

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. This entitlement has been extended until the young person reaches the age of 25 by the Children and Social Work Act (CSWA) 2017.
- 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 National Health Service (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).

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 1.72–1.83 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 10.24–10.39, 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. These should have materially improved the experiences of those in the transition process. Equally, the extension of education, health and care (EHC) plans from birth to 25 should have assisted in a more effective transition to adult services for those young people

- 1 As the Children and Families Act (CFA) 2014 creates a single special educational needs and disability (SEND) 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.

who benefit from them, being young people with significant levels of special educational needs (SEN); see further para 10.10 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 Special Educational Needs and Disability (SEND) Code (chapter 8): 'Preparing for adulthood from the earliest years'. The benefits of effective transition planning for disabled young people are summarised in the SEND Code.⁶ Since the Children and Families Act (CFA) 2014, local authorities have had a duty⁷ to offer information and advice which supports children and young people to prepare for adult life.⁸ Every 'local offer' (see paras 3.27, 4.41 and 5.31) must include provision which will help children and young people prepare for adulthood and independent living⁹; and under the Children and Social Work Act (CSWA) 2017 this has been strengthened with a further duty to provide a local offer of services to assist care leavers with the transition to adulthood.¹⁰

10.4 Despite this strengthening of statutory duties since 2014, reports of the Local Government and Social Care Ombudsman (LGSCO) have continued to reveal significant failings by local authorities in providing for transition. The ombudsman's *Review of Adult Social Care Complaints 2014/15* reported that:

While complaints and enquiries about the transition of support from children's to adults' services have reduced by more than a third on the previous year [to 13], where we investigated we were more likely to uphold the complaint than any other area [87 per cent as compared with 55 per cent of complaints generally]. Common areas of fault included a lack of timely transition planning and assessment of needs, poor communication during the transition process and lack of suitable education and housing provision, leaving young people and families without the support they needed. Councils should ensure

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 CSWA 2017 s2

they commit sufficient resources to make sure they are getting the crucial transition process right for all the young people they support.

- 10.5 This pattern was replicated in the ombudsman's 2015/16 review, which was the last to include details of complaints regarding transition. As at August 2019, the ombudsman's website showed ten complaints in relation to transition in 2019, all of which had been upheld.
- 10.6 Similarly, in the field of health, the National Institute for Health and Care Excellence (NICE) has commented that despite 'a wealth of policy and guidance on agreed principles in respect of good transitional care . . . there is also evidence that these principles are often not reflected in practice'.¹¹
- 10.7 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 2004 has almost certainly exacerbated this profound and long-standing problem.¹² This danger was acknowledged by the statutory guidance concerning the role of 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 by £7 billion since 2010 which, together with similar reductions in funding for primary and community healthcare, have resulted in a 'vicious spiral for social care'.¹⁴
- 10.8 The courts have highlighted the public law requirement that statutory bodies' co-ordinate their actions to protect the wellbeing of

11 NICE Guideline NG43, 'Transition from children's to adults' services for young people using health or social care services, 2016, p32.

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

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

14 ADASS Annual Budget Survey, June 2019, pp5–6.

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 duties. . . .¹⁶

10.9 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

10.10 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’.

10.11 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 ‘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

15 [2015] EWHC 1004 (Admin); (2015) 18 CCLR 326.

16 [2015] EWHC 1004 (Admin); (2015) 18 CCLR 326 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].

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

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

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

- 10.12 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 his or her 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:

Local 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

- 10.13 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 Children Act 1989 ss1(3) and 17(4A) and Children Act 2004 s59(2) 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 (LGO) found

20 There are abundant local government ombudsmen reports which highlight failures of this kind – but for a typical example, see Complaint no 16/002/997 against Buckinghamshire County Council, 3 January 2017, in which the council started its transition process in October 2014 (almost two years before a disabled child was due to turn 18) however, ‘a staff member left the Council, someone wrongly closed the case and there were staff shortages [so] the Council took no further action until March 2016 [and was] then been unable to get plans for his transition in place before he turned 18’.

21 DOH, *National service framework for children, young people and maternity services: standard 8*, 2004, p38; DOH, *Valuing people: a new strategy for learning disability for the 21st century: towards person centred approaches*, 2002; NICE Guideline NG43, *Transition from children's to adults' services for young people using health or social care services*, 2016.

22 SEND Code, para 8.1.

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

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 Isle of Anglesey CC*²⁴ concerned a 15-year-old disabled person for whom the local authority's transition care plan was '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.

- 10.14 Young people in transition and their families should not feel that they have to limit their ambitions. The National Service Framework (NSF) 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 (DOH) 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

Similarly, for looked after children and care leavers, CSWA 2017 s1 sets out corporate parenting principles for local authorities, including a requirement to have regard to the need to 'promote high aspirations, and seek to secure the best outcomes, for [looked after children and care leavers]'; and the associated statutory guidance makes clear that this applies equally to disabled children.²⁷ Transition

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

25 DOH, *National service framework for children, young people and maternity services: core standards*, 2004, Standard 8, p38.

26 DOH, *Valuing people now: from progress to transformation*, 2007.

27 Department for Education, *Applying corporate parenting principles to looked-after children and care leavers: Statutory guidance for local authorities*, February 2018, para 4.9: 'These principles include and apply to every looked after child, regardless of their age, circumstances or needs. This includes children with disabilities, education needs (for example speech, language and communication difficulties) or other complex needs . . .'

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'.²⁸ In relation to leisure opportunities, local authorities in England have a duty²⁹ to take reasonable steps to secure leisure activities for young people in their area, including disabled young people up to the age of 25.

10.15 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.³⁰ Some young people may require forms of communication other than speech and may be prevented from participating if this is not fully acknowledged.³¹ In what is an essentially personal process, concerns, tensions and differences of view may emerge between family members.

10.16 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

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

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

30 L 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.

31 P 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.

young people.³² 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.³³

Social care

- 10.17 Far too many disabled young people experience a disrupted transition from children to adult social care services. The LGO has repeatedly expressed concern about failures in transition planning and the severe shortfalls in provision at this crucial stage.
- 10.18 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'.³⁴
- 10.19 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.³⁵
- 10.20 Not infrequently it appears that authorities fail properly to manage complex social care transitions. Two local government ombudsman investigations, over a decade apart, illustrate these difficulties. A 2005 report³⁶ 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

32 B 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.

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

34 DOH, *Guidance on the Statutory Chief Officer Post of Director of Adult Social Services*, 2006, para 27; see also the Department for Education, *Statutory guidance on the roles and responsibilities of the Director of Children's Services and the Lead Member for Children's Services*, 2013, para 14.

35 *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/DOH, *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; and NICE Guideline NG43, *Transition from children's to adults' services for young people using health or social care services*, 2016.

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

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 National Health Service (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'.

- 10.21 Twelve years later, and despite the new legislative frameworks and guidance described above, a 2017 ombudsman report³⁷ described a local authority's failure to put in place any plans in place for a young person turning 18. The teen, who had significant disabilities, had received a care package which included six nights a month at a respite centre and 18 days a year at a holiday club. Despite his needs not changing, no arrangements were in place when his care moved from being the responsibility of children's services to adult services when he turned 18 in October 2015. The ombudsman, when announcing his report, said:

This family fell between the cracks as it moved from one council service to another. They were left without the essential support they needed for more than five months, and without any explanation as to why, when the council decided their previous level would be almost halved.

- 10.22 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 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

37 Complaint no 16 000 780 against Bromley LBC, 14 February 2017. See also Complaint no 11 019 601 against Lincolnshire County Council, 24 October 2013; Complaint no 00/B/18600 against East Sussex CC, 29 January 2003, Complaint no 02/C/17068 against Bolton MBC, 30 November 2004.

are secondary. Vague statements about ‘funding panels’ or ‘cost caps’ should be challenged and always clarified in writing.³⁸

- 10.23 The law relating to the provision of social care services to disabled adults is reviewed comprehensively by Clements and Thompson³⁹ 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

- 10.24 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’.⁴⁰
- 10.25 The Care Act 2014 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

- 10.26 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 assessments can be combined with those required by other statutory provisions⁴¹ which should always include an assessment of the following:

38 Camilla Parker, *Transition to Adulthood: A Guide for Parents*, Cerebra, 2014.

39 L Clements, *Community care and the law*, 7th edn, LAG, 2019.

40 Care and Support Statutory Guidance, para 1.25.

41 See, for example, Children Act 1989 ss17ZA and 17ZD; Carers (Recognition and Services) Act 1995 s1; and Care and Support Statutory Guidance, para 16.27.

- 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.⁴²
- 10.27 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.⁴³
- 10.28 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.⁴⁴ 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.
- 10.29 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 monitored.⁴⁶ There should be no gaps in services, and the Care Act 2014 requires that children’s services continue providing support until adult services are in place to take over (see paras 10.48–10.51 below).

42 Care and Support Statutory Guidance, para 16.24.

43 Care and Support Statutory Guidance, para 16.25.

44 The ombudsman has also held that no assumption should be made that parents of disabled children are willing to care – see Complaint no 14/015/230 against Kent County Council, 7 June 2016, considered further at para 8.11 above.

45 Care and Support Statutory Guidance, para 16.31.

46 Care and Support Statutory Guidance, para 16.33.

Disabled children in transition

10.30 The Care Act 2014 provisions (ss58 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 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.

10.31 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,

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

48 Care 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.

49 Care Act 2014 s59(5).

and which may aid planning that helps to prevent, reduce or delay the development of needs for care or support. . . .

Likely need

- 10.32 Care and Support Statutory Guidance para 16.9 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.

Significant benefit

- 10.33 Care and Support Statutory Guidance para 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 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
- 10.34 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.
- 10.35 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

50 SEND Code, para 8.9.

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

illustrative list of factors that should be considered when trying to establish the right time to assess – namely:

- the stage the young person or carer 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 his or her parental home into his or her own accommodation;
- whether the young person will have care leaver status when he or she becomes 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.

10.36 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

10.37 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

52 Care and Support Statutory Guidance, para 16.15.

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

- 10.38 A 2008 LGO 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 European Convention on Human Rights (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.

- 10.39 Where the young person has an EHC plan then the transitional planning process under the education provisions will ‘lead’.⁵⁵ The same will generally apply for young people with rights under the ‘Children Leaving Care’ provisions (see para 10.52 below) where the statutory pathway planning process will generally be the more appropriate process to follow – considered at para 10.57 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 2014 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

53 Care and Support Statutory Guidance, para 16.15.

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

55 See 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.

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

- 10.40 Whether disabled young people remain living in the family home 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 10.26–10.28 above) and to offer other adult carers' an assessment.
- 10.41 Specific provisions additionally exist for adult carers who are caring for a disabled child in transition. Care Act 2014 ss60–62 place 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 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 10.32–10.38 above as to how 'significant benefit' and 'likely to have needs' should be construed.
- 10.42 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

56 SEND Code, para 8.69.

57 A 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)).

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

59 Care Act 2014 s60(6).

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

10.43 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

10.44 The difficulties faced by carers in the event of failures in transition planning are starkly illustrated by one recent ombudsman decision,⁶³ in which a local authority left a woman to care for her disabled adult son largely unaided for more than two years after he turned 18, causing her to have to care for him full-time and restricting her ability to work. After she complained to the ombudsman, the council agreed to pay her £40,000, representing the direct payments to which she would have been entitled, together with £1,400 for 'harm, risk, distress and time and trouble', as well as to arrange staff training.

Young carers in transition

10.45 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

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

61 Care and Support Statutory Guidance, para 16.20.

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

63 Complaint no 17/015/332 against the Royal Borough of Greenwich, 17 January 2019.

terms)⁶⁴ requires that a local authority undertakes a needs assessment of a young carer if it considers that he or she 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 or 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 10.32– 10.38 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 the necessary mental capacity to agree to the assessment, the local authority must make a best interest determination on this question.⁶⁵

10.46 Research suggests that young carers have, in general, significantly lower educational attainments than their non-carer peers.⁶⁶ 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’.⁶⁷ 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

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

65 Care 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.

66 Young 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.

67 Care and Support Statutory Guidance, para 16.22.

needs of any family members that were previously being met by the young carer.⁶⁸

Co-operation

- 10.47 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 co-operate with each other (see para 10.8 above). The guidance to the Care Act 2014 makes the traditional exhortation for joint working in relation to transitional planning⁶⁹ 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’.⁷⁰ 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 planning across different agencies, and helps them to navigate through numerous systems and processes that can sometimes be complicated.’⁷¹

The 18th birthday

- 10.48 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 Care Act 2014.⁷² 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.⁷³ As the guidance to the Care Act 2014 advises where it is decided that the young person’s or carer’s needs are to be met under the Care Act 2014 after they have turned 18,

68 Care and Support Statutory Guidance, para 16.23.

69 Care and Support Statutory Guidance, paras 16.41–16.43.

70 Care 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.

71 Care and Support Statutory Guidance, paras 16.45–16.49.

72 See 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.

73 See 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.

the authority must ‘undertake the care planning process as for other adults – including creating a care and support plan and producing a personal budget’.⁷⁴ Funding issues must also be highlighted at an early stage and should be agreed early in the process where it is identified that the young person will require funding after turning 18.⁷⁵

10.49 Care Act 2014 s66 places an obligation on 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.⁷⁶

10.50 Section 66 enables an authority to continue providing support under Children Act 1989 s17 and/or Chronically Sick and Disabled Persons Act (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 Care Act 2014, then it is required to undertake a new assessment and continue with the previous provision to the young person or carer until it has made an eligibility determination. In this respect the Statutory Guidance to the Care Act stresses⁷⁷ 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:

- 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).⁷⁸

74 Care and Support Statutory Guidance, para 16.63.

75 See CQC, *From the Pond to into the Sea*, 2014.

76 SEND Code, para 8.67; see also the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care, March 2018 at para 348: ‘No services or funding should be unilaterally withdrawn unless a full joint health and social care assessment has been carried out and alternative funding arrangements have been put in place.’

77 Care and Support Statutory Guidance, para 16.66.

78 Care and Support Statutory Guidance, para 16.67.

- 10.51 The innovative provisions in section 66 are mirrored by provisions relating to young people with EHC plans⁷⁹ and for care leavers in foster placements.⁸⁰ As the guidance to the Care Act explains, authorities must have a ‘Staying Put’ policy⁸¹ ‘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’.⁸²

Duties to disabled young people ‘leaving care’⁸³

- 10.52 As detailed in chapter 3 (para 3.145), where a disabled child is accommodated under the Children Act 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.⁸⁴
- 10.53 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 Children Act 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.⁸⁵ This guidance is binding ‘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

79 Children Act 1989 s17ZG.

80 Children Act 1989 s23CZA which enables local authorities to extend these placements beyond the age of 18.

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

82 Care and Support Statutory Guidance, para 16.69.

83 See 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.

84 Department of Education/DOH, *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.

85 Care 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.

provided with comprehensive personal support so that they achieve their potential as they make their transition to adulthood.⁸⁶ The duties introduced by the CLCA 2000 have been further reinforced and extended by the CSWA 2017.

10.54 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’.⁸⁷ If a child has been looked after at any time after reaching the age of 16 then, on ceasing to be looked after, they will become a ‘person qualifying for advice and assistance’ under Children Act 1989 ss24A and 24B.⁸⁸ This will last until they reach the age of 21 or, in relation to assistance in relation to accommodation during vacations from a course of full-time education, until the age of 25.⁸⁹

10.55 Further duties are set out by the CLCA 2000 in relation to particular groups, namely:

- **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.⁹⁰
- **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.⁹¹
- **Former relevant children:** a young person who was either an eligible or relevant child before turning 18.⁹²

10.56 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 13 weeks have been

86 The Children Act 1989 Volume 3 Guidance 2015, para 1.3.

87 Children Act 1989 Sch 2 para 19A.

88 Children Act 1989 s24.

89 Children Act 1989 s24B(3).

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

91 Children Act 1989 s23A(2); and the Care Leavers (England) Regulations 2010 SI No 2571 reg 3.

92 Children Act 1989 s23C(1).

reached.⁹³ 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’.

10.57 The duties set out in relation to eligible and relevant children and former relevant children are:

- **Eligible children:** in addition to all the provisions of the looked-after system (see para 3.152), an eligible child is entitled to a needs assessment leading to a pathway plan⁹⁴ and to have a personal adviser⁹⁵ (see below).
- **Relevant children** are also entitled to a pathway plan⁹⁶ and personal adviser.⁹⁷ 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.⁹⁸ 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.⁹⁹ If a local authority has lost touch with a relevant child, they must take reasonable steps to re-establish contact.¹⁰⁰
- **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.¹⁰¹ Furthermore, authorities must provide former relevant children with assistance with employment and education and training.¹⁰² They must also provide other assistance ‘to the extent that [the former relevant

93 Care 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’.

94 Children Act 1989 Sch 2 para 19B(4).

95 Children Act 1989 Sch 2 para 19C.

96 Children Act 1989 s23B(3).

97 Children Act 1989 s23B(2).

98 Children Act 1989 s23B(8).

99 Care Leavers (England) Regulations 2010 reg 9.

100 Children Act 1989 s23B(11).

101 Children Act 1989 s23C(3).

102 Children Act 1989 s23C(4)(a) and (b).

child's] welfare requires it'.¹⁰³ This 'other assistance' can include the provision of accommodation,¹⁰⁴ 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.¹⁰⁵

10.58 The local authority's main duties and powers in respect of former relevant children (under Children Act 1989 s23C) generally last until the young person reaches the age of 21,¹⁰⁶ except where the young person is pursuing a programme of education or training set out in their pathway plan which extends beyond their 21st birthday.¹⁰⁷ However, the CSWA 2017 inserted a new section 23CZB into the Children Act 1989 which entitles former relevant children to a personal adviser and a pathway plan until the age of 25, together with an assessment as to '(a) whether any services offered by the local authority (under this Act or otherwise) may assist in meeting his or her need and (b) if so, what advice and support it would be appropriate for the local authority to provide for the purpose of helping the former relevant child to obtain those services'¹⁰⁸ (which the authority must then provide¹⁰⁹). Although this does not appear to create any new entitlement to services for former relevant children, it should ensure that they are assisted by the local authority to access the services to which they are entitled during their transition to adulthood.

10.59 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 regulations¹¹⁰ and include providing advice and support, co-ordinating the provision of services and participating in

103 Children Act 1989 s23C(4)(c).

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

105 Children Act 1989 s23C(2).

106 Children Act 1989 s23C(6).

107 Children Act 1989 s23C(7).

108 Children Act 1989 s23CZB(5).

109 Children Act 1989 s23CZB(6).

110 Care Leavers (England) Regulations 2010 reg 8.

pathway planning and reviews. However, the personal adviser must not themselves develop the pathway plan¹¹¹ or carry out the review, albeit that particularly in relation to reviews they may play a very active role.¹¹² Young people should be given a choice of personal adviser.¹¹³ 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 10.57).¹¹⁴

10.60 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.¹¹⁵ 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.¹¹⁶ The young person must be properly involved in the assessment.¹¹⁷

10.61 Pathway plans should be produced 'as soon as possible' after the assessment is completed.¹¹⁸ 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'.¹¹⁹ Pathway plans should contain contingency plans¹²⁰ to address potential difficulties and should be reviewed every six months¹²¹ to check that the plan 'continues to respond to all the dimensions of the young person's needs' as well as

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

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

113 The Children Act 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.

114 The Children Act 1989 Volume 3 Guidance 2010, paras 3.30 and 4.39.

115 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).

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

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

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

119 The Children Act 1989 Volume 3 Guidance 2015, para 3.32.

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

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

establishing ‘that they have settled into their accommodation and that this is, in practice, suitable in the light of their needs’.¹²²

10.62 In *R (J) v Caerphilly CBC*,¹²³ 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.¹²⁴ 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.¹²⁵ Munby J further emphasised the need to involve the young person in the planning process, even if they are ‘unco-operative’.¹²⁶

10.63 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 LGO report¹²⁷ also concerned a young man who was at times unco-operative 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 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

122 The Children Act 1989 Volume 3 Guidance 2015, para 3.2.

123 [2005] EWHC 586 (Admin); (2005) 8 CCLR 255.

124 [2005] EWHC 586 (Admin); (2005) 8 CCLR 255 at [45]–[46].

125 [2005] EWHC 586 (Admin); (2005) 8 CCLR 255 at [41].

126 [2005] EWHC 586 (Admin); (2005) 8 CCLR 255 at [56].

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

. . . 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. [Comment: Deleted footnote as reference is already given above]

- 10.64 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 his or 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 Children Act 1989 s20 (see para 3.136) that he or she will benefit from the leaving care provisions.

Healthcare responsibilities

- 10.65 The difficulties that disabled young people experience during the social care transitional process are, sadly, also evident in relation to their healthcare needs. A 2014 Care Quality Commission (CQC) report on this issue¹²⁸ 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.
- 10.66 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

128 CQC, *From the Pond to into the Sea*, 2014.

children and adults (see para 5.36). 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.

10.67 Given the potential disruptions in young people's healthcare, the Children Act 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 well-being.¹²⁹ 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.

10.68 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.¹³⁰ 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.

10.69 A 2008 DOH good practice guidance, *Transition: moving on well*,¹³¹ 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.¹³² 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.¹³³ Planning should start at the latest when the child is 13.¹³⁴ An example of a health transition planning tool is given at

129 DOH, *Children Act 1989 Guidance and Regulations*, Vol 6, *Children with disabilities*, 1991, para 16.11.

130 DfES/DOH, *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.

131 DOH, *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.

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

133 *Transition: moving on well*, p11.

134 *Transition: moving on well*, p11.

annex B in the guidance. Similarly, *Valuing people*¹³⁵ 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 para 5.51). These are completed with young people by a range of staff, most commonly a community nurse or a school nurse.

- 10.70 The focus on the importance of transition in health services has continued in recent years. In 2016 NICE released its Guideline NG43, *Transition from children's to adults' services for young people using health or social care services* addressed to health and social care providers, practitioners and 'Young people using health or social care services who may need support from adults' services in the future, and their parents or carers'. The Guideline states that:

While the Care Act and other legislation describe what organisations must do, this guideline is focused on 'what works' in terms of how to fulfil those duties.¹³⁶

It stresses the importance of:

- adults' services taking joint responsibility with children's services for transition;
- joint planning, development and commissioning of services involved in transition across children's and adults' health and social care;
- improving front-line practice with young people through training;
- improving front-line practice with young people through training; and
- the challenge: maximising opportunities for young people who have become disengaged or who are not eligible for adults' services to access care and support.

- 10.71 Further, in 2018 NHS England published its *Quick Guide: Commissioning for transition to adult services for young people with Special Educational Needs and Disability (SEND)* to help local areas develop their transition processes for young people with SEND from childhood to adulthood.

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

136 Page 32.

NHS continuing healthcare

- 10.72 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 5.91–5.102 (and see also para 5.156 above where aspects of the transition planning responsibilities of the NHS are also considered).
- 10.73 In England, two DOH framework documents provide 'strong'¹³⁷ guidance concerning the eligibility of adults and young people for NHS Continuing healthcare funding: (1) a 2016 *National Framework for Children and Young People's Continuing Care*; and (2) a 2018 *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* (for adults).
- 10.74 Paragraph 335 of the 2018 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.¹³⁸
- 10.75 The 2016 children's framework sets out a clear timetable for the transition planning process, including in summary (para 117):
- At 14 years of age, the young person should be brought to the attention of the CCG as likely to need an assessment for NHS Continuing Healthcare.

137 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.

138 DOH, *National Framework for Children and Young People's Continuing Care*, 2010, para 81.

- At 16–17 years of age, screening for NHS Continuing Healthcare should be undertaken using the adult screening tool, and an agreement in principle that the young person has a primary health need, and is therefore likely to need NHS Continuing Healthcare.
 - At 18 years of age, full transition to adult NHS Continuing Healthcare or to universal and specialist health services should have been made, except in instances where this is not appropriate.
- 10.76 The importance of early assessments for NHS continuing health-care funding eligibility was highlighted by a 2013 ombudsman report.¹³⁹ 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

- 10.77 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 guidance¹⁴⁰ summarised the difficulties faced by these young people in transition to adulthood and suggests good practice ways in which these difficulties can be addressed.
- 10.78 The 2016 framework stresses the importance of young people who require fast-track assessment (because of the nature of their needs – such as a palliative care need) being identified early and their needs met as quickly as possible. The continuing care process should not restrict access to end-of-life care for children and young people who require immediate support over a shorter period, and

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

140 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.transitionssupportprogramme.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.

should not result in any delay to appropriate treatment or care being put in place.¹⁴¹

Mental health

- 10.79 The law in relation to meeting the mental health needs of disabled young people is covered extensively in chapter 5, see paras 5.110–5.137. 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.¹⁴²

Multi-agency disputes

- 10.80 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 Wales¹⁴³ in 2008 is not 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.

- 10.81 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,

141 National Framework for Children and Young People’s Continuing Care, 2016, para 54.

142 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.transitionssupportprogramme.org.uk/pdf/HowTo_FPLD.pdf.

143 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.

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 para 5.22). 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.

- 10.82 The 2016 framework for children and young people’s continuing care makes clear (at para 113) that:

Every child or young person with a package of continuing care who is approaching adulthood should have a multi-agency plan for an active transition process to adult or universal health services.

Mental capacity

- 10.83 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

- 10.84 ‘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.¹⁴⁴ The development of such arrangements in the 1990s owed much to the philosophy of the independently living/deinstitutionalisation movement: enabling disabled people to live ordinary lives in the community with the same choices as others.¹⁴⁵ It is likely that ‘supported living’ will be discussed as an option for many disabled children and young people as they transition into adulthood.
- 10.85 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.¹⁴⁶ 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 authorities¹⁴⁷ and for many providers they have the twin

144 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.

145 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.

146 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.

147 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.

benefits of being ‘lucrative’¹⁴⁸ and less regulated. Not infrequently, a person may have little or no practical choice over his or her 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.

10.86 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.¹⁴⁹ The care provider will, however, generally be required to be registered with the CQC. 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 higher rates than for non-disabled people.¹⁵⁰ Such schemes require, however, that the housing body provides care, support or supervision for the tenant.¹⁵¹

10.87 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 accommodation¹⁵² and the local authority is required to provide or

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

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

150 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.

151 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.

152 Care Act 2014 s30(1).

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.¹⁵³ 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.¹⁵⁴

10.88 For the purposes of the ordinary residence¹⁵⁵ and choice of accommodation provisions,¹⁵⁶ ‘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
 - (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

10.89 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’.

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

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

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

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

- 10.90 In general, it applies to adults but schemes can and do cover 16- to 17-year-olds. As at 2019, there were over 150 shared lives schemes in the UK with over 10,000 shared lives carers.¹⁵⁷ It is the scheme that is registered and regulated in England by the CQC.¹⁵⁸ Schemes are most typically local authority led.
- 10.91 The dramatic growth in shared lives schemes is almost certainly due to the significant cost savings they deliver¹⁵⁹ although there is also evidence concerning its potential to materially improve individual well-being.¹⁶⁰
- 10.92 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.¹⁶¹
- 10.93 As with supported living placements (see para 10.87 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.¹⁶² 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

157 See generally information at Shared Lives Plus, *What is Shared Lives?*, 2019.

158 Care Quality Commission (Registration) Regulations 2009 SI No 3112 – and see generally CQC, *Supporting Information – Shared Lives schemes*, CQC, 2013.

159 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.

160 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.

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

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

funding authority's area (ie its continuing responsibility) even though in fact they are resident elsewhere.¹⁶³

- 10.94 For the purposes of the ordinary residence¹⁶⁴ and choice of accommodation provisions,¹⁶⁵ '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.

- 10.95 Children Act 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 Children Act 1989 Sch 2 paras 19B and 19BA).

Residential care

- 10.96 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 their needs. Such placements have the advantage of being inspected by the CQC 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

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

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

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

capping the level of care provided at home at the cost of a residential placement.¹⁶⁶

- 10.97 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 para 10.87 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 accommodation¹⁶⁷ 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 to meet the person’s assessed needs, then it can require a ‘top-up’ payment from a third party to cover the additional cost.¹⁶⁸ 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.¹⁶⁹

Higher education – disabled student allowances

- 10.98 As support for disabled young people in further education is now governed primarily by EHC plans which can extend to age 25, issues in relation to further education are considered in the chapter on education (see chapter 4).¹⁷⁰
- 10.99 For those disabled students able to access higher education,¹⁷¹ disabled student allowances (DSAs) are grants to help meet the extra course costs students can face as a direct result of a disability, ongoing

166 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’.

167 Care Act 2014 s30(1).

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

169 Care and Support (Ordinary Residence) (Specified Accommodation) Regulations 2014 – see generally L Clements *Community Care and the Law* (7th edn) LAG, 2019, chapter 7.

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

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

health condition, mental health condition or specific learning difficulty.¹⁷² DSAs can be used to meet a wide range of additional disability-related costs, including:

- 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.¹⁷³

10.100 The amount of support available through a DSA is dependent on the extent of the person's needs, not their financial circumstances. For the 2019/20 academic year, the maximum general allowance was £1,899 a year for full-time students and £1,424 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 helper¹⁷⁴ to support the student.¹⁷⁵

10.101 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.¹⁷⁶ These duties are considered at para 9.89 onwards.

172 See: www.gov.uk/disabled-students-allowances-dsas.

173 See: www.gov.uk/disabled-students-allowances-dsas.

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

175 Applications should be made to local authorities online or using the form DSA1 (disabled students' allowance form), which can be downloaded from the gov.uk website.

176 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.