 'the fulfilment of the hopes, dreams and potential of the disabled young person, in particular to maximise education, training and employment opportunities, to enjoy social relationships and to live independently'.²⁵ In this context, 2007 Department of Health guidance noted that 'work defines us ... [but] because so few people with learning disabilities do work, there is no expectation from others that they can, and consequently little is done to offer them the opportunity'.²⁶ Transition planning should, therefore, focus on realistic but ambitious plans for disabled young people in adulthood. This is endorsed by 2009 guidance which stated that planning for employment should be a 'key objective in person centred plans, including person centred transition plans'.²⁷ In relation to leisure opportunities, local authorities in England have a duty²⁸ to take reasonable steps to secure leisure activities for young people in their area, including disabled young people up to the age of 25.

10.13 Proper transition planning involves a process that takes time, skill and sensitivity and works to avoid common pitfalls. For example, if the planning starts too late, there is a danger that those involved will simply go through the motions, that young people and their parents will not participate fully and that only limited options will be on offer that do not reflect the range of outcomes which young people might wish to aim for. While people may feel protected by formal procedures, they may also find them inhibiting when it comes to expressing their opinions and aspirations. Some may find it difficult if policy and practice appear to privilege cultural norms that are not their own.²⁹ Some young people may require forms of communication other than speech and may be prevented from

²⁵Department of Health, *National service framework for children, young people and maternity services: core standards*, 2004, standard 8, p38.

²⁶Department of Health, *Valuing people now: from progress to transformation*, 2007.

²⁷HM Government, *Valuing people now: a new three-year strategy for people with learning disabilities*, 2009, 3.29.

²⁸Education Act 1996 s507B, inserted by Education and Inspections Act 2006 s6(1).

²⁹L Jones, K Atkin and W Ahmad, 'Supporting Asian deaf young people and their families: the role of professionals and services', (2001) 16 *Disability and Society*, pp51-70.

participating if this is not fully acknowledged.³⁰ In what is an essentially personal process, concerns, tensions and differences of view may emerge between family members.

10.14 All these issues need to be addressed for transition planning to succeed in its object of promoting fulfilling lives for disabled young people. Above all, regardless of the formal legal obligations on individual services which are set out below, multi-agency co-operation is essential if satisfactory outcomes are to be achieved for disabled young people.³¹ For disabled young people as for their non-disabled peers, autonomy and independence should increase as they reach adulthood, though the meaning and expression of independence and autonomy will differ considerably between individuals.³²

Social care

10.15 Far too many disabled young people experience a disrupted transition from children to adult social care services. Half the councils responding to a 2007 survey by the Commission for Social Care Inspection reported that young people's care packages changed at, or after, transition to adulthood and that this generally represented a significant reduction in services.³³ The local government ombudsman has repeatedly expressed concern about failures in transition planning and the severe shortfalls in provision at this crucial stage. The ombudsman has in particular emphasised the duty to continue to meet assessed needs and not to 'use available services as a starting point and just fit people into them'.³⁴

10.16 The statutory guidance on the role of director of adult social services requires that 'adequate arrangements' are in place 'to ensure all young people with long-term social care needs have been assessed and, where eligible, receive a service which meets their needs throughout their transition to becoming adults'.³⁵ To deliver on this expectation, many local areas have set up transition teams – either 'actual', multi-disciplinary teams based together, usually either in

³⁰P Rabiee, P Sloper and B Beresford, 'Desired outcomes for children and young people with complex health care needs and children who do not use speech for communication', (2005) 135 *Health and Social Care in the Community*, pp478-487. See also (undated) guidance published by the Council for Disabled Children and Participation Works, *How to involve children and young people with communication impairments in decision-making*, available from www.participationworks.org.uk.

³¹B Beresford, 'On the road to nowhere? Young disabled people and transition', (2004) 306 *Child: Care, Health and Development*, pp581-587. See also SEND Code, para 9.59.

³²J Read, L Clements and D Ruebain, *Disabled children and the law - research and good practice*, Jessica Kingsley Publishers, 2006, ch 7.

³³CSCI, *Growing up matters: Better transition planning for young people with complex needs*, 2007.

³⁴Complaint no 03/C/16371 against Stockton-on-Tees BC, 18 January 2005.

³⁵Department of Health, *Guidance on the Statutory Chief Officer Post of Director of Adult Social Services*, 2006, para 27.

children's services or adult social care, or 'virtual' teams which meet regularly and have effective systems for communicating between agencies.

10.17 Because young people with learning disabilities are often particularly disadvantaged in transition to adulthood, 2001 guidance called for person-centred transition planning for these young people to be a priority.³⁶

10.18 Despite the abundant guidance in this area, the evidence suggests that all too often local authorities fail properly to manage complex social care transitions. Typically the problem stems from local authorities resource difficulties (both financial and personnel) and inflexible bureaucratic arrangements. Two local government ombudsman investigations illustrate these difficulties. A 2005 report³⁷ concerned a care plan that had identified a number of suitable placements for a young person as part of his transition from his residential college. The authority's care purchasing panel refused to fund any of the proposed placements and instead determined that he should move to a council-run facility with significantly lower costs. The young person's behaviour deteriorated rapidly at this facility such that he had to be moved again to a secure psychiatric unit where he was sedated for eight months. Once at the unit, which was run by the NHS, the authority withdrew all its funding. In finding maladministration (and recommending compensation of £35,000), the ombudsman held that the placement in the council-run facility 'flew in the face of the assessment'.

10.19 A 2003 ombudsman report³⁸ concerned a young person due to leave college, for whom his parents had identified a suitable independent residential placement which the social worker agreed met his needs. Although the council was aware that there was considerable demand for this placement and a quick funding decision was needed, it required the funding request to be put to a series of 'panels' (see para 10.18 above) – with the consequence that the placement was delayed by two years. The ombudsman again found maladministration (and recommended similar levels of compensation). In his opinion, once a need such as this had been identified, it had to be met (regardless of resources) and it 'was unacceptable for it not to have made specific budgetary provision that would enable it to respond more quickly once a placement was offered'.

10.20 Given the not infrequent failings of statutory bodies to co-ordinate and plan for a young person's transition into adulthood, it is generally necessary for families

³⁶*Valuing people: a new strategy for learning disability for the 21st century*, Circular HSC 2001/016: LAC(2001)23, para 3.38. Person-centred approaches to transition planning are also required by the DfES/Department of Health, **National service framework for children, young people and maternity services: standard 8: disabled children and young people and those with complex health needs**, 2004, ch 7.

³⁷Complaint no 04/A/10159 against Southend on Sea BC, 1 September 2005.

³⁸Complaint no 00/B/18600 against East Sussex CC, 29 January 2003. See also the similar report on complaint no 02/C/17068 against Bolton MBC, 30 November 2004, where the ombudsman found that the service user was not in any way properly prepared for his return to the community on leaving school and that 'there is overwhelming evidence that' the council's reluctance to fund the parents' preferred option was because of the impact this would have 'on the Social Services agency budget'.

to adopt an active and demanding role in the process. In this context, Parker provides the following advice:

You are going to have to manage a medium term project (a bit like restoring a building). You will need to get various experts to work together; you will need them to agree to work to deadlines and then ensure that they keep to these deadlines. You will need to keep records and to remind the experts of what needs to be done in each phase and by when. If the experts give explanations which you find unconvincing, you may need to challenge these. You will also need to be clear on 'costs'. Generally, councils and NHS bodies must meet the needs of a disabled young person or adult: needs are fundamental and costs are secondary. Vague statements about 'funding panels' or 'cost caps' should be challenged and always clarified in writing.³⁹

10.21 The law relating to the provision of social care services to disabled adults is reviewed comprehensively by Clements and Thompson⁴⁰ and there is insufficient space in this book to go into the detail of this substantial subject. The following sections, therefore, provide an outline only of the law.

Social care transition responsibilities

10.22 The Care Act 2014 places detailed legal obligations on local authorities to assess and prepare care plans for carers and disabled children whose care and support needs are likely to transfer to the adult social services department. Chapter 16 of the Care and Support Statutory Guidance provides considerable detail on the responsibilities of local authorities to ensure that the transition process is a success. It also articulates the obligations in the language of wellbeing – the importance of young people and their families being in 'control' – and that this encompasses the idea being in control over the move 'from children's services to the adult system without fear of suddenly losing care and support'.⁴¹

10.23 The Act has a formulaic approach to the duty – essentially that if it appears to an authority that: (1) it is 'likely' that a disabled child and/or the child's carer and/or a young carer will have care and support needs after transition; and (2) it will be of 'significant benefit' to be assessed – then the authority must assess or give reasons if it refuses to assess.

Transitional assessments

10.24 Chapter 16 of the Care and Support Statutory Guidance provides considerable detail on the way authorities should approach their duties in relation to disabled children, the parents of disabled children and young carers. Transition

³⁹Camilla Parker, *Transition To Adulthood: A Guide for Parents*, Cerebra, 2014.

⁴⁰L Clements, *Community care and the law*, 6th edn, LAG, 2016.

⁴¹Care and Support Statutory Guidance, para 1.25.

assessments can be combined with those required by other statutory provisions⁴² which should always include an assessment of the following:

- current needs for care and support and how these impact on wellbeing;
- whether the child or carer is likely to have needs for care and support after the child in question becomes 18;
- if so, what those needs are likely to be, and which are likely to be eligible needs;
- the outcomes the young person or carer wishes to achieve in day-to-day life and how care and support (and other matters) can contribute to achieving them.⁴³
- 10.25 Transition assessments for young carers or adult carers must also consider whether the carer:
 - is able to care now and after the child in question turns 18;
 - is willing to care now and will continue to after 18;
 - works or wishes to do so;
 - is or wishes to participate in education, training or recreation.⁴⁴

10.26 The requirement that assessments for carers must consider whether they are willing to provide care is of fundamental importance. It needs to be emphasised to carers of disabled adults that there is no legal requirement on them to provide care. Adopting an ongoing caring role for a disabled young person once they turn 18 must be a genuine choice for young person carers and other family members – a choice which should be informed by a proper understanding of the level of support available to them through the assessment and support planning process.

10.27 Authorities should always provide details of the timescale for assessments⁴⁵ and should not only identify short, medium and longer-term needs/aspirations – but also be clear about how progress towards achieving these will be monitored.⁴⁶

Disabled children in transition

10.28 The Care Act 2014 provisions (sections 58 and 59) relating to disabled children (as well as those concerning carers 'in transition' to adulthood) are overly complicated – as the Act contains considerable detail on the issue of consent/capacity to consent and what must be included in the assessment.⁴⁷ Put

⁴²See for example Children Act 1989 s17ZA and s17ZD; Carers (Recognition and Services) Act 1995 s1; and Care and Support Statutory Guidance, para 16.27.

⁴³Care and Support Statutory Guidance, para 16.24.

⁴⁴Care and Support Statutory Guidance, para 16.25.

⁴⁵Care and Support Statutory Guidance, para 16.31.

⁴⁶Care and Support Statutory Guidance, para 16.33.

⁴⁷Important as these issues are – it is a level of detail one would have expected to find in the regulations rather than the primary statute.

simply, however, the general formula (above) applies – namely: a local authority must undertake a needs assessment of a disabled child if it considers that the child is likely to have needs for care and support after becoming 18. The assessment must be carried out at the time when it would be of ‘significant benefit’ to the child to do so. If the young person lacks the necessary mental capacity to agree to the assessment, the local authority must make a best interest determination on this question.⁴⁸ Such an assessment is referred to as a ‘child’s needs assessment’. If a local authority decides not to undertake such an assessment it must give reasons for its refusal together with information about ‘about what can be done to prevent or delay the development by the child of needs for care and support in the future’.⁴⁹ However, given the low threshold, it should be rare that a request for a transition assessment is refused.

10.29 The mere fact that a disabled child may not require social care support services as an adult is not in itself a conclusive reason for refusing a transitional assessment. As the Care and Support Statutory Guidance advises:

16.4 ... The purpose of carrying out transition assessments is to provide young people and their families with information so that they know what to expect in the future and can prepare for adulthood.

16.5 Transition assessments can in themselves be of benefit in providing solutions that do not necessarily involve the provision of services, and which may aid planning that helps to prevent, reduce or delay the development of needs for care or support. ...

Likely need

10.30 Paragraph 16.9 of the Care and Support Statutory Guidance advises that a young person or carer is ‘likely to have needs’ if they have ‘any likely appearance of any need for care and support as an adult’:

... not just those needs that will be deemed eligible under the adult statute. It is highly likely that young people and carers who are in receipt of children’s services would be ‘likely to have needs’ in this context, and local authorities should therefore carry out a transition assessment for those who are receiving children’s services as they approach adulthood, so that they have information about what to expect when they become an adult.

⁴⁸Care Act 2014 s58(3) and see also Care and Support Statutory Guidance, para 16.38, which advises that for those without the requisite capacity a person with parental responsibility will need to be involved in their transition assessment, – or an independent advocate provided if there is no one appropriate to act on their behalf (either with or without parental responsibility). It is difficult to envisage situations in which it would not be in the young person’s best interests to undertake an assessment – given that the assessment need not be intrusive and the outcome does not bind the young person to any particular course of action. There may, however, be situations when the timing of the assessment may need to be adjusted: the guidance suggests for example that an assessment might be delayed if a child is sitting their exams: para 16.13.

⁴⁹Care Act 2014 s59(5).

Significant benefit

10.31 Paragraph 16.6 advises that it will generally be of 'significant benefit' to assess 'at the point when their needs for care and support as an adult can be predicted reasonably confidently, but will also depend on a range of other factors'. In relation to young people with special educational needs (SEN) who have an EHC plan, the guidance is unequivocal in stating that the transition assessment process should begin from year 9,⁵⁰ adding that even 'for those without EHC plans, early conversations with local authorities about preparation for adulthood are beneficial'.⁵¹

10.32 Paragraph 16.7 gives further guidance as to the point at which the young persons' needs for care and support (as an adult) can be predicted reasonably confidently, stating:

- Transition assessments should take place at the right time for the young person or carer and at a point when the local authority can be reasonably confident about what the young person's or carer's needs for care or support will look like after the young person in question turns 18. There is no set age when young people reach this point; every young person and their family are different, and as such, transition assessments should take place when it is most appropriate for them.
- 10.33 Paragraph 16.10 states that the considering of 'significant benefit' is 'not related to the level of a young person or carer's needs, but rather to the timing of the transition assessment'. It then provides an illustrative list of factors that should be considered when trying to establish the right time to assess – namely:
 - the stage they have reached at school and any upcoming exams;
 - whether the young person or carer wishes to enter further/higher education or training;
 - whether the young person or carer wishes to get a job when they become a young adult;
 - whether the young person is planning to move out of their parental home into their own accommodation;
 - whether the young person will have care leaver status when they become 18;
 - whether the carer of a young person wishes to remain in or return to employment when the young person leaves full time education;
 - the time it may take to carry out an assessment;
 - the time it may take to plan and put in place the adult care and support;
 - any relevant family circumstances;
 - any planned medical treatment.

⁵⁰SEND Code, para 8.9.

⁵¹Care and Support Statutory Guidance, paras 16.11, 16.12.

10.34 If the authority believes that the timing is such that the assessment should not take place at the particular moment (even though there will be a need for care/support after turning 18), it has responsibility 'to contact the young person or carer to agree the timing of the transition assessment, rather than leaving the young person or carer in uncertainty or having to make repeated requests for an assessment'.⁵²

10.35 An informative case study as to the timing of a transition assessment, is provided in the guidance. It concerns a 15-year-old disabled child who attends an education funded residential school and who also receives a funding package from social services – both at the school and on the weekends/holidays with her parents. The parents request a transition assessment on her 16th birthday. After a discussion with the family, the local authority realises that when the young person leaves school at 19 'it will not be appropriate for her to live with her parents and she will require substantial supported living support and a college placement'. The local authority then appreciates that this will necessitate 'a lengthy transition in order to get used to new staff, a new environment and a new educational setting' not least because the 'college has also indicated that that they will need up to a year to plan for her start'. On this basis, the local authority concludes that it would be of 'significant benefit' for the transition assessment to take place.⁵³

10.36 A 2008 local government ombudsman report⁵⁴ illustrates the problems that can arise where a disabled young person and her family seek a transitional plan that will enable her to live in the family home. In this case, although the young person was in a good quality residential placement and college, she and her parents wanted her to live at the family home – subject to adaptations being undertaken to make it suitable. The local authority failed to progress these adaptations (and the associated disabled facilities grant) with the necessary expedition – such that the ombudsman considered that the young person spent at least two-and-a-half years in residential care unnecessarily. The ombudsman also considered that this delay engaged the young person's rights under article 8 of ECHR, and in his opinion:

The greater a person's disability, the greater is the need to give proper and timely consideration to that person's basic rights and, what concerns me most, the values and principles underlying those rights – such as dignity, equality, fairness and respect.

10.37 Where the young person has an EHC plan then the transitional planning process under the education provisions will 'lead' – and this is considered at para 10.9 above.⁵⁵ The same will generally apply for young people with rights under the 'Children Leaving Care' provisions (see para 10.49) where the statutory

⁵²Care and Support Statutory Guidance, para 16.15.

⁵³Care and Support Statutory Guidance, para 16.15.

⁵⁴Report on an investigation into complaint no 07 A 11108 against Surrey County Council, 11 November 2008.

⁵⁵See Care and Support Statutory Guidance, para 16.11. See also the SEND Code at paras 8.59–8.64 in relation to transition assessments for young people with EHC plans.

pathway planning process will generally be the more appropriate process to follow – considered at para 10.54 below. However, it is essential that whichever group of professionals take the lead, there is an accurate and transition assessment completed under the Care Act to ensure there is appropriate social care support in place when the young person turns 18. The SEND Code gives the following guidance in relation to young people with EHC plans and post-18 care needs:

Where young people aged 18 or over continue to have EHC plans, and are receiving care and support, this will be provided under the Care Act 2014. The statutory adult care and support plan should form the ‘care’ element of the young person’s EHC plan. While the care part of the EHC plan must meet the requirements of the Care Act 2014 and a copy should be kept by adult services, it is the EHC plan that should be the overarching plan that is used with these young people to ensure they receive the support they need to enable them to achieve agreed outcomes.⁵⁶

Parent carers in transition

10.38 Whether disabled young people remain with their families or progress towards living separately, it is important that the rights of family carers are not neglected. Although there is no legal obligation on parents to provide or continue to provide care for their adult children, many continue to offer a great deal of support to their disabled sons and daughters as they become young adults. Local authorities are under a statutory duty, when the young person is being assessed for adult care services, to assess parent carers (see paras 10.24–10.26 above) and to offer other adult carers’ an assessment.

10.39 Specific provisions additionally exist for adult carers who are caring for a disabled child in transition. Sections 60 to 62 of the Act places obligations on local authorities to assess the disabled child’s adult carers⁵⁷ during this transition process. In simple terms,⁵⁸ the Act provides that a local authority must undertake a needs assessment of the carer of a disabled child if it considers that the carer is likely to have needs for support after the child becomes 18. The assessment must be carried out at the point it would be of significant benefit to the carer. Such an assessment is referred to as a ‘child’s carer’s assessment’. If a local authority decides not to undertake such an assessment it must give reasons for its refusal together with information about ‘about what can be done to prevent or delay the development by the carer of needs for support in the future’.⁵⁹ See discussion above at paras 10.30 and 10.31–10.33 as to how ‘significant benefit’ and ‘likely to have needs’ should be construed.

⁵⁶SEND Code, para 8.69.

⁵⁷A child’s carer is defined as ‘an adult an adult (including one who is a parent of the child) who provides or intends to provide care for the child’ (s61(7)) but is not paid to provide the care or a formal volunteer (s61(8)).

⁵⁸The Act, again, contains overly complicated provisions on the issue of consent/capacity to consent and what must be included in the assessment.

⁵⁹Care Act 2014 s60(6).

10.40 For many parents, the transitional process poses additional challenges with the loss of the regular routine of their child attending school. In this context (illustrating the Care Act's emphasis on carers being able to work or participate in education, training or leisure activities⁶⁰), the guidance to the Care Act 2014 advises as follows:

... some carers of disabled children are able to remain in employment with minimal support while the child has been in school. However, once the young person leaves education, it may be the case that the carer's needs for support increase, and additional support and planning is required from the local authority to allow the carer to stay in employment.⁶¹

10.41 The guidance continues by stressing the importance of full-time programmes for young people aged 16 and over, particularly those who are not in colleges that offer five-day placements. It advises that in such situations, transition assessments should explore the options for other provision (for example volunteering, community participation or training) which 'not only allows the carer to remain in full time employment, but also fulfils the young person's wishes or equips them to live more independently as an adult'.⁶²

Young carers in transition

10.42 The Care Act 2014 ss63 and 64 concern young carers 'in transition'. A young carer is defined as 'a person under 18 who provides or intends to provide care for an adult but is not paid to provide the care or a formal volunteer' (see para 8.31 above). Again the Act (in simple terms)⁶³ requires that a local authority undertakes a needs assessment of a young carer if it considers that she/he is likely to have needs for support after becoming 18 and the assessment must be carried out when it would be of significant benefit to him/her. Such an assessment is referred to as a 'young carer's assessment'. If a local authority decides not to undertake such an assessment, it must give reasons for its refusal together with information 'about what can be done to prevent or delay the development by the young carer of needs for support in the future'. See discussion above at paras 10.30 and 10.31–10.33 as to how 'significant benefit' and 'likely to have needs' should be construed. As with assessments of disabled young people, if the young carer lacks

⁶⁰The wellbeing principle with its emphasis on 'participation in work, education, training or recreation': Care Act 2014 s1(2)(e).

⁶¹Care and Support Statutory Guidance, para 16.20.

⁶²Care and Support Statutory Guidance, para 16.21. See also SEND Code at paras 8.41–8.44.

⁶³The Act contains overly complicated provisions on the issue of consent/capacity to consent and what must be included in the assessment.

the necessary mental capacity to agree to the assessment, the local authority must make a best interest determination on this question.⁶⁴

10.43 Young carers have, in general, significantly lower educational attainments than their non-carer peers.⁶⁵ The guidance notes that many of them 'feel that they cannot go to university or enter employment because of their caring responsibilities' and advises that the transition process must address this question to support them 'to prepare for adulthood and how to raise and fulfil their aspirations'.⁶⁶ This requirement extends to other members of the disabled child's household including the caring impact on:

... siblings' school work, or their aspirations to go to university. Young carers' assessments should include an indication of how any care and support plan for the person(s) they care for would change as a result of the young carer's change in circumstances. For example, if a young carer has an opportunity to go to university away from home, the local authority should indicate how it would meet the eligible needs of any family members that were previously being met by the young carer.⁶⁷

Co-operation

10.44 Disabled children with complex needs may have many professionals and different organisations involved in their care. Public bodies have many statutory duties requiring them to cooperate with each other (see para 10.6 above). The guidance to the Care Act makes the traditional exhortation for joint working in relation to transitional planning⁶⁸ and notes the frustration that families experience when having to attend 'multiple appointments for assessments, and who have to give out the same information repeatedly'.⁶⁹ The guidance contains practical advice on how the various agencies should co-ordinate their assessments and support arrangements including giving emphasis to the value many families attach to having 'one designated person who co-ordinates assessments and transition

⁶⁴Care Act 2014 s53(3). As noted above, it is difficult to envisage situations in which it would not be in the young person's best interests to have an assessment - given that the assessment need not be intrusive and the outcome does not bind the young person to any particular course of action. There may, however, be situations when the timing of the assessment may need to be adjusted: the Care and Support Statutory Guidance suggests for example that an assessment might be delayed if a child is sitting their exams: para 16.13.

⁶⁵Young Carers at GCSE achieve the equivalent to nine grades lower overall than their peers, eg, the difference between nine Bs and nine Cs, and are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19. Department of Health, *The Care Act and Whole-Family Approaches*, 2015, and see also The Children's Society, *Hidden from view*, 2013.

⁶⁶Care and Support Statutory Guidance, para 16.22.

⁶⁷Care and Support Statutory Guidance, para 16.23.

⁶⁸Care and Support Statutory Guidance, paras 16.41-16.43.

⁶⁹Care and Support Statutory Guidance, para 16.44; see also the SEND Code at paras 8.25, 9.33 and 9.47 and its emphasis on the 'tell us once' approach to gathering information; and see also chapter 1 at paras 1.48-1.52.

planning across different agencies, and helps them to navigate through numerous systems and processes that can sometimes be complicated.⁷⁰

The 18th birthday

10.45 Once a person who has had a transitional assessment becomes 18 (or in the case of a parent carer, their child becomes 18) then the local authority is required to determine whether or not to treat the assessment as a needs assessment under the 2014 Act.⁷¹ In determining whether this is or is not appropriate, the authority must consider when the assessment was carried out and whether any of the circumstances may have changed since that time.⁷² As the guidance to the Care Act advises where it is decided that the young person's or carer's needs are to be met under the Care Act after they have turned 18 the authority must 'undertake the care planning process as for other adults – including creating a care and support plan and producing a personal budget'.⁷³

10.46 Section 66 of the Care Act contains a valuable power – enabling the Children Services and the Adult Services departments to determine the best time for transferring their respective responsibilities. As the SEND Code states:

Under no circumstances should young people find themselves suddenly without support and care as they make the transition to adult services. Very few moves from children's to adult services will or should take place on the day of someone's 18th birthday.⁷⁴

10.47 Section 66 enables an authority to continue providing support under CA 1989 s17 and/or CSDPA 1970 s2 even though the young person has reached the age of 18. If on reaching the 18th birthday the authority decides not to treat it as a needs assessment under the 2014 Act, then it is required to undertake a new assessment and continue with the previous provision to the young person/ carer until it has made an eligibility determination. In this respect the Statutory Guidance to the Care Act stresses⁷⁵ the importance of ensuring that families are not faced with a gap in provision of care and support on the relevant 18th birthday and if by that date the necessary care and support not in place then the existing services must be continued until the 'relevant steps have been taken' – which it explains means that the local authority:

⁷⁰Care and Support Statutory Guidance, paras 16.45-16.49.

⁷¹See Care Act 2014 s59(6) in relation to a disabled child; s61(6) in relation to a parent carer; and s64(7) in relation to a young carer.

⁷²See Care Act 2014 s59(7) in relation to a disabled child; s61(7) in relation to a parent carer; and s64(8) in relation to a young carer.

⁷³Care and Support Statutory Guidance, para 16.63.

⁷⁴SEND Code, para 8.67.

⁷⁵Care and Support Statutory Guidance, para 16.66.

- concludes that the person does not have needs for adult care and support; or
- concludes that the person does have such needs and begins to meet some or all of them ...; or
- concludes that the person does have such needs but decides they are not going to meet any of those needs (for instance, because their needs do not meet the eligibility criteria under the Care Act 2014).⁷⁶

10.48 The innovative provisions in section 66 are mirrored by provisions relating to young people with EHC plans⁷⁷ and for care leavers in foster placements.⁷⁸ As the guidance to the Care Act explains, authorities must have a 'Staying Put' policy⁷⁹ 'to ensure transition from care to independence and adulthood that is similar for care leavers to that which most young people experience, and is based on need and not on age alone'.⁸⁰

Duties to disabled young people 'leaving care'⁸¹

10.49 As detailed in chapter 3 (para 3.144), where a disabled child is accommodated under CA 1989 s20, the child becomes a 'looked after' child. The child is then entitled to the same protection and support as a child who is in the local authority's care under a care order. Disabled young people who are looked after have the same entitlements when leaving care as other looked after young people.⁸²

10.50 In recognition of the poor outcomes for children looked after by local authorities, the Children (Leaving Care) Act (CLCA) 2000 introduced significant new duties into the CA 1989, requiring local authorities to continue to support these young people into adulthood. These duties are clarified by regulations and guidance issued by the Department for Education.⁸³ This guidance is binding

⁷⁶Care and Support Statutory Guidance, para 16.67.

⁷⁷CA 1989 s17ZG.

⁷⁸CA 1989 s23CZA which enables local authorities to extend these placements beyond the age of 18.

⁷⁹HM Government, *'Staying Put' Arrangements for Care Leavers aged 18 and above to stay on with their former foster carers*, 2013.

⁸⁰Care and Support Statutory Guidance, para 16.69.

⁸¹See further chapter 7 of I Wise QC, S Broach, J Burton, C Gallagher, A Pickup, B Silverstone, A Sutterwalla, *Children In Need: Local Authority Support for Children and Families*, 2nd edn, LAG, 2013.

⁸²Department of Education/Department of Health, *National service framework for children, young people and maternity services: standard 8: disabled children and young people and those with complex health needs*, 2004, para 7.2.

⁸³Care Leavers (England) Regulations 2010 SI No 2571; Care Planning, Placement and Case Review (England) Regulations 2010 SI No 959 and Department for Education, *The Children Act 1989 guidance and regulations. Volume 3: planning transition to adulthood for care leavers*, 2010 (The CA 1989 Volume 3 Guidance 2015), revised January 2015.

'policy' guidance issued under Local Authority Social Services Act 1970 s7 (see para 2.41) and states that '[t]he main aim of the Care Leavers Regulations and of this guidance is to make sure that care leavers are provided with comprehensive personal support so that they achieve their potential as they make their transition to adulthood'.⁸⁴

10.51 The general duty on local authorities in relation to children leaving care is to 'advise, assist and befriend [such a child] with a view to promoting his welfare when they have ceased to look after him'.⁸⁵ However, the CLCA 2000 also inserts a range of specific duties and powers into the CA 1989 in relation to young people leaving care. These duties and powers generally apply until a young person reaches 21. As an exception to this, help given to meet expenses concerned with education or training may continue to the young person's 24th birthday⁸⁶ or, in the case of a former relevant child (see para 10.52), to the end of an agreed programme of education or training as set out in their pathway plan.⁸⁷

10.52 The leaving care duties apply to the following groups of young people:

1. Eligible children: children aged 16 and 17 who have been looked after for at least 13 weeks since the age of 14 and who remain looked after.⁸⁸
2. Relevant children: children aged 16 and 17 who were looked after for at least 13 weeks since the age of 14, were looked after at some time while 16 or 17 but have stopped being looked after.⁸⁹
3. Former relevant children: a young person aged 18–21 who was either an eligible or relevant child.⁹⁰ Importantly, if a former relevant child's pathway plan (see paras 10.54 and 10.55) sets out a programme of education or training extending beyond his or her 21st birthday, he or she remains a relevant child until that programme is completed.⁹¹

10.53 To become an eligible or relevant child, the child must have been accommodated by the local authority and, therefore, 'looked after' for at least 13 weeks since the age of 14. Importantly in relation to disabled children, short-term periods of respite care should be ignored for the purposes of calculating whether

⁸⁴The CA 1989 Volume 3 Guidance 2015, para 1.3.

⁸⁵CA 1989 Sch 2 para 19A.

⁸⁶CA 1989 s24B(3).

⁸⁷CA 1989 s23C(7).

⁸⁸CA 1989 Sch 2 para 19B(2) and the Care Planning, Placement and Case Review (England) Regulations 2010 SI No 959 reg 40.

⁸⁹CA 1989 s23A(2) and the Care Leavers (England) Regulations 2010 SI No 2571 reg 3.

⁹⁰CA 1989 s23C(1).

⁹¹CA 1989 s23C(7).

13 weeks have been reached.⁹² This means that disabled children who receive residential short breaks lasting less than four weeks at a time but are not otherwise accommodated by the local authority will not become 'care leavers'.

10.54 The CLCA 2000 imposes different duties on local authorities in respect of eligible, relevant and former relevant children. These are:

1. Eligible children: in addition to all the provisions of the looked-after system (see paras 3.144–3.147), an eligible child is entitled to a needs assessment leading to a pathway plan⁹³ and to have a personal adviser⁹⁴ (see below).
2. Relevant children are also entitled to a pathway plan⁹⁵ and personal adviser.⁹⁶ In addition, relevant children must be supported and maintained by the local authority, unless they are satisfied that the child's welfare does not require such support and maintenance.⁹⁷ In particular, local authorities must provide assistance (including cash if required) in order to meet a relevant child's needs in relation to education, training or employment as provided for in his or her pathway plan.⁹⁸ If a local authority has lost touch with a relevant child, they must take reasonable steps to re-establish contact.⁹⁹
3. Former relevant children: local authorities must continue to appoint a personal adviser for a former relevant child and keep his or her pathway plan under review.¹⁰⁰ Furthermore, authorities must provide former relevant children with assistance with employment and education and training.¹⁰¹ They must also provide other assistance 'to the extent that [the former relevant child's] welfare requires it'.¹⁰² This 'other assistance' can include

⁹²Care Leavers (England) Regulations 2010 reg 3(3). This provides that for the purposes of calculating time towards the required 13 weeks 'no account is to be taken of any period in which the child was looked after by a local authority in the course of a pre-planned series of short-term placements, none of which individually exceeded four weeks, where at the end of each such placement the child returned to the care of their parent, or a person who is not a parent but who has parental responsibility for them'.

⁹³CA 1989 Sch 2 para 19B(4).

⁹⁴CA 1989 Sch 2 para 19C.

⁹⁵CA 1989 s23B(3).

⁹⁶CA 1989 s23B(2).

⁹⁷CA 1989 s23B(8).

⁹⁸Care Leavers (England) Regulations 2010 reg 9.

⁹⁹CA 1989 s23B(11).

¹⁰⁰ CA 1989 s23C(3).

¹⁰¹ CA 1989 s23C(4) (a) and (b).

¹⁰² CA 1989 s23C(4) (c).

the provision of accommodation,¹⁰³ although only where suitable accommodation is not otherwise available to the young person (for example they are ineligible for accommodation under the Housing Act 1996). Local authorities must take reasonable steps to keep in touch with former relevant children, whether or not the young person remains in their area, and to re-establish contact if they lose touch.¹⁰⁴

10.55 Eligible, relevant and former relevant children are, therefore, all entitled to both personal advisers and pathway plans. Personal advisers must be appointed by the local authority to support and befriend the young person. The functions of the personal adviser are specified by the regulations¹⁰⁵ and include providing advice and support, co-ordinating the provision of services and participating in pathway planning and reviews. However, the personal adviser must not themselves develop the pathway plan¹⁰⁶ or carry out the review, albeit that particularly in relation to reviews they may play a very active role.¹⁰⁷ Young people should be given a choice of personal adviser.¹⁰⁸ The expectation is that the same personal adviser will remain with the young person once he or she becomes a former relevant child (see above, para 10.54).¹⁰⁹

10.56 Pathway plans must set out the result of the needs assessment which must be completed within three months of a young person's 16th birthday.¹¹⁰ The assessment must address a wide range of issues, including the young person's health and development, need for education, training and employment, financial needs and care and support needs.¹¹¹ The young person must be properly involved in the assessment.¹¹²

¹⁰³ As determined by the Court of Appeal in *R (O) v Barking and Dagenham LBC* [2010] EWCA Civ 1101; [2011] 1 WLR 1283.

¹⁰⁴ CA 1989 s23C(2).

¹⁰⁵ Care Leavers (England) Regulations 2010 reg 8.

¹⁰⁶ *R (J) v Caerphilly CBC* [2005] EWHC 586 (Admin); (2005) 8 CCLR 255.

¹⁰⁷ *R (A) v Lambeth LBC* [2010] EWHC 1652.

¹⁰⁸ The CA 1989 Volume 3 Guidance 2010, paras 3.24 and 3.37. It will be ideal if the range of advisers is sufficiently wide to provide young people with a choice.

¹⁰⁹ The CA 1989 Volume 3 Guidance 2010, paras 3.30 and 4.39.

¹¹⁰ Care Planning, Placement and Case Review (England) Regulations 2010 SI No 959 reg 42(1) - but see also Care Leavers (England) Regulations 2010 SI No 2571 reg 5(2).

¹¹¹ Care Planning, Placement and Case Review (England) Regulations 2010 reg 42(2) and Care Leavers (England) Regulations 2010 reg 5(4).

¹¹² Care Planning, Placement and Case Review (England) Regulations 2010 reg 42(2) and Care Leavers (England) Regulations 2010 reg 5(4).

10.57 Pathway plans should be produced 'as soon as possible' after the assessment is completed.¹¹³ They should cover all the issues identified in the assessment and the guidance states that young people should be 'central to discussions and plans for their futures and it will be exceptional for decisions about their futures to be made without their full participation'.¹¹⁴ Pathway plans should contain contingency plans¹¹⁵ to address potential difficulties and should be reviewed every six months¹¹⁶ to check that the plan 'continues to respond to all the dimensions of the young person's needs' as well as establishing 'that they have settled into their accommodation and that this is, in practice, suitable in the light of their needs'.¹¹⁷

10.58 *In R (J) v Caerphilly CBC*,¹¹⁸ Munby J (as he then was) considered the assessments and pathway planning produced in relation to a relevant child with complex needs and a history of offending behaviour. The local authority's efforts were all declared to be unlawful, as none of the versions of the plan produced amounted to a 'detailed operational plan' clarifying who would do what and by when to help J.¹¹⁹ Munby J held that one of the 'telling indicators' of the plan's inadequacy was the failure to identify specialist support for J – a relevant factor in pathway planning for many disabled young people.¹²⁰ Munby J further emphasised the need to involve the young person in the planning process, even if they are 'unco-operative'.¹²¹

10.59 Specific and substantial as are the duties on local authorities in such cases, the evidence suggests that the failures highlighted by the *Caerphilly judgment* (above) are not isolated. While a number of the young people to whom these duties are owed may be unco-operative this was not considered an adequate excuse for failure in the *Caerphilly judgment*. A 2009 local government ombudsman report¹²² also concerned a young man who was at times uncooperative and who had been in local authority care since the age of 13, and for whom, therefore, the CLCA 2000 duties were engaged. Sadly, his pathway plans were materially defective and agreed action was not followed through; his personal adviser failed to provide appropriate support and assistance and when

¹¹³ Care Planning, Placement and Case Review (England) Regulations 2010 reg 43(1) and Care Leavers (England) Regulations 2010 reg 6(1).

¹¹⁴ The CA 1989 Volume 3 Guidance 2015, para 3.32

¹¹⁵ Care Planning, Placement and Case Review (England) Regulations 2010 Sch 8 para 10 and Care Leavers (England) Regulations 2010 Sch 1 para 4.

¹¹⁶ Care Leavers (England) Regulations 2010 reg 7(2).

¹¹⁷ The CA 1989 Volume 3 Guidance 2015, para 3.2.

¹¹⁸ [2005] EWHC 586 (Admin); (2005) 8 CCLR 255.

¹¹⁹ [2005] EWHC 586 (Admin); (2005) 8 CCLR 255 at [45]–[46].

¹²⁰ [2005] EWHC 586 (Admin); (2005) 8 CCLR 255 at [41].

¹²¹ [2005] EWHC 586 (Admin); (2005) 8 CCLR 255 at [56].

¹²² Report on an investigation into complaint no 08 013 283 against Lambeth LBC, 18 May 2009.

he went on sick leave, he was not replaced. During this period, the young man endeavoured to sustain his place on a university course and in his lodgings – although ultimately his lack of support led him to leave the course and to be threatened with eviction for rent arrears. The ombudsman identified multiple maladministration in the way that this case had been handled, and observed:

In its corporate parenting role the Council should persevere in keeping in touch with the young person. ... In this case I consider that the Council had to take account of the effects of Mr Smith's bouts of depression and to make sure that relevant details of his vulnerability and background were known to those who were working with him ... That made it all the more important for the Council to put effective mechanisms in place to prevent a recurrence of past failures. It did not do so and that was further maladministration by the Council.¹²³

10.60 The leaving care scheme offers valuable services and supports to young people who have been accommodated by local authorities. This is a primary reason why it is so important to establish under which statutory provision a disabled child who lives away from her family home is being accommodated. If a child is not in local authority care, it will generally only be if the accommodation is being provided under one of the duties or powers contained in CA 1989 s20 (see para 3.136) that they will benefit from the leaving care provisions.

Healthcare responsibilities

10.61 The difficulties that disabled young people experience in relation to the social care transitional process are, sadly, also evident in relation to their healthcare needs. A 2014 Care Quality Commission Report on this issue¹²⁴ found that 80 per cent of cases had no transition plan and concluded that the health and social care system was 'not working' and was 'letting down many desperately ill youngsters at a critical time in their lives'; that this was because 'we have put the interests of a system that is no longer fit for purpose above the interests of the people it is supposed to serve.' It considered that the elements of good practice that were not being followed were:

- There should be good planning for transition.
- There should be a good transition plan in place.
- Health passports should be used more widely.
- There should be a lead professional to support young people and their families through transition.
- Health care settings and services should be responsive to the needs of young people and their families when transferring to adult services.
- The needs of parents as carers should be assessed and addressed.
- Responsibility for finding should be agreed early in the process.

¹²³ Report on an investigation into complaint no 08 013 283 against Lambeth LBC, 18 May 2009, para 54.

¹²⁴ Care Quality Commission, *From the Pond to into the Sea*, 2014.

10.62 As with social care, there is no legal reason for this system failure, as the duties under the NHS Acts remain fundamentally the same for children and adults (see paras 5.30–5.31). However, a genuine difficulty is created by the fact that many therapeutic interventions, particularly speech and language therapy, are delivered to disabled children through their EHC plans/statements of SEN (see chapter 4) as educational provision and so adult health services will need to take on an additional responsibility for meeting the young person's therapeutic needs.

10.63 Given the potential disruptions in young people's healthcare, the CA 1989 guidance stresses the 'crucial' role of GPs through their knowledge of the whole family and their ability to monitor the individual young person's health and wellbeing.¹²⁵ The focus of the guidance is on ensuring that as far as possible disabled young people are not accommodated in hospital on a long-stay basis.

10.64 Since 2004, the National Service Framework in England (the Children's NSF) has required that health services develop appropriate adolescent/young persons services with a view to enabling smooth transition to comprehensive adult multi-disciplinary care.¹²⁶ Standard 4 of the Children's NSF, heading 'Growing up into adulthood', emphasises the importance of age-appropriate services which respond to young people's specific needs as they grow into adulthood.

10.65 A 2008 Department of Health good practice guidance, *Transition: moving on well*,¹²⁷ for health services in England on transition to adulthood emphasises the importance of a health transition plan. The guidance is clear that a health transition plan should be 'an integral part of the broader transition plan', linked closely to plans held by education and social care.¹²⁸ The health plan should be developed by the young person alongside a multi-disciplinary team (including the GP), supported by the most relevant health professional who can review it regularly with them.¹²⁹ Planning should start at the latest when the child is 13.¹³⁰ An example of a health transition planning tool is given at Annex B in the guidance. Similarly, *Valuing people*¹³¹ stressed the need for all young people with learning disabilities approaching the end of their secondary schooling to have a health action plan (see chapter 5 at paras 5.47–5.50). These are completed with young people by a range of staff, most commonly a community nurse or a school nurse.

¹²⁵ Department of Health, *Children Act 1989 Guidance and Regulations*, Vol 6, *Children with disabilities*, 1991, para 16.11.

¹²⁶ DfES/Department of Health, *National service framework for children, young people and maternity services: standard 8: disabled children and young people and those with complex health needs*, 2004, ch 7.

¹²⁷ Department of Health, *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*, 2008.

¹²⁸ *Transition: moving on well*, pp10–11.

¹²⁹ *Transition: moving on well*, p11.

¹³⁰ *Transition: moving on well*, p11.

¹³¹ Department of Health, *Valuing people: a new strategy for learning disability for the 21st century*, Circular HSC 2001/016: LAC(2001)23, para 6.15.

NHS continuing healthcare

10.66 Where a disabled young person has a significant level of health needs, responsibility for meeting those needs may rest with the NHS under the children's continuing care provisions: see paras 5.82–5.100 (and see also paras 5.146–5.152 above where aspects of the transition planning responsibilities of the NHS are also considered).

10.67 In England, two Department of Health framework documents provide 'strong'¹³² guidance concerning the eligibility of adults and young people for NHS Continuing healthcare funding: (1) a 2012 National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (for adults); and (2) a 2010 National Framework for Children and Young People's Continuing Care. Both these framework documents are under review at the time of writing, albeit that the proposed revisions appear to be minor in scope.

10.68 Paragraph 80 of the 2010 children's framework emphasises the importance of adhering to the key transition guidance for health professionals, Transition: moving on well (see above). It requires that all CCGs:

- be actively involved in development and oversight of transition planning processes;
- ensure they are represented in all transition planning meetings regarding individuals who may be eligible for NHS; and
- have systems in place to ensure that appropriate referrals are made when either organisation is supporting a young person who may have a need for services from the other agency on reaching adulthood.¹³³
- 10.69 The guidance then sets out a clear timetable for the transition planning process – requiring that all PCTs (now CCGs) must (paras 83–85):
- at 14, identify young people for whom it is likely that adult NHS continuing healthcare will be necessary and notify the relevant PCT (CCG);
- at 16, make a formal referral for screening to the relevant adult NHS continuing healthcare team;
- by 17, decide eligibility for adult NHS continuing healthcare in principle, so that the PCT (CCG) can:
- by 18, commission an effective package of care.

¹³² The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 SI No 2996 require that CCGs and the NHS England 'have regard' to the adult National Framework (reg 21(12)) and the courts have treated the guidance as authoritative – see for example *R (Whapples) v Birmingham Cross-city Clinical Commissioning Group* [2015] EWCA Civ 435; (2015) 18 CCLR 300. Given its expert authorship and prescriptive content it is likely, in the views of the authors, that the children's national framework would also be given significant weight in any dispute which came before the courts.

¹³³ Department of Health, *National Framework for Children and Young People's Continuing Care*, 2010, para 81.

10.70 The importance of early assessments for NHS continuing healthcare funding eligibility was highlighted by a 2013 ombudsman report.¹³⁴ It concerned a young man in 'transition', and for which it found the health body's eligibility decision to be flawed. The ombudsman found maladministration in relation to the transition planning process. The young man was due to be 18 in November 2011 but the NHS transition process only started in April 2010 when he was 16. Given the complexity of the young man's needs, the ombudsman considered that this was too short a period.

Palliative care

10.71 Young people with life-limiting and life-threatening conditions will have additional support needs at transition to adulthood. As young people with life-limiting conditions are now surviving much longer, this has become an important issue. 2009 guidance¹³⁵ summarises the difficulties faced by these young people in transition to adulthood and suggests good practice ways in which these difficulties can be addressed.

Mental health

10.72 The law in relation to meeting the mental health needs of disabled young people is covered extensively in chapter 5, see paras 5.107–5.131. Given the high incidence of mental ill-health among disabled young people, particularly those with learning disabilities, it is essential that child and adolescent mental health services (CAMHS) and adult mental health services engage effectively in transition planning, at an individual and strategic level.¹³⁶

Multi-agency disputes

10.73 Problematical as it is for many disabled young people to sustain adequate social care support during their transition into adulthood, these difficulties are frequently compounded if there is (or is thought to be) NHS responsibility for some or all of the package. In such cases, the usual difficulties can be exacerbated as disabled young person and their families find themselves caught in the paralysing crossfire of an inter-authority funding dispute. In this respect, a complaint considered by the Public Services Ombudsman for Wales¹³⁷ in 2008 is not

¹³⁴ Public Services Ombudsman for Wales Report on complaint No 201201350 against Aneurin Bevan Health Board, 30 April 2013.

¹³⁵ National Transition Support Team, *'How to' guide: moving on to adult care services - young people with life-limiting and life-threatening conditions*, NCB, 2009, available at www.transitionsupportprogramme.org.uk/pdf/ACT.pdf. See also ACT, *Transition care pathway: a framework for the development of integrated multi-agency care pathways for young people with life-threatening and life-limiting conditions*, 2007.

¹³⁶ See National Transition Support Team, *'How to' guide: How to support young people with learning disabilities and mental health issues*, NCB, 2009, available at www.transitionsupportprogramme.org.uk/pdf/HowTo_FPLD.pdf.

¹³⁷ Report by the Public Services Ombudsman for Wales on an investigation into a complaint against Torfaen Local Health Board Gwent Healthcare NHS Trust and Torfaen County Borough Council, 24 February 2008, Report Reference Numbers 1712/200701931, 1712/200701932 and 1712/200702681.

untypical: it contains elements of delay, officers leaving their post, disputes over funding and parents being required to make 'snap' decisions about fundamental matters, without having the relevant information.

10.74 The complaint concerned a young person with learning disabilities and extreme challenging behaviour who, when aged 14, was assessed by the local authority as in need (when he left school) of 2:1 support in a community environment. A year later, when aged 15, a transition worker from the council met with the parents and discussed various options – however, nothing came of this and the transition worker left and was not replaced. Three years later (when he became 18), no firm plans had been made and the parents were told that they had to make a quick decision as a potential placement had become available; however, they were unable to act on this, in part because they were unable to visit the placement, due to their son being ill. At this time, the council had formed the view that the young man ought to be funded by the NHS under its continuing healthcare responsibilities – and as a consequence, in the opinion of the ombudsman, there was a 'jockeying for position' between these two bodies over who was to be responsible. The ombudsman held that the failure of the local authority's transitional planning constituted maladministration as did its failure – and that of the NHS bodies – to co-operate (see in this respect paras 5.20–5.26). A consequence of the failure had been that the young man had been cared for over 15 months by his parents in their home with little support. The ombudsman considered that the agencies had thereby profited (because they had avoided funding an expensive package during this time). The ombudsman recommended that an award be paid of £25,000 (£20,000 from the local health board and £5,000 from the council) and that this be placed in trust for the young man, with terms of the trust being agreed with his parents. This case illustrates the imperative for local agencies to meet the needs of disabled young people first, resolving any disputes which may arise as to which agency should take sole or lead funding responsibility only once needs have been met.

Mental capacity

10.75 Issues relating to the capacity of children to consent to decisions which affect them and the changing presumptions as children turn 16 and come within the scope of the Mental Capacity Act 2005 are considered in chapter 7 above.

Housing

Supported housing/supported living

10.76 'Supported living' is a generic term which has come to describe arrangements whereby a disabled person has the benefit of a package of care and support together with accommodation – for which they will ordinarily have a tenancy.¹³⁸ The development of such arrangements in the 1990s owed much to

¹³⁸ Where a disabled person is not considered to have sufficient mental capacity to enter into a tenancy agreement – procedures exist for the Court of Protection to give authority for the arrangements – see Court of Protection, *Guidance on tenancy agreements*, 2011.

the philosophy of the independently living/deinstitutionalisation movement: enabling disabled people to live ordinary lives in the community with the same choices as others.¹³⁹ It is likely that 'supported living' will be discussed as an option for many disabled children and young people as they transition into adulthood.

10.77 While a persuasive case has been made about the virtues of 'supported living' much has also been written about the problems such schemes have encountered.¹⁴⁰ As with many of the 'personalisation' initiatives in social care, their enthusiastic adoption by providers and commissioners has frequently been attributable to other policy objectives. Supported living arrangements are often less expensive for local authorities¹⁴¹ and for many providers they have the twin benefits of being 'lucrative'¹⁴² and less regulated. Not infrequently, a person may have little or no practical choice over their placement in a supported living scheme. Where a disabled person requires a substantial package of care, there are risks with supported living arrangements (unless there is a clear agreement to the contrary with the local authority) which include the risk that the care provider can be changed at short notice and the risk that the person(s) providing the necessary care may have insufficient understanding/expertise to provide adequate the necessary care and support.

10.78 Supported living arrangements separate the delivery of care from the provision of accommodation. Because these are provided by separate entities, 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.¹⁴³ The care provider will, however, generally be required to be registered with the Care Quality Commission. A consequence of not being a registered care home is that those living in such schemes are entitled to claim housing benefit – and crucially housing benefit at

¹³⁹ For an excellent overview paper see Dr Lucy Series, *A stupid question (about supported living)*, Small Places Blog, 18 February 2015 – which point to the 1990s development of 'supported living' to enable people with learning disabilities to enjoy rights to live in their own homes, with support. The ideal arrangements conform to 'Reach Standards' developed by Paradigm UK which today are little different from the requirements of article 19 of the UN Convention on the Rights of Persons with Disabilities: based on the principle of choice – where to live and with whom, buttressed by high quality supports.

¹⁴⁰ Mansell highlights the failure, not of the concept, but of 'management and leadership' noting that all too often the problem has been 'wrong buildings, in the wrong places, with the wrong furnishings, staffed by people with the wrong training, managed according to the wrong rules, with the wrong policies, the wrong leadership and the wrong purposes' – see J Mansell, 'The "implementation gap" in supported accommodation for people with intellectual disabilities', foreword to Clement and Bigby, *Group Homes for People with Intellectual Disabilities: Encouraging Inclusion and Participation*, Jessica Kingsley, 2009.

¹⁴¹ Research suggests that significant savings can be made by moving people with learning disabilities into supported living – see Local Government Association, *Learning Disability Services Efficiency Project Interim position report*, 2015.

¹⁴² P Kinsella, *Supported living: a new paradigm*, National Development Team, 1993.

¹⁴³ Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 SI No 2936.

higher rates than for non-disabled people.¹⁴⁴ Such schemes require, however, that the housing body provides care, support or supervision for the tenant.¹⁴⁵

10.79 Where a local authority has determined that a person has a need that it proposes to meet by way of a supported living arrangement, the individual has the right to 'express a preference' for a particular accommodation¹⁴⁶ and the local authority is required to provide or arrange that accommodation – even if it is in another local authority's area. If the cost of the placement is more than the authority considers necessary, then it can require a 'top-up' payment from a third party to cover the additional cost.¹⁴⁷ Where a local authority funds a supported living package in the area of another authority, the disabled person is 'deemed' to be ordinarily resident in the funding authority's area (ie its continuing responsibility) even though in fact they are resident elsewhere if the accommodation meets the criteria set down in regulations.¹⁴⁸

10.80 For the purposes of the ordinary residence¹⁴⁹ and choice of accommodation provisions,¹⁵⁰ 'supported living accommodation' means:

- (1) (a) accommodation in premises which are specifically designed or adapted for occupation by adults with needs for care and support to enable them to live as independently as possible; and
- (b) accommodation which is provided–
 - (i) in premises which are intended for occupation by adults with needs for care and support (whether or not the premises are specifically designed or adapted for that purpose), and

¹⁴⁴ Most supported living schemes access higher rates of housing benefit as they are 'exempt accommodation – ie exempt from the general cap on housing benefit by virtue of the maximum 'local reference' rent – Housing Benefit and Council Tax Benefit (Consequential Provisions) Regulations 2006 SI No 217 Sch 3 para 4(10) – ie accommodation provided by a non-metropolitan county council in England; a housing association (as defined in Housing Associations Act 1985 s1(1)); a registered charity (as defined in Charities Act 2006 Part 1), or voluntary organisation (as defined in Housing Benefit Regulations 2006 SI No 213 reg 2(1)); see also Commissioner's decisions CH/423/2006, CH/3811/2006 and CH/779/2007 – the 'Turnbull' decision.

¹⁴⁵ For example, the provision of an alarm; help ensuring rent is paid; liaising with all relevant agencies, both statutory and voluntary, on the tenant's behalf; assisting people to claim housing benefit and other welfare benefits; helping to keep people safe by monitoring visitors, including contractors and professionals, and by carrying out health and safety and risk assessments of property.

¹⁴⁶ Care Act 2014 s30(1).

¹⁴⁷ The Care and Support and After-care (Choice of Accommodation) Regulations 2014 SI No 2670.

¹⁴⁸ The Care and Support (Ordinary Residence) (Specified Accommodation) Regulations 2014 SI No 2828.

¹⁴⁹ The Care and Support (Ordinary Residence) (Specified Accommodation) Regulations 2014 reg 5.

¹⁵⁰ The Care and Support and After-care (Choice of Accommodation) Regulations 2014 reg 8.

(ii) in circumstances in which personal care is available if required.

(2) The accommodation referred to in paragraph (1)(a) does not include adapted premises where the adult had occupied those premises as their home before the adaptations were made.

(3) For the purposes of paragraph (1)(b)(ii) personal care may be provided by a person other than the person who provides the accommodation.

Shared lives accommodation/adult placement schemes

10.81 Shared lives (previously known as adult placement) is a care support arrangement that has historically focussed on supporting people with learning disabilities but increasingly is used for the support of a much wider range of individuals 'in need'.

10.82 In general, it applies to adults but schemes can and do cover 16–17-year-olds. As at 2015, there were over ¹⁵⁰ shared lives schemes in the UK with over 8,000 shared lives carers.¹⁵¹ It is the scheme that is registered and regulated in England by the Care Quality Commission.¹⁵² Schemes are most typically local authority led.

10.83 The dramatic growth in shared lives schemes (14 per cent in 2015)¹⁵³ is almost certainly due to the significant cost savings they deliver¹⁵⁴ although there is also evidence concerning its potential to materially improve individual wellbeing.¹⁵⁵

10.84 The purpose of shared lives schemes 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. The individual shares family and community life with the shared lives carer. About half of shared lives arrangements involve the disabled person living with their shared lives carer and half visit their shared lives carer for day support or overnight breaks.¹⁵⁶

¹⁵¹ See generally information at Shared Lives Plus, *What is Shared Lives?*, 2015.

¹⁵² Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 SI No 781; Care Quality Commission (Registration) Regulations 2009 SI No 3112 – and see generally The Care Quality Commission, *Supporting Information – Shared Lives schemes*, CQC, 2013.

¹⁵³ Shared Lives Plus, *What is Shared Lives?*, 2015.

¹⁵⁴ See for example Shared Lives Plus, *A Shared Life is a Healthy Life How the Shared Lives model of care can improve health outcomes and support the NHS*, 2015, and The Institute for Research and Innovation in Social Service, *Money matters: Case Study One Shared Lives*, IRISS, 2011.

¹⁵⁵ See for example, Shared Lives Plus, *A Shared Life is a Healthy Life How the Shared Lives model of care can improve health outcomes and support the NHS*, 2015.

¹⁵⁶ Shared Lives Plus, *What is Shared Lives?*, 2015.

10.85 As with supported living placements (see paras 10.76–10.80 above) where a local authority has determined that a person has a need that it proposes to meet by way of a Shared Lives arrangement, the individual has the right to ‘express a preference’ for a particular accommodation (Care Act 2014 s30(1)) and the local authority is required to provide or arrange that accommodation – even if it is in another local authority area. If the cost of the placement is more than the authority considers necessary, then it can require a ‘top-up’ payment from a third party to cover the additional cost.¹⁵⁷ Where a local authority funds a Shared Lives package in the area of another local authority, the disabled person is ‘deemed’ to be ordinarily resident in the funding authority’s area (ie its continuing responsibility) even though in fact they are resident elsewhere.¹⁵⁸

10.86 For the purposes of the ordinary residence¹⁵⁹ and choice of accommodation provisions,¹⁶⁰ ‘shared lives scheme accommodation’ means:

- accommodation which is provided for an adult by a shared lives carer, and for this purpose–
- ‘shared lives carer’ means an individual who, under the terms of a shared lives agreement, provides, or intends to provide, personal care for adults together with, where necessary, accommodation in the individual’s home;
- ‘shared lives agreement’ means an agreement entered into between a person carrying on a shared lives scheme and an individual for the provision, by that individual, of personal care to an adult together with, where necessary, accommodation in the individual’s home; and
- ‘shared lives scheme’ means a scheme carried on (whether or not for profit) by a local authority or other person for the purposes of–
 - a) recruiting and training shared lives carers;
 - b) making arrangements for the placing of adults with shared lives carers; and
 - c) supporting and monitoring placements.

10.87 CA 1989 s23CZA enables local authorities to extend the foster care placements of care leavers beyond the age of 18 (and in this respect see also CA 1989 Sch 2 para 19B and para 19BA).

Residential care

10.88 For some disabled young people, particularly those with profound and enduring impairments, a placement in a registered care home (with or without nursing) will be the most appropriate care and support arrangement which meets

¹⁵⁷ Care and Support and After-care (Choice of Accommodation) Regulations 2014 SI No 2670.

¹⁵⁸ Care and Support (Ordinary Residence) (Specified Accommodation) Regulations 2014 SI No 2828.

¹⁵⁹ Care and Support (Ordinary Residence) (Specified Accommodation) Regulations 2014 reg 4.

¹⁶⁰ Care and Support and After-care (Choice of Accommodation) Regulations 2014 reg 7.

their needs. Such placements have the advantage of being inspected by the Care Quality Commission and are (perhaps) less likely to result in sudden changes: in supported living placements, there is a risk of the local authority changing the care provider with little advance notice. It is important, however, that residential care is a genuine choice and is not forced on the young person by any policies or decisions of the public authority, for example, a policy capping the level of care provided at home at the cost of a residential placement.¹⁶¹

10.89 Disabled young people in registered care placements have the right to the full range of support services to meet their needs (ie appropriate daycare/community based supports). As with supported living placements (see paras 10.76–10.80 above) where a local authority has determined that a person has a need that it proposes to meet by way of a residential care arrangement, the individual has the right to 'express a preference' for a particular accommodation¹⁶² and the local authority is required to provide or arrange that accommodation – even if it is in another local authority area. If the cost of the care home is more than the authority considers necessary, then it can require a 'top-up' payment from a third party to cover the additional cost.¹⁶³ Where a local authority funds a care home in the area of another local authority, the disabled person is 'deemed' to be ordinarily resident in the funding authority's area (ie its continuing responsibility) even though in fact they are resident elsewhere.¹⁶⁴
Higher education – disabled student allowances

10.90 As support for disabled young people in further education is now governed primarily by EHC plans which can extend to 25, issues in relation to further education are considered in the Education chapter (see chapter 4).¹⁶⁵

10.91 For those disabled students able to access higher education,¹⁶⁶ disabled student allowances (DSAs) are grants to help meet the extra course costs students can face as a direct result of a disability, ongoing health condition, mental health condition or specific learning difficulty.¹⁶⁷ DSAs can be used to meet a wide range of additional disability-related costs, including:

¹⁶¹ See the Care and Support Statutory Guidance at para 11.22: 'Local authorities should not have arbitrary ceilings to personal budgets that result in people being forced to accept to move into care homes against their will'.

¹⁶² Care Act 2014 s30(1).

¹⁶³ Care and Support and After-care (Choice of Accommodation) Regulations 2014.

¹⁶⁴ Care and Support (Ordinary Residence) (Specified Accommodation) Regulations 2014.

¹⁶⁵ See also chapter 7 of the SEND Code, which deals specifically with the application of the scheme under Part 3 of the Children and Families Act 2014 to further education.

¹⁶⁶ See the SEND Code at paras 8.43–8.48 in relation to transition to higher education generally.

¹⁶⁷ See www.direct.gov.uk/dsas.

- specialist equipment needed for studying – for example, computer software;
- non-medical helpers, such as a note-taker or reader;
- extra travel costs resulting from a student’s disability; and
- other costs – for example, tapes or Braille paper.¹⁶⁸

10.92 The amount of support available through a DSA is dependent on the extent of the person’s needs, not their financial circumstances. As at July 2015 the maximum general allowance was £1,741 a year for full-time students and £1,305 a year for part-time students. More significant specific amounts are also available in respect of the provision of specialist equipment and the funding of a non-medical helper¹⁶⁹ to support the student.¹⁷⁰

10.93 It is important to note that the availability of financial support through DSAs does not absolve higher education providers of their responsibilities under the Equality Act 2010, and in particular their duties to make reasonable adjustments to ensure equality of access for disabled people. These duties are considered at para 9.82 onwards. Indeed the government’s policy intention¹⁷¹ is to reduce availability of DSAs and require higher education institutions to do more by way of reasonable adjustments to ensure that disabled students can access courses on an equal basis to others. Any changes to the DSAs scheme to deliver this policy intention are likely to come into force for the academic year 2016/17. If proposals put out to consultation are taken forward it is likely that only more specialist forms of non-medical help will be routinely available through DSAs in future.

¹⁶⁸ See www.direct.gov.uk/dsas.

¹⁶⁹ Readers, sign-language interpreters, notetakers and other non-medical assistants.

¹⁷⁰ Applications should be made to local authorities using the form DSA1 (disabled students’ allowance form), which can be downloaded from the www.direct.gov.uk site.

¹⁷¹ See *Disabled students in higher education: funding proposals*, a consultation by the Department for Business, Innovation and Skills which ran from 1 July 2015 to 24 September 2015.