

CHAPTER 5

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Key points

- Disabled children have the same right as other children to access universal health services.
- Disabled children and young people with an education, health and care (EHC) plan which includes health provision have a specific right to have this provision arranged by the National Health Service (NHS).
- NHS bodies have a duty to engage disabled children and their families in decisions about the planning and delivery of health services.
- NHS bodies and local authorities have duties to co-operate to ensure that disabled children's health needs are met.
- Disabled children may require a range of specialist health services, including therapy services and equipment.
- Where disabled children have particularly severe and/or complex health needs, the NHS will have the primary responsibility for providing them with 'continuing care'.
- Disabled children may also require Child and Adolescent Mental Health Services (CAMHS) input.
- It is always essential to determine whether a disabled child can and does consent to treatment, and to know if a child cannot or does not consent what the appropriate legal route is in each individual case.
- Children with life-limiting conditions will require high-quality palliative care.
- The transition from children's to adult health services is vital for the well-being of disabled young people and must be properly planned.

Introduction

- 5.1 Health services are critically important for many disabled children. It is often health services such as GPs, hospital-based services and health visitors that first identify that a child may have an impairment. Disabled children also need and have a right to access the same range of universal health services provided for other children. However, many disabled children also require additional specialist health services. These will range from therapeutic services such as

physiotherapy to equipment and technology which may assist severely disabled children to lead more ordinary lives.

5.2 Historically, the health needs of children in general, and disabled children in particular, were not given national priority status. However, in around 2009, this began to change with the introduction of National Health Service (NHS) operating frameworks in England that explicitly stated that children should be one of four national priorities, alongside cancer, stroke and maternity. The health and well-being of children was also shown to be a priority with the publication in February 2009 of 'Healthy lives, brighter futures', the English government's first-ever strategy for children and young people's health. Since then the Department of Health (DOH) has published *Improving Children and Young People's Health Outcomes: a system-wide response* (February 2013), identifying the need for co-ordinated, tailored and integrated care and promising greater efficiency and accountability, with children, young people and their families being involved in decisions about their care and the design of services.¹ At the same time, the government published a pledge, supported by many signatories including NHS England, the Care Quality Commission (CQC), Healthwatch and Public Health England, to improve the health outcomes of children and young people, including by providing better care for disabled children and young people.²

5.3 The prioritisation of children and young people's health needs was reflected in the first mandate from the government to the NHS Commissioning Board (NHS England), the body responsible for supervising and developing health commissioning since the reorganisation of the NHS in April 2013.³ That mandate, which ran from April 2013 to March 2015, asked the NHS England to pursue as part of its objectives the support of children with disabilities, including ensuring access to services.⁴ A further mandate published for the period April 2015 to March 2016⁵ set an objective that disabled

1 Department of Health (DOH) with Department of Education and others, *Better health outcomes for children and young people: A system wide response*, February 2013.

2 DOH, *Better health outcomes for children and young people: Our pledge*, February 2013.

3 Issued under NHS Act 2006 s13A, as added by Health and Social Care Act (HSCA) 2012 s23. Under NHS Act 2006 s13A(7), NHS England must 'seek to achieve the objectives specified in the mandate'.

4 DOH, *A mandate from the government to the NHS commissioning board: April 2013 to March 2015*, November 2013.

5 DOH, *A mandate from the government to NHS England: April 2015 to March 2016*, December 2014.

children should have access to the services identified in their education, health and care (EHC) plan (see below) and that ‘parents of children who could benefit have the option of a personal budget based on a coordinated assessment across health, social care and education’.⁶

5.4 Disabled children’s health needs have been addressed through the reforms introduced under Part 3 of the Children and Families Act (CFA) 2014,⁷ despite the fact that the CFA 2014 is primarily focused on children’s special educational needs (SEN).⁸ Some of the key requirements of the CFA 2014 relating to health⁹ include:

- The duty to assess some disabled children’s health needs as part of an education, health and care needs assessment¹⁰ (see para 5.45 below) and to specify provision to meet certain of those needs in an EHC plan (see para 5.47 below).¹¹
- The obligation to include ‘[h]ealth care provision for children and young people with special educational needs or a disability that is additional to or different from that which is available to all children and young people in the area’ within the ‘local offer’ for every area (see para 5.31 below).¹²
- Co-ordination duties, including a duty on local authorities and partner commissioning bodies to put in place joint commissioning arrangements (see para 5.23 below).¹³

6 DOH, *A mandate from the government to NHS England: April 2015 to March 2016*, December 2014, para 4.13.

7 See Department for Education/DOH, *0 to 25 SEND code of practice: a guide for health professionals, Advice for clinical commissioning groups, health professionals and local authorities*, September 2014.

8 See Council for Disabled Children, *Using the Children and Families Act 2014 to improve outcomes for children and young people with SEN and disability: a briefing for health services* for a summary of the health-related elements of the CFA reforms. See further Council for Disabled Children, *Making it happen: Improving outcomes for children and young people with SEN and disability, a resource for CCGs* to explain the CFA 2014 and its implications for health services.

9 See further the summary annexed to the letter from Jane Cummings for NHS England to CCG Accountable Officers dated 10 August 2015 (Publications Gateway reference: 02838).

10 CFA 2014 s36.

11 CFA 2014 s37.

12 CFA 2014 s30; and Special Educational Needs and Disability Regulations (SEND Regs) 2014 reg 53 and Sch 2 para 12.

13 CFA 2014 s26.

- A duty on health bodies to bring children who have or probably have SEN or a disability to the attention of the appropriate local authority.¹⁴
- The appointment of a ‘designated medical officer’ (DMO) to support each clinical commissioning group (CCG) in meeting its statutory responsibilities for children and young people with SEN and disabilities (see para 5.17 below).¹⁵ The DMO has a particular role to support schools with their duties under the *Supporting Pupils with Medical Conditions* guidance.¹⁶

5.5 This emphasis on the healthcare needs of disabled children is underpinned by international obligations – particularly those enshrined in Article 25 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and Article 24 of the United Nations Convention on the Rights of the Child (UNCRC). However, despite this clear focus nationally and internationally, health outcomes for disabled children remain problematic. The UN Committee on the Rights of the Child has found that inequality in access to health services remains in the UK, with disabled children in particular facing barriers to the realisation of this basic right.¹⁷ A 2011 green paper¹⁸ recorded that families struggled to get the right support from health services and that the system could feel bureaucratic, impenetrable and inefficient¹⁹ and, in March 2012, a CQC review²⁰ found that it could take up to 15 years for children’s disabilities to be diagnosed, that health service providers often failed to consult disabled children and their families and that there was a lack of ‘joined up’ thinking between different health providers.

5.6 In 2013, the Chief Medical Officer’s report stated that, ‘[w]hile disabled children and young people can lead full and fulfilling lives, for many, disability is associated with limited development and social

14 CFA 2014 s23. There is also a requirement on NHS bodies to inform parents if it is thought that a particular voluntary organisation is likely to be able to give the parent advice or assistance in connection with any special educational needs or disability the child may have, see s23(4).

15 SEND Code, para 3.45.

16 Department for Education, *Supporting pupils at school with medical conditions. Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*, September 2014; see further chapter 4 at para 4.62.

17 UN Committee on the Rights of the Child, *Concluding observations*, 2008.

18 Department for Education, *Support and aspiration: A new approach to special educational needs and disability*, CM 8027, TSO, 2011.

19 Department for Education, *Support and aspiration: A new approach to special educational needs and disability*, CM 8027, TSO, 2011.

20 CQC, *Healthcare for disabled children and young people*, 2012.

participation, and with poor educational, health and employment outcomes',²¹ finding in particular that 'it is widely recognised that there is a serious lack of appropriate mental health provision' for children,²² of whom approximately ten per cent have a clinically diagnosable mental disorder.²³ Similar findings were made by the House of Commons Health Committee in 2014, which concluded that there are 'serious and deeply ingrained' problems with the commissioning and provision of Child and Adolescent Mental Health Services (CAMHS).²⁴ The cuts in funding to CAMHS services are of particular concern: Young Minds has reported that, in the period 2010–2013, two-thirds of local authorities in England reduced their CAMHS budget.²⁵ In a 2018 survey of family members of disabled children by the Disabled Children's Partnership²⁶, 75 per cent of the respondents considered that 'the quality of health services to support their children had grown significantly worse in the past few years'. In 2019, the Children's Commissioner for England reported²⁷ that this failure was particularly acute for children with learning disabilities or autism: that too many were being admitted to secure hospitals unnecessarily and for whom there was 'shocking evidence of poor and restrictive practices and sedation'.

5.7 In addition to concerns about inadequate access to healthcare generally, since the 1980s there has been considerable public, professional and legal debate about decisions to withhold or withdraw medical treatments which save or extend the lives of disabled children. Prior to that time, it was common practice to bring about the deaths of some infants with learning disabilities and physical impairments and decisions about 'selective non-treatment' were largely confined to the domain of medical practice and conduct. Without doubt, some decisions and associated protocols were underpinned by the assumption that disabled children's lives were of less value than

- 21 Chief Medical Officer, *Our Children Deserve Better: Prevention Pays*, 2013.
- 22 Chief Medical Officer, *Our Children Deserve Better: Prevention Pays*, 2013, chapter 9, p6.
- 23 Chief Medical Officer, *Our Children Deserve Better: Prevention Pays*, 2013, chapter 10, p2.
- 24 House of Commons Health Committee, *Children's and adolescents' mental health and CAMHS*, third report of session 2014–15, p10.
- 25 Young Minds, *Local authorities and CAMHS budgets 2012/2013*, 2014.
- 26 Disabled Children's Partnership *Changes in quality of health and social services for disabled children and their families* (June 2018): research based on 1,510 survey responses.
- 27 Children's Commissioner for England *Far less than they deserve: Children with learning disabilities or autism living in mental health hospitals* (May 2019).

their non-disabled peers. In the early 1980s, a number of landmark legal judgments confronted this practice and established that the courts were the proper place to determine issues of principle in relation to the right to life of disabled children.²⁸ Since that time, disabled people and parents of disabled children have written extensively about the value accorded to disabled children's lives and the implications of this for medical and healthcare decisions.²⁹

5.8 There continue to be cases brought before the courts by healthcare providers and parents seeking judgments on practice which may result in the death of a child.³⁰ Where these challenges concern decisions as to the cost-effectiveness of embarking on expensive treatments, the courts have held that these are primarily for the NHS and not for courts to make.³¹ However, when the NHS seeks to withdraw life-sustaining treatment (or to embark on a treatment regime that may accelerate death) then, if there is a dispute between the medical professionals and the parents or others,³² the court should adjudicate.³³ In such cases, the test will be the child's 'best interests' – which must be given a wide interpretation, and although the guiding principle will be to prolong life, other factors are relevant including the pain and suffering caused by the treatment and the quality of the life which will be prolonged. Where this is considered to be intolerable, from the point of view of the person concerned, then life-prolonging treatment may not be in their best interests.³⁴ The views, wishes and feelings of the parent(s) should always be

28 For a detailed discussion of these issues, see L Clements and J Read (eds), *Disabled people and the right to life: the protection and violation of disabled people's most basic human rights*, Routledge, 2008.

29 See, for example, J Campbell 'It's my life—it's my decision?: assisted dying versus assisted living', in L Clements and J Read (eds), *Disabled people and the right to life: the protection and violation of disabled people's most basic human rights*, Routledge, 2008.

30 See by way of example, *Re Jake (A Child)* [2015] EWHC 2442 (Fam); *Great Ormond Street Hospital v Yates and Gard* [2017] EWHC 1909 (Fam); *Alder Hey Hospital v Evans* [2018] EWHC 308 (Fam) and *Kings College Hospital NHS Foundation Trust v Thomas* [2018] EWHC 127 (Fam).

31 *R v Cambridge Health Authority ex p B* [1995] 1 WLR 898, CA.

32 See, for example, *Re B (a minor) (wardship: medical treatment)* [1981] 1 WLR 1421; [1990] 3 All ER 927; *An NHS Trust v D* [2000] 2 FLR 677; [2000] 2 FCR 577.

33 *Glass v UK* (2004) App No 61827/00, 9 March 2004; (2005) 8 CCLR 16.

34 See, for example, *Portsmouth NHS Trust and Derek Wyatt and Charlotte Wyatt* [2004] EWHC 2247 (Fam); *Re L (a child) (medical treatment: benefit)* [2004] EWHC 2713 (Fam). The Supreme Court considered the requirements of a best interests approach to decisions about end of treatment in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67; (2013) 16 CCLR 554.

taken fully into account in the best interests assessment, including where the parent has significant learning disabilities.³⁵

5.9 This chapter sets out the duties and powers governing the provision of health services to disabled children, both in terms of universal and specialist services. It also considers the duties to provide specific services, whether by way of continuing care to disabled children with severe and/or complex health needs, mental health services or palliative care for children with life-limiting conditions.

5.10 The principal statute that places obligations on health bodies to provide services, the NHS Act 2006, is not (unlike those that govern social care and education rights – see chapters 3 and 4 above) drafted in specific and individualistic terms. Nevertheless, it has been held by the courts to place fundamental and enforceable obligations on health bodies. Furthermore, disabled children with the benefit of an EHC plan, as introduced by the CFA 2014, have a specific right to have the health services specified in the plan arranged for them, as discussed further below.

The NHS today

5.11 In 2011, the then DOH published the NHS constitution. The version currently in force was issued on 27 July 2015 after a consultation process³⁶ on various amendments. The constitution sets out what service users can expect from the NHS and what the NHS expects from them in return – and as such, is an important advocacy tool. The Secretary of State for Health and Social Care and all NHS bodies (such as CCGs, NHS trusts etc) must have regard to the NHS constitution when they exercise functions in relation to the health service.³⁷ Key aspects of the NHS constitution for disabled children include:

- The first principle, that ‘The NHS provides a comprehensive service, available to all irrespective of . . . disability’.
- The statement, in relation to the value of ‘respect and dignity’, that ‘We value every person – whether patient, their families or carers, or staff – as an individual, respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits’.
- Four statements of rights:

35 *Re Jake (a child)* [2015] EWHC 2442 (Fam) at [44].

36 DOH, *A consultation on updating the NHS Constitution*, February 2015.

37 NHS Act 2006 s1B and Health Act 2009 s2 respectively.

- ‘You have the right to access NHS services. You will not be refused access on unreasonable grounds’;
 - ‘You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences’;
 - ‘You have the right to expect your NHS to assess the health requirements of your community and to commission and put in place the services to meet those needs as considered necessary’; and
 - ‘You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of . . . disability’.
- The commitment ‘to make decisions in a clear and transparent way, so that patients and the public can understand how services are planned and delivered’.
 - Statements about the right to decent quality of care and environment.
 - Statements in relation to the provision of care with dignity and in a way that respects people’s human rights.
 - The statement that ‘You have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end of life care, and to be given information and support to enable you to do this. Where appropriate, this right includes your family and carers. This includes being given the chance to manage your own care and treatment, if appropriate’.

5.12 The NHS in England is structured as follows:

- The Secretary of State for Health and Social Care has the overarching duty³⁸ to promote a comprehensive health service ‘designed to secure improvement in the physical and mental health of the people of England’. The secretary of state must particularly have regard to ‘the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service’.³⁹
- 191 CCGs⁴⁰ are responsible for planning and purchasing local healthcare services, including secondary healthcare and mental

38 NHS Act 2006 s1, as substituted by HSCA 2012 s1.

39 NHS Act 2006 s1C, as added by HSCA 2012 s4.

40 As at October 2019: the function of CCGs is to ‘arrange for the provision of services for the purposes of the health service in England’ – NHS Act 2006 s11.

healthcare services.⁴¹ This includes children's healthcare services, children's mental healthcare services and maternity services. CCGs have a number of duties relevant to disabled children, including in relation to reducing inequalities⁴² and promoting patient involvement⁴³. While CCGs have significant GP representation, their members include other professionals and representatives of the public. CCGs commission services from hospitals, private and voluntary sector providers and community mental health services.

- NHS England acts as the commissioning body responsible for planning primary care and specialist services for which it would be inefficient to have local commissioning.⁴⁴ For example, there is a clinical reference group within NHS England which deals with the commissioning of 'complex disability equipment', including specialist wheelchair services for disabled children.⁴⁵ NHS England holds the overarching duty to continue the promotion of a comprehensive health service in England concurrently with the secretary of state.⁴⁶ NHS England also has a number of duties relevant to disabled children, including in relation to reducing inequalities⁴⁷ and promoting patient involvement.⁴⁸
- Healthwatch England⁴⁹ and Local Healthwatch⁵⁰ are intended to act as 'consumer champion organisations' to increase patient involvement in health and social care provision. Local Healthwatch has the power to conduct 'Enter and Views' on children's health settings, which involve speaking to the children and young people using the services and observing policies and practices in action.⁵¹

41 See NHS Act 2006 s3, as amended by HSCA 2012 s13 to transfer the primary responsibility for commissioning health services from the secretary of state to CCGs.

42 NHS Act 2006 s14T, as added by HSCA 2012 s26.

43 NHS Act 2006 s14U, as added by HSCA 2012 s26.

44 See NHS Act 2006 s1H, as added by HSCA 2012 s9.

45 See www.england.nhs.uk/commissioning/spec-services/npc-crg/group-d/d01/.

46 NHS Act 2006 s1H(2).

47 NHS Act 2006 s13G, as added by HSCA 2012 s23.

48 NHS Act 2006 s13H, as added by HSCA 2012 s23.

49 Established under HSCA 2012 s181, amending HSCA 2008 Sch 1 and adding ss45A–45C.

50 See HSCA 2012 ss182–189, amending the Local Government and Public Involvement in Health Act 2007 in various respects.

51 Healthwatch, *Healthwatch, children and young people: The role of local Healthwatch*, November 2014, p3.

- Public Health England (an executive agency of the DOH) has overall responsibility for addressing health inequalities and improving health outcomes in England.
 - Monitor (the financial regulator for health services in England that sits alongside the CQC) acts as an independent regulator for quality in health and social care in England.⁵² Monitor has a specific oversight role for NHS Foundation Trusts, which are independent legal entities with significant financial freedoms. A significant number of hospitals now have Foundation Trust status.
 - Local authorities are required to establish Health and Wellbeing Boards.⁵³ The primary purpose of these boards is to encourage integrated working in the provision of health and social care services ‘for the purpose of advancing the health and wellbeing of the people in [the] area’.⁵⁴
- 5.13 The responsibility for commissioning children’s public health services (as with public health services for adults) now rests with local authorities.⁵⁵
- 5.14 The NHS is governed by the following five principles set out in the NHS Outcomes Framework:
- Preventing people from dying prematurely.
 - Enhancing the quality of life for people with long-term conditions.
 - Helping people to recover from episodes of ill health or following injury.
 - Ensuring people have a positive experience of care.
 - Treating and caring for people in a safe environment and protecting them from avoidable harm.
- 5.15 A key practical question for disabled children and their families will be whether their health needs are the responsibility of their local CCG or NHS England. In the vast majority of cases, the CCG will hold the responsibility, and where it does not it should refer the child and family to NHS England. There is a detailed ‘Manual’ which describes which elements of specialised services are directly commis-

52 See HSCA 2012 ss61–71 and Sch 8.

53 See HSCA 2012 ss194–199.

54 HSCA 2012 s195.

55 See the Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013 SI No 351 (as amended).

sioned by NHS England and which by CCGs, the most recent version of which was published in September 2018.⁵⁶

- 5.16 One of the NHS England ‘National Programmes of Care’ is for ‘Women and Children’, which includes many specialist paediatric health services. There are published ‘Commissioning Intentions’ which set out NHS England’s approach to its specialist commissioning remit.⁵⁷ An important service for many disabled children, which remains commissioned by NHS England, is Tier 4 CAMHS; see paras 5.121–5.122 below. These are highly specialised services with a primary purpose of the assessment and treatment of severe and complex mental health disorders in children. NHS England also commissions secure CAMHS services.
- 5.17 Every CCG is required to appoint a DMO, whose primary role is ‘providing a point of contact for local partners, when notifying parents and local authorities about children and young people they believe have, or may have, SEN or a disability, and when seeking advice on SEN or disabilities’.⁵⁸ The DMO should be a senior clinician, often a paediatrician, who will be responsible for ensuring that assessment, planning and health support is carried out.⁵⁹
- 5.18 In addition, a number of ‘national change programmes’ are being implemented which will impact on health services for young people with disabilities. These include: the Personalised Care programme, the Transforming Care programme, the Mental Health Transformation programme and the Changing Commissioning Landscape.

Children and families’ views to inform health services

- 5.19 NHS bodies have a duty⁶⁰ to make arrangements to ensure that users of services are, either directly or through representatives, involved in:
- the planning of the provision of health services;
 - the development and consideration of proposals for changes in the way those services are provided, if implementation of the

56 NHS England, *Manual for Prescribed Specialised Services 2018/19*, September 2018.

57 NHS England, *Commissioning Intentions 2017/18 and 2018/19 for Prescribed Specialised Services*.

58 SEND Code, para 3.45.

59 SEND Code, para 3.46.

60 Under NHS Act 2006 s242(1B)–(1F).

proposal would have an impact on the manner in which services are provided or the range of services available; and

- decisions to be made by the NHS body affecting the operation of those services, if the decision would have an impact on the manner in which services are provided or the range of services available.

5.20 The views of disabled children, young people and their families are, therefore, expected to inform local design and delivery of health services. Frequently, however, disabled children have been found to be less actively involved in decisions about both their treatment and service development than children who are not disabled. Standard 8 of the National Service Framework (NSF) for Children (see below), required local and NHS bodies to ensure disabled children and their parents are routinely involved and supported in making informed decisions.⁶¹ The importance of involving children and families in decision-making was reinforced in England by the *Aiming high for disabled children* review⁶² and by the Local Government and Public Involvement in Health Act 2007 (as amended) to require the establishment of Health and Wellbeing Boards (see para 5.12 above) which can provide important forums for the voices of disabled children and families to be heard. The requirement for the NHS to take account of the views of its users, including disabled children and their families, is also central to the NHS Constitution (see para 5.11 above).

5.21 In addition, the NHS Long Term Plan makes clear that ‘the time has come to give people the same choice and control over their mental and physical health that they have come to expect in every other part of their life’.⁶³

Co-operation between health bodies and local authorities

5.22 An important issue for many disabled children and their families is which body will take the lead responsibility for meeting their needs

61 DOH, *National service framework for children, young people and maternity services: disabled children and young people and those with complex health needs*, 2004 (‘Disabled Child Standard, Children’s NSF’), pp5, 29, 30.

62 HM Treasury/DfES, 2007.

63 NHS England, *Universal Personalised Care: Implementing the Comprehensive Model* (2019) p3; and see also *The NHS Long Term Plan* (2019).

– the local authority or the relevant health body? The answer to this question is that health bodies and local authorities are expected to work together to meet the health needs of disabled children. This expectation comes from (among other sources):

- NHS Act 2006 s82, which states that, in exercising their respective functions, NHS bodies and local authorities must co-operate with one another in order to secure and advance the health and welfare of the people of England and Wales.
- Children Act 2004 s10, which requires local authorities to co-operate with their ‘relevant partners’, including health bodies, to safeguard and promote the welfare of children in their area, as explained in the statutory guidance, *Working together to safeguard children: A guide to inter-agency working to safeguard and promote the welfare of children* (July 2018).

5.23 Further, CFA 2014 s26 requires local authorities and ‘partner commissioning bodies’ (including CCGs and NHS England) to make ‘joint commissioning arrangements’ about the education, health and care provision to be secured for children and young people with special educational needs and disabled young people. A lengthy list of requirements for these joint arrangements is imposed by CFA 2014 s26(3). There are further requirements in relation to co-operation between local authorities and NHS bodies imposed by CFA 2014 s25 (headed ‘promoting integration’), ss28–29 (‘co-operating generally’) and s31 (‘co-operating in specific cases’).

5.24 For children ‘in need’ generally, including disabled children, local authorities have a clear obligation to take the lead in ensuring their needs are met, bringing in different agencies (including health) where necessary. However, for children with particularly severe and/or complex health needs, the NHS may be the lead agency – for example, when a child is eligible for ‘continuing care’ funding (see para 5.91 below).

5.25 To deliver co-operation and joint working on the ground, ‘key workers’ or ‘care co-ordinators’ are essential (see chapter 3 at para 3.25). Standard 8 of the Children’s NSF stated that the key workers should be ‘the main point of contact with the family’ and should take responsibility for co-ordinating review meetings and liaising with professionals to ensure all agreed support is delivered.

5.26 A multidisciplinary approach requires co-ordinated assessment, planning and commissioning. A 2013 publication from the Children

and Young People's Health Outcomes Forum,⁶⁴ advises how agencies should work together so as to integrate health, social care, education and other services, and reinforces the requirements of Standard 8 of the Children's NSF. Additionally, the 2006 English *Joint planning and commissioning framework for children, young people and maternity services*⁶⁵ introduced a framework to help local commissioners (both health bodies and local authorities) to design a unified system in each local area to achieve a joined-up picture of children and young people's needs and for collaboration to achieve the best use of joint resources for 'better outcomes'.⁶⁶

5.27 Local areas are required to prepare a joint strategic needs assessment⁶⁷ to (among other things) inform the joint commissioning decisions made for children and young people with SEN and disabilities. This requires agreement on a strategy and a set of holistic outcomes that local authorities and CCGs want to achieve for children, young people and their families.⁶⁸

5.28 Additionally, since 2015, NHS and local authority partners across England have been developing Sustainability and Transformation Partnerships (STPs). These have no formal status and/or mechanism of local accountability,⁶⁹ but their stated aims include improvement and better integration of services.⁷⁰

5.29 Since there is no explicit statutory obligation on the NHS or the local authority to act as the lead agency, there is obvious scope for a disabled child's needs to be allowed to 'drift' while each authority

64 *Improving Children and Young People's Health Outcomes: a system wide response*, English Guidance, February 2013.

65 HM Government, *Joint planning and commissioning framework for children, young people and maternity services*, 2006.

66 This is reinforced in DOH, *Improving Children and Young People's Health Outcomes: a system wide response*, February 2013; and DOH, *The commissioning framework for health and well-being*, 2007. See also *Commissioning a good child health service*, Royal College of General Practitioners, Royal College of Paediatrics and Royal College of Nursing, March 2013.

67 Local Government and Public Involvement in Health Act 2007 s116 (as amended).

68 Council for Disabled Children, *Designated Medical/ Clinical Officer Handbook* (2019).

69 Bob Hudson, 'Citizen accountability in the 'New NHS' in England' in *Critical Social Policy* 2018 38(2) 418–427; and see also S Boyle, J Lister and R Steer, *Sustainability and Transformation Plans: How Serious are the Proposals? A Critical Review* (South Bank University, 2017)

70 See generally, NHS England, *Next Steps on the NHS Five Year Forward View* (2017) p31; and NHS England, *Breaking down barriers to better health and care* (2019).

blames the other for a service failure. In such cases, a complaint (or if sufficiently urgent, an application for judicial review: see chapter 11) should be made against both authorities. The complaint or application for judicial review should be framed not only in terms of the failure to meet the specific need but also in terms of the authorities' failure to 'work together' as required by NHS Act 2006 s82, Children Act 2004 s10 and multiple provisions of the CFA 2014, not least the requirement for joint commissioning arrangements in section 26. The ombudsmen in general expect the authority that is in touch with the child to 'grasp the nettle' and secure the provision, before entering into protracted negotiations with the other authority on liability for the care costs.⁷¹

- 5.30 Such a complaint will also be appropriate when the dispute is between different NHS bodies (which are under a duty to co-operate with each other by virtue of NHS Act 2006 s72). The ombudsmen have found maladministration⁷² where disputing health bodies have, in such a case, failed to agree which one of them would accept funding responsibility on an interim basis. In the current NHS structures, this would include a case where there is a dispute as to responsibility for meeting a disabled child's needs between a CCG and NHS England.

The 'local offer' and health

- 5.31 One of the key reforms introduced by the CFA 2014 is the requirement for every area to establish a 'local offer' covering education, health and care provision and other related services.⁷³ Although the duty to publish this information falls on the local authority, the local offer can only be an effective tool if health bodies, particularly CCGs, co-operate in its development. When preparing and reviewing its local offer, a local authority must consult a range of health bodies, including NHS England and any CCG within its area.⁷⁴ The central

71 Complaint no 96/C/3868 against Calderdale MBC.

72 Report by the Public Services Ombudsman for Wales and the Health Service Ombudsman for England of an investigation of a complaint about the Welsh Assembly Government (Health Commission Wales) Cardiff and Vale NHS Trust and Plymouth Teaching Primary Care Trust, Third Report, Session 2008–2009, HC 858, TSO, 2009.

73 CFA 2014 s30. See chapter 3 at para 3.27 for the local offer in relation to social care and chapter 4 at para 4.41 in relation to education.

74 SEND Regs 2014 reg 54(2).

requirement to publish comments on the local offer⁷⁵ will include comments on health provision.

- 5.32 The health provision which must be included in the local offer is: Health care provision for children and young people with special educational needs or a disability that is additional to or different from that which is available to all children and young people in the area, including—
- (a) services for relevant early years providers, schools and post-16 institutions to assist them in supporting children and young people with medical conditions, and
 - (b) arrangements for making those services which are available to all children and young people in the area accessible to children and young people with special educational needs or a disability.⁷⁶
- 5.33 The SEND Code (see para 4.25 above) also specifies that the local offer must include:⁷⁷
- speech and language therapy and other therapies such as physiotherapy and occupational therapy and services relating to mental health;
 - wheelchair services and community equipment, children's community nursing, continence services;
 - palliative and respite care and other provision for children with complex health needs;
 - other services such as emergency care provision and habilitation support;
 - provision for children and young people's continuing care arrangements;
 - support for young people when moving between healthcare services for children to healthcare services for adults.

Health services – fundamental duties

- 5.34 The NHS Act 2006 s1(1) requires the secretary of state to:
- ... continue the promotion in England of a comprehensive health service, designed to secure improvement—
- (a) in the physical and mental health of the people of England, and
 - (b) in the prevention, diagnosis and treatment of illness.

75 SEND Regs 2014 reg 56.

76 SEND Regs 2014 Sch 2, para 12.

77 SEND Code, para 4.40

5.35 Section 3 of the NHS Act 2006, as amended, places a duty on each CCG to:

... arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the persons for whom it has responsibility:

- (a) hospital accommodation,
- (b) other accommodation for the purpose of any service provided under this Act,
- (c) medical, dental, ophthalmic, nursing and ambulance services,
- (d) such other services or facilities for the care of pregnant women, women who are breastfeeding and young children as the CCG considers are appropriate as part of the health service,
- (e) such other services or facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness as the CCG considers are appropriate as part of the health service,
- (f) such other services or facilities as are required for the diagnosis and treatment of illness.

5.36 The NHS Act 2006 requires, therefore, that there be a ‘comprehensive’ health service which all can access – including disabled children. This entitlement of universal access to the NHS is emphasised by the NHS constitution, see para 5.11 above.

5.37 Health services can be categorised into those delivered as ‘primary care’ and ‘secondary care’. Primary care describes the health services that play a central role in local community including GPs, pharmacists, dentists and midwives. Primary care providers are usually the first point of contact for a patient and a continuing point of contact, even if the patient is receiving services from a hospital or from some other ‘secondary’ NHS facility.

5.38 Secondary care is acute or specialist healthcare provided in a hospital or other secondary care setting. Patients are usually referred from a primary care professional – for example, a GP. The 2013 *Who Pays?* guidance identifies who is responsible for the funding of a specific patient’s needs.⁷⁸ In England, responsibility is primarily linked to registration with a GP, and for those who are not registered with a GP, it is based on where they are ‘usually resident’.

78 NHS England, *Who Pays?* September 2013.

The responsibilities of GPs and other primary health services

- 5.39 As with all children, GPs act as the main point of access or referral to all appropriate medical and health services that a disabled child may need. At the primary care level, these may include:
- medical services provided directly by the GP;
 - physiotherapy;
 - speech and language therapy;
 - occupational therapy;
 - early intervention rehabilitation programmes;
 - general community nursing; and
 - health visiting.

The GP also is responsible for referring a child for services in the secondary healthcare sector (and liaising with other healthcare professionals in this respect).⁷⁹ This can include obtaining a ‘second opinion’ on a child’s diagnosis and healthcare treatment – as well as referrals for in- and out-patient paediatric care in hospital settings and some interventions such as physiotherapy, speech and language therapy and occupational therapy which may also be provided in this sector as well as in primary care. Some children, particularly those with complex impairments, may require assessment, treatment and monitoring by a range of medical and healthcare specialists working in different in- and out-patient departments of hospitals.

- 5.40 The GP contract⁸⁰ requires, among other things, that they refer their patients for ‘other services under the [2006] Act’. Since the 2006 Act places substantial duties on social services authorities,⁸¹ it follows that GPs are contractually obliged to make appropriate referrals to social services where it appears that a patient may be entitled to such services.
- 5.41 As noted above, disabled children – especially if their impairment is diagnosed in hospital at birth – may be subjected to multiple health assessments to diagnose their condition to the satisfaction of the medical practitioners. However, they may then be – in effect – abandoned by the

79 National Health Service (General Medical Services Contracts) Regulations 2004 SI No 291 reg 15(4)(b) (as amended).

80 National Health Service (General Medical Services Contracts) Regulations 2015 SI No 1862 (as amended).

81 This is particularly so in relation to the NHS’s public health functions (for example, under NHS Act 2006 s2B, Part 3 and Sch 1).

statutory services. This phenomenon has been expressed in the following terms:⁸²

As soon as a condition or impairment has been identified or diagnosed, service professionals may fade away without any support or significant information being provided for the family. All too often nothing further is done until a crisis develops.

- 5.42 The child may then be discharged with only limited liaison with the local GP surgery and the health visitor and without any proper co-ordination with the local authority concerning social care support services. In such cases, immediate contact should be made with the GP surgery to ensure that the child's and family's needs are addressed and that timely referrals can then be made to the relevant expert services as and when a need arises (for example, physiotherapy, speech and language therapy as well as social care support from the local authority).

Duty to assess healthcare needs

- 5.43 Notwithstanding the absence of an explicit provision in the NHS Act 2006 requiring a health body to assess the healthcare needs of a disabled child, there are a number of reasons why such a duty almost certainly exists. The first concerns the analogous findings of the House of Lords in *R (G) v Barnet LBC and others*⁸³ that a duty to assess exists under the Children Act 1989, despite it lacking an explicit obligation. The second and more cogent reason concerns the general obligations imposed by the law on public bodies – essentially that in order to exercise their duties towards disabled children, health bodies must follow a process that is, by any other name, an assessment – ie the gathering of all relevant information about the child and his or her care needs and the rational determination of whether it is necessary to provide services to meet these needs.⁸⁴
- 5.44 Assessment is, therefore, the means by which the health body 'assembles the relevant information and applies it to the statutory ends, and hence affords good evidence to any inquirer of the due

82 J Read, L Clements and D Ruebain, *Disabled children and the law: research and good practice*, 2nd edn, Jessica Kingsley Publishers, 2006, p116.

83 [2003] UKHL 57; [2004] 2 AC 208.

84 In effect 'asking themselves the right question', one of the fundamental public law requirements on all public bodies, see *Secretary of State for Education and Science v Tameside MBC* [1977] AC 1014.

discharge of its statutory duties'.⁸⁵ Further evidence of such a duty to assess can be implied from the obligations created by Children Act 2004 s11 which requires health bodies and others to safeguard and promote children's welfare and from the 2013 DOH guidance which includes a 'pledge' to improve the health outcomes of children and young people, including by providing better care for disabled children and young people.⁸⁶ This builds on the previous child health strategy in England, which made a commitment that 'by 2010, all children with complex health needs will have an individual care plan' – a commitment which rests on there being a duty to assess a child's individual needs so that such a plan can be meaningfully drawn up.⁸⁷

Education, health and care needs assessments

- 5.45 Some disabled children with significant special educational needs will now have the benefit of the education, health and care needs assessment duty imposed by CFA 2014 s36 (EHC assessments). Although the local authority takes the lead in this assessment process and the key question to determine is whether it may be necessary for special educational provision to be made for the child or young person in accordance with an EHC plan,⁸⁸ the NHS still has an important role to play.
- 5.46 The process of carrying out EHC assessments is governed by the SEND Regs 2014 regs 3–10.⁸⁹ Under these regulations:
- Where the local authority is considering securing an EHC needs assessment it must also notify the responsible commissioning body.⁹⁰
 - Where the local authority decides to assess, it must seek 'medical advice and information from a health care professional identified

85 *R v Islington LBC ex p Rixon* (1997–98) 1 CCLR 119 at 128.

86 DOH, *Improving Children and Young People's Health Outcomes: a system wide response*, 2013; and see also DOH, *Better health outcomes for children and young people: Our pledge*, 2013.

87 Department for Children Schools and Families/DOH, *Healthy lives, brighter futures*, 2009, p72 at 6.42.

88 CFA 2014 s36(8)(b).

89 SI No 1530. See further chapter 4 at para 4.80.

90 SEND Regs 2014 reg 4(2)(a). The commissioning body must also be notified of the decision on whether or not to conduct an EHC needs assessment, see reg 5(2).

by the responsible commissioning body'.⁹¹ This information and advice must be considered by the local authority when securing the assessment.⁹²

- NHS bodies must respond to requests for input into EHC assessments within six weeks, unless it is impractical for them to do so for one of a limited set of specified reasons.⁹³
- If, following an assessment, the local authority determines not to secure an EHC plan for the child (see below and further at chapter 4, para 4.102) then the responsible commissioning body must be notified.⁹⁴

Education, health and care plans

5.47 On completion of an EHC assessment, the local authority must secure and maintain an EHC plan for the child or young person where the assessment shows that it is necessary for special educational provision to be made in accordance with an EHC plan.⁹⁵

5.48 Although the duty to put an EHC plan in place is dependent on the child or young person having significant SEN, the presence of an EHC plan can have important consequences for the child or young person's right to health services. First, an EHC plan must include 'any health care provision reasonably required by the learning difficulties and disabilities which result in him or her having special educational needs'.⁹⁶

5.49 Second and most importantly, the effect of the inclusion of health care provision within an EHC plan is to establish a specific right for the child or young person to obtain the specified provision. This is the consequence of CFA 2014 s42(3), which reads: 'If the plan specifies health care provision, the responsible commissioning body must arrange the specified health care provision for the child or

91 SEND Regs 2014 reg 6(1)(c) – unless such advice has previously been provided for any purpose and the person providing that advice, the local authority and the child's parent or the young person are satisfied that it is sufficient for the purposes of an EHC needs assessment, see reg 6(4).

92 SEND Regs 2014 reg 7(c).

93 SEND Regs 2014 reg 8.

94 SEND Regs 2014 reg 10(2).

95 CFA 2014 s37(1).

96 CFA 2014 s37(2)(d). An EHC plan may also specify other health care and social care provision reasonably required by the child or young person, see s37(3).

young person'. The 'responsible commissioning body' will generally be the CCG, but as noted above (see para 5.12) may also be NHS England for more specialised services. The SEND Code also states that young people and parents of children who have EHC plans have the right to request a personal budget, which may contain elements of education, social care and health funding.⁹⁷ See para 5.107 below in relation to health personal budgets generally.

5.50 The preparation of EHC plans is governed by the SEND Regs 2014 regs 11–17. Relevant provisions of these regulations from the health perspective include:

- When preparing an EHC plan, the local authority must take into account the evidence received when undertaking the EHC needs assessment, including information and advice from health professionals.⁹⁸
- The plan must set out in section C 'the child or young person's health care needs which relate to their special educational needs'.⁹⁹
- The plan must set out in section G 'any health care provision reasonably required by the learning difficulties or disabilities which result in the child or young person having special educational needs'.¹⁰⁰ This must be agreed by the responsible commissioning body.¹⁰¹
- Where the child is in or beyond year 9 at school, the plan must include health care provision 'to assist the child or young person in preparation for adulthood and independent living'.¹⁰²
- Advice and information, including from health professionals, must be set out in the appendices to the plan (section K).¹⁰³
- The final plan must be sent to the responsible commissioning body (and of course the parents or young person and the school) as soon as practicable and, in any event, within 20 weeks of the request for an EHC needs assessment,¹⁰⁴ unless any of the exemptions to this timeframe¹⁰⁵ apply.

97 SEND Code, para 3.38.

98 SEND Regs 2014 reg 11.

99 SEND Regs 2014 reg 12(1)(c).

100 SEND Regs 2014 reg 12(1)(g).

101 SEND Regs 2014 reg 12(2).

102 SEND Regs 2014 reg 12(3).

103 SEND Regs 2014 reg 12(4).

104 SEND Regs 2014 reg 13(2).

105 Being those specified in SEND Regs 2014 reg 10(4)(a)–(d) in relation to EHC assessments. See further chapter 4 at para 4.133.

- Commissioning bodies must liaise in the event that a child or young person moves to a new commissioning body's area but remains the responsibility of the same local authority.¹⁰⁶

Health action plans

- 5.51 Health action plans (HAPs) for people with learning disabilities became official policy with the publication of *Valuing People* in 2001.¹⁰⁷ This required that people with learning disabilities be offered a HAP by the relevant health bodies – although primary responsibility rested with primary care nurses and GPs.
- 5.52 HAPs consider the person's needs for 'health interventions' such as oral health and dental care, fitness and mobility, continence, vision, hearing, nutrition and emotional needs as well as details of medication taken, side effects, and records of any screening tests. There needs to be, in each case, someone who supports the person with the development of their HAP – and this is referred to as a 'Health Facilitator' – ideally this person is chosen by the person with learning difficulties and may be a family member, friend, support worker or health professional. There is no standard format for a HAP but a number of examples exist. The 2001 guidance¹⁰⁸ states that HAPs are to be offered and reviewed at the following stages:
- transition from secondary education with a process for ongoing referral;
 - leaving home to move into a residential service;
 - moving home from one provider to another;
 - moving to an out-of-area placement;
 - changes in health status, for example as a result of a period of out-patient care or in-patient treatment;
 - on retirement; and
 - when planning transition for those living with older family carers.
- 5.53 Good practice guidance on the preparation of HAPs has been issued by the Royal College of GPs.¹⁰⁹

106 SEND Regs 2014 reg 16.

107 DOH, *Valuing people: A new strategy for learning disability for the 21st century*, Cm 5086, 2001, at paras 6.15–6.18.

108 DOH, *Valuing people: A new strategy for learning disability for the 21st century*, Cm 5086, 2001, at para 6.16.

109 Matt Hoghton, *A step by step guide for GP practices: Annual health checks for people with a learning disability*, Royal College of GPs, 2010.

- 5.54 In 2008, the Joint Committee on Human Rights in its report *A Life Like Any Other*¹¹⁰ called into question the commitment of (among others) health bodies to the implementation of the government's policy in *Valuing People* and this resulted in follow-up guidance in 2008¹¹¹ which acknowledged that 'achievement of the health-related targets in *Valuing People*' had been 'one of the areas where least progress' had been made.¹¹² This guidance made a commitment that in addition there would be annual health checks for people with learning disabilities (who are known to local authorities) through a directed enhanced scheme. This scheme is available from GPs whose practices have agreed to undertake this additional function – in addition to their core obligations under the GP Contract.¹¹³

Children's health services – the Children's National Service Framework

- 5.55 In 2003, in an effort to drive up the standard of care provided to all children by the NHS and social services authorities in England, the government commenced publication of a *National Service Framework for children, young people and maternity services*,¹¹⁴ which sets national standards and provides best practice guidance for children's health and social care. The Children's NSF, which comprises 11 separate documents focusing on distinct issues/disabling conditions, is best considered as 'practice guidance' (see chapter 2 at para 2.44). As such it acts as a benchmark – setting a standard to which public bodies should aspire. A significant failure to reach the standards set out in the Children's NSF may be evidence of maladministration. Although the ten-year programme under the Children's NSF has now reached an end, the standards it set are still relevant guidance as to what disabled children and their families can expect from the NHS.

110 Joint Committee on Human rights, *A life like any other*, Seventh Report of Session 2007–08, HL Paper 40-I HC 73-I, The Stationery Office Limited, 2008.

111 DOH, *Health action planning and health facilitation for people with learning disabilities: good practice guidance*, 2008.

112 DOH, *Health action planning and health facilitation for people with learning disabilities: good practice guidance*, 2008, p1 and see also NHS England *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. Service model for commissioners of health and social care services* (2015).

113 The Primary Medical Services (Directed Enhanced Services) Directions 2019.

114 DOH, *National service framework for children, young people and maternity services: core standards*, 2004 (Core document, Children's NSF).

- 5.56 Part 1 of the Children's NSF set out five core standards concerning service provision for all children and young people and their parents and carers. Each core standard is summarised below.

Standard 1: Promoting health and well-being, identifying needs and intervening early

The health and well-being of all children and young people is promoted and delivered through a co-ordinated programme of action including prevention and early intervention wherever possible, to ensure long-term gain, led by the NHS in partnership with local authorities.

- 5.57 Under the Healthy Child Programme introduced to achieve Standard 1, the local NHS (now CCGs) must ensure that a systematic assessment of each child's physical, emotional and social development and family needs is completed by the child's first birthday and in the absence of regular contact a review takes place when the child is aged between two and three. Key issues must be identified and interventions required must be documented.¹¹⁵ In addition, all professionals working with children and young people need to be aware of health and developmental problems and proactive in identifying opportunities to promote a child's health and well-being. CCGs and local authorities also have a responsibility to tailor health promotion services to the needs of disadvantaged groups, including children in special circumstances, identified through a local population needs assessment.¹¹⁶

Standard 2: Supporting parenting

Parents or carers are enabled to receive the information, services and support which will help them to care for their children and equip them with the skills they need to ensure that their children have optimum life chances and are healthy and safe.

- 5.58 The markers of good practice for this standard include the provision of information and services to support parenting through local multi-agency partnerships, that parents whose children are experiencing difficulties receive early support and evidence-based interventions and that the local NHS and local authorities ensure that parents are involved in the planning and delivery of services, with representation from all local communities and groups.¹¹⁷

115 Core Document, Children's NSF, p40.

116 Core Document, Children's NSF, p22.

117 Core Document, Children's NSF, p66.

Standard 3: Child, young person and family-centred services

Children and young people and families receive high quality services which are co-ordinated around their individual and family needs and take account of their views.

5.59 This standard recognises that children have a right to be involved in decisions about their care. Particular effort should be made to ensure that children and young people who are often excluded from participation in activities are supported in giving their views and that parents' views are considered in planning and service development.¹¹⁸ Formal working arrangements need to be in place for the provision of link workers, advocates to support children and young people, interpreters and/or support workers for children in special circumstances or from minority groups, to represent their needs during individual consultations and on multi-disciplinary review and development groups.¹¹⁹

5.60 All children and young people have a right to care and support which meets their developmental needs and provides them with the opportunity to achieve, or maintain, their optimal standard of health, development and well-being, regardless of their individual circumstances or those of their families and communities.¹²⁰ To achieve this, there needs to be a high degree of co-ordination between different children's service providers with the highest degree of integration and co-ordination required when a child or young person is suffering abuse or neglect and local safeguarding children procedures are being followed.¹²¹

Standard 4: Growing up into adulthood

All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood.

5.61 This standard is considered in chapter 10 at para 10.68.

Standard 5: Safeguarding and promoting the welfare of children and young people

All agencies work to prevent children suffering harm and to promote their welfare, provide them with the services they require to address

118 Core Document, Children's NSF, p91.

119 Core Document, Children's NSF, p92.

120 Core Document, Children's NSF, p93.

121 Core Document, Children's NSF, p99.

their identified needs and safeguard children who are being or who are likely to be harmed.

- 5.62 Safeguarding and promoting children's welfare must be a priority. All agencies should ensure that the Local Safeguarding Children Board (LSCB), is effective in safeguarding and promoting the welfare of children and young people through the provision of adequate financial and human resources, senior management representation and adherence to its policies and procedures (see also the *Working together to safeguard children* guidance, as discussed in chapter 3 at para 3.158).

Disabled children's health services and the NSF

- 5.63 While the core standards of the NSF apply to all children, the needs of disabled children and their families were specifically addressed in Standard 8, the headline standard within which reads as follows:

Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family centred services which are based on assessed needs, which promote social inclusion and where possible, enable them and their families to live ordinary lives.¹²²

- 5.64 When read with the five core standards of the Children's NSF, Standard 8 provides comprehensive best practice guidance on the provision of health and related services to disabled children.

Identification of disability and the NSF

- 5.65 Standard 8 of the Children's NSF requires that local authorities, CCGs, NHS Trusts and schools ensure that children with possible impairments have prompt access to a diagnostic assessment facility, that diagnosis is followed and that the assessment includes the parents' and siblings' needs for support.

Hospital services and the NSF

- 5.66 Disabled children's need to attend hospital appointments can be disruptive to school and family life. Under Standard 8, the NHS should ensure that hospital departments and clinics synchronise

122 Disabled Child Standard, Children's NSF, p5.

their appointment systems as far as possible, so that families make a minimum number of visits and that systems are in place to ensure that children and young people who find it hard to wait, eg those with autistic spectrum disorders, do not have to wait unduly at out-patient clinics or general practice surgeries. Children and young people with complex healthcare needs who are prone to health crises must be seen urgently on request.¹²³

5.67 The standard for hospital services for children in the Children's NSF aims to deliver hospital services that meet the needs of children, young people and their parents, and 'provide effective and safe care, through appropriately trained and skilled staff working in suitable, child-friendly and safe environments'.¹²⁴

5.68 The above requirement for the standard of hospital-based care is considered by the NSF to comprise three distinct elements, namely:

1. Child-centred hospital services¹²⁵

Children and young people should receive care that is integrated and co-ordinated around their particular needs, and the needs of their family. They, and their parents, should be treated with respect, and should be given support and information to enable them to understand and cope with the illness or injury, and the treatment needed. They should be encouraged to be active partners in decisions about their health and care, and, where possible, be able to exercise choice.

2. Quality and safety of care provided¹²⁶

Children and young people should receive appropriate high quality, evidence-based hospital care, developed through clinical governance and delivered by staff who have the right set of skills.

3. Quality of setting and environment¹²⁷

Care will be provided in an appropriate location and in an environment that is safe and well suited to the age and stage of development of the child or young person.

5.69 In meeting these three elements of the standard, hospitals need to recognise and meet the very particular needs of disabled children

123 Disabled Child Standard, Children's NSF, p12.

124 DOH, *Getting the right start: National Service Framework for Children: Standard for Hospital Services* ('Standard for Hospital Services, Children's NSF'), 2003, p8.

125 Standard for Hospital Services, Children's NSF, p13.

126 Standard for Hospital Services, Children's NSF, p21.

127 Standard for Hospital Services, Children's NSF, p36.

and involve them and their parents in the planning of services.¹²⁸ Disabled children, young people and their parents need to know that staff understand how to support them and have a sound knowledge of the needs of disabled children. Where necessary, this includes how to communicate, support with eating and drinking, the use of specialised aids and equipment, and the delicacy required in dealing with ethical issues, such as consent to intensive therapy.¹²⁹ Staff need competencies in supporting children with a range of disabilities, including those with learning disabilities or autistic spectrum disorders. There should be procedures for managing challenging behaviour and suitable equipment should be available.¹³⁰

5.70 A multi-agency plan developed and agreed with the disabled child or young person and their parents should be put in place while they are in hospital. For disabled children with complex health needs, this should be expanded into a personal record with a clinical summary of what they require, for example, therapies and equipment, support with eating and drinking, going to the toilet or communicating.¹³¹

5.71 Sadly it appears that the reality of hospital services for children (including disabled children) remains very different from the NSF's vision. In February 2009, the Healthcare Commission published a report on the care provided to children in NHS hospitals outside of specialist paediatric settings.¹³² This reported the need for 'significant improvement' in areas such as child protection, managing children's pain, life support and skills of surgeons and anaesthetists. Specifically, it found almost two-thirds of health trusts did not train enough nurses to administer pain relief to children, and that there was 'very limited progress' in training staff to provide life support to children, with 94 per cent failing to provide basic resuscitation training to surgeons. The CQC made similar findings in its 2012 report into healthcare for disabled children, noting that nearly 60 per cent of primary care providers did not involve disabled children or young people in their assessment processes and that hospital services were

128 Standard for Hospital Services, Children's NSF, p32 at 4.52.

129 See in this respect, Cerebra Legal Entitlements Research Project Digest, Digest of Opinions 2014, 'Terri's Story', Cardiff Law School, 2015, which concerns a disabled young person's strongly expressed wishes concerning the care arrangements for her intimate personal care needs.

130 Standard for Hospital Services, Children's NSF, p32 at 4.54.

131 Standard for Hospital Services, Children's NSF, p33 at 4.55.

132 Healthcare Commission, *Improving services for children in hospital*, 2009.

disjointed from community services.¹³³ These are all areas of poor practice that disproportionately affect disabled children.

NHS therapy services

5.72 The importance of disabled children receiving appropriate and timely therapies – such as speech and language therapy or physiotherapy – is emphasised in a number of official documents¹³⁴ – not least the NSF (see para 5.55). Speech and language therapy should generally be considered as special educational provision and, accordingly, provided by the local education authority where a SEN statement/EHC plan exists.¹³⁵ Where there is no statement/plan (or when the child has a need other than an educational need for therapy) then these crucial services must be accorded a high priority by the relevant health body – not least in relation to speech and language therapy since the positive obligation on a state to facilitate a child's right of expression comes within the sphere of fundamental human rights.¹³⁶ If delay in providing these supports occurs due to a dispute between an education authority and the NHS, then consideration should be given to making a joint complaint about the failure of these bodies to work together (see para 5.29).

5.73 As noted above (see para 5.48 and further in chapter 4 at para 4.115) where an EHC plan exists, it must contain a separate section (G) that provides specific details of the health provision required to address the disabilities which result in the young person's SEN and how this support will help enable him or her to achieve their personal educational outcomes. The Code of Practice¹³⁷ notes that this may:

133 CQC, *Healthcare for disabled children and young people*, March 2012.

134 HM Treasury and Department for Education and Skills, *Aiming high for disabled children: better support for families*, 2007; Department for Children Schools and Families, *The Bercow report: a review of services for children and young people (0–19) with speech, language and communication needs*, 2008; DOH, Department of Education and others, *Improving Children and Young People's Health Outcomes: a system wide response*, 2013.

135 See chapter 4 at para 4.10; and CFA 2014 s21(5).

136 For example, ECHR Articles 8 and 10 and UNCRC Article 13: this assertion is made by J Morris, *Assessing human rights: Disabled children and the Children Act*, The Who Cares? Trust, London, 1998, p20, and accepted by the DOH: see DOH, *Assessing children in need and their families: practice guidance*, HMSO, 2000, para 3.125.

137 SEND Code, p167.

... include specialist support and therapies, such as medical treatments and delivery of medications, occupational therapy and physiotherapy, a range of nursing support, specialist equipment, wheelchairs and continence supplies.

- 5.74 As also noted above at para 5.49, CFA 2014 s42 creates a specifically enforceable duty in relation to the health care provision specified in the plan – that the CCG must ensure that it is made available to the child or young person.¹³⁸
- 5.75 Despite the vital importance of such healthcare supports, children and young people’s access to rehabilitation and therapy services appears to be inconsistent across regions, with long waits in some areas. In meeting standard 8 of the Children’s NSF, local authorities and NHS bodies are expected to review local therapy services in order to:
- a) promote self-referral, simplifying the care pathway, and reduce excessive waits that may affect a child’s development;
 - b) improve administrative systems and processes for referral and discharge, and the effectiveness of outcomes of different therapeutic regimes, such as group sessions; and
 - c) ensure that the supply of timely therapy services is sufficient to meet the needs of children and young people who require it, based on assessed needs. This may involve increased capacity to ensure that all children and young people attending early education settings and mainstream or special schools have equal access to therapy.¹³⁹
- 5.76 Ultimately, local authorities and CCGs need to ensure that:
- parents or carers, children and young people are active partners in decisions about rehabilitation or therapy services, with agreed goals for what it is intended to achieve and how they can help;
 - therapeutic interventions are agreed and overseen by specialist paediatric therapists; and
 - therapy is delivered in the most appropriate setting, which may include the home or educational settings.¹⁴⁰

138 SEND Code, para 9.141.

139 Disabled Child Standard, Children’s NSF, p15.

140 Disabled Child Standard, Children’s NSF, p15.

NHS equipment provision

- 5.77 NHS Act 2006 s3 requires the NHS to provide – among other things – services and facilities to address people’s healthcare needs. The NHS’s equipment provision obligations are broad and complementary to those on local authorities concerned with social care support (see chapter 3 at para 3.77). They include, for example, providing specialist beds for children living at home, ceiling rails for hoists, refrigerators for medicines, walking frames, wheelchairs and so on. The provision of such equipment may have to be sanctioned by the local health body although GPs are authorised to provide a wide range of ‘appliances’, eg medical aids, dressings, pads etc as well as basic equipment to help overcome the effects of disability.¹⁴¹
- 5.78 Because of concerns over the inadequate nature of equipment services,¹⁴² steps have been taken to require local health bodies and councils to establish joint ‘integrated equipment services’.¹⁴³ Paragraph 7 of the relevant guidance¹⁴⁴ provides an illustrative list of the type of equipment that might be available from such an integrated service, namely:

Community equipment is equipment for home nursing usually provided by the NHS, such as pressure relief mattresses and commodes, and equipment for daily living such as shower chairs and raised toilet seats, usually provided by local authorities. It also includes, but is not limited to:

- Minor adaptations, such as grab rails, lever taps and improved domestic lighting.
- Ancillary equipment for people with sensory impairments, such as liquid level indicators, hearing loops, assistive listening devices and flashing doorbells.
- Communication aids for people with speech impairments.
- Wheelchairs for short-term loan, but *not* those for permanent wheelchair users, as these are prescribed and funded by different NHS services.¹⁴⁵

141 NHS (General Medical Services Contracts) Regulations 2015 SI No 1862 reg 56.

142 See, for example, Audit Commission, *Fully equipped: the provision of equipment to older or disabled people by the NHS and social services in England and Wales*, 2000.

143 DOH, *Community equipment services guidance*, HSC 2001/0: LAC (2001)13, 27 March 2001.

144 DOH, *Community equipment services guidance*, HSC 2001/0: LAC (2001)13, 27 March 2001.

145 See para 5.81.

- Telecare equipment such as fall alarms, gas escape alarms and health state monitoring for people who are vulnerable.
- 5.79 Notwithstanding the aim of making equipment an integrated support service, disputes inevitably arise as to which authority is responsible for provision. This may be a dispute between a council and a CCG – but disputes can also arise between health bodies themselves. An example would be where a disabled child is attending a school in an area outside his or her home NHS area¹⁴⁶ and the equipment is needed at the school (for example, an additional walking frame). If hardship is caused by such a dispute then a joint complaint or application for judicial review about the failure of these bodies to work together should be considered (see para 5.29 above).
- 5.80 A 2007 ombudsman's report¹⁴⁷ concerned such a case, where the patient required a specialist profiling bed and a specialised seating system. The ombudsman considered that one of the health bodies should have funded the necessary equipment as an interim measure, pending the resolution of the dispute – and that a failure to do this amounted to maladministration.

Wheelchair provision

- 5.81 The provision of publicly funded wheelchairs is an NHS responsibility.¹⁴⁸ The need for a suitable wheelchair will often be capable of being expressed in the language of human rights, for example, in terms of a right under Article 8 of the European Convention on Human Rights (ECHR) for a child to be enabled to interact with other people and the environment.¹⁴⁹ Not infrequently, considerable hardship and pain (particularly postural pain) will be caused by the use of an unsuitable wheelchair such that this could be expressed as

146 In such cases, guidance exists as to how to decide the 'responsible commissioner' – DOH, *Who Pays?* 2013.

147 Public Services Ombudsman for Wales, Complaint against Bro Morgannwg NHS Trust, Cardiff & Vale NHS Trust, Vale of Glamorgan Council and Vale of Glamorgan Local Health Board, Case Refs 200501955, 200600591 and 200700641, 28 November 2007 – see pp28 and 30.

148 Under NHS Act 2006 s3: see, for example, DOH/Care Services Improvement Partnership, *Out and about: Wheelchairs as part of a whole-systems approach to independence*, 2006, p30.

149 See, for example, *Botta v Italy* (1998) 26 EHRR 241 at [32]; and see also paras 2.14–2.19 above.

degrading treatment (contrary to Article 3¹⁵⁰) or contrary to Article 8 in relation to the impact on the person's physical and psychological integrity, or dignity.¹⁵¹

5.82 Assessments for wheelchairs and their provision are the responsibility of local NHS wheelchair services in England. Assessments are undertaken by specialists, usually an occupational therapist or physiotherapist, although GPs should support children in seeking such equipment and provide advice on the process. As noted above, responsibility for commissioning specialist wheelchairs has transferred from NHS England to CCGs.

5.83 Brief guidance on wheelchair provision was issued in 1996¹⁵² albeit that it concentrates on the provision of electrically powered indoor/outdoor wheelchairs (EPIOCs). A voucher scheme also exists that gives the option of purchasing a non-motorised wheelchair from an independent supplier – although in such cases, the user will be responsible for its maintenance and repair. In May 2016, it was announced that NHS England would be developing a personal health budgets model (see further at para 5.107 below) for the provision of wheelchairs. It is said that the new personal health budget scheme will offer more choice of where wheelchairs can be bought as well as a detailed care plan that will help users make informed decisions about their wheelchair. The care plans will also go beyond purchasing the chair to include guidance on future maintenance, repair and replacement needs. Since April 2017, all CCGs in England have been expected to start developing local personal wheelchair budget offers to replace the old wheelchair voucher system. At the time of writing (October 2019), wheelchair vouchers are still operating alongside personal wheelchair budgets.¹⁵³ In some cases, powered wheelchairs/scooters can also be purchased through the Motability Scheme by those in receipt of the high rate mobility component of the disability living allowance (DLA) or the enhanced rate of the mobility component of the personal independence payment (PIP).

5.84 The 1996 guidance concerning EPIOCs gave as suggested criteria for their provision that the person is:¹⁵⁴

150 See, for example, *Price v UK* (2002) 34 EHRR 1285.

151 See again *Botta v Italy* (1998) 26 EHRR 241 at [32] and *R (Bernard) v Enfield LBC* [2002] EWHC 2282 (Admin); (2002) 5 CCLR 577.

152 HSG (96)34, *Powered indoor/outdoor wheelchairs for severely disabled people* and HSG (96)53, *The wheelchair voucher scheme*.

153 NHS England, *Personal wheelchair budgets*.

154 NHS Executive, *Powered indoor/outdoor wheelchairs for severely disabled people*, HSG (96)34, May 1996.

- unable to propel a manual chair outdoors;
 - able to benefit from the chair through increased mobility leading to improved quality of life; and
 - able to handle the chair safely.
- 5.85 In practice there have in the past been severe concerns about the adequacy of the NHS wheelchair services¹⁵⁵ which have resulted in many families seeking charitable and other support in order to address their child's mobility needs – for example, from charities such as Whizz-Kidz and Cerebra.¹⁵⁶ It is hoped that the roll-out of personal wheelchair budgets will improve the picture, so that families will not have to rely on charitable support.

Short breaks

- 5.86 Although short breaks¹⁵⁷ are services most commonly provided by local authorities (and are considered in chapter 3 at paras 3.92–3.97 above), the NHS also has important responsibilities to provide such support. The need for short breaks or respite will now form an important part of the right to a parent carer's assessment under Children Act 1989 ss17ZD and 17ZE (see chapter 8 at para 8.19 below). The NHS duty was recognised in *R (T, D and B) v Haringey LBC*¹⁵⁸ (see para 5.92 below) and is highlighted in a number of important NHS guidance documents.¹⁵⁹ Where, therefore, the child would need access to healthcare supports during a period of short break provision, the NHS should ensure that this service is available.

155 See, for example, Audit Commission, *Fully equipped 2002: assisting independence*, 2002; DOH, *Evaluation of the powered wheelchair and voucher system 2000*, 2002; emPower, *NHS wheelchair and seating services mapping project: final report*, Limbless Association, 2004; and Prime Minister's Strategy Unit, *Improving the life chances of disabled people*, 2005. See also, N Sharma with J Morrison, *Don't push me around! Disabled children's experiences of wheelchair services in the UK*, 2006, a joint report published by Barnardo's and Whizz-Kidz and endorsed by the UK's four Children's Commissioners; the 2010 Inquiry commissioned in Wales – Welsh Assembly Government (2010) Health, Wellbeing and Local Government Committee: Ministerial Evidence session HWLG(3)–04–10–p4: 4 March 2010 and Every Disabled Child Matters, *Disabled children and health*, 2009, p13.

156 See: www.whizz-kidz.org.uk and <http://w3.cerebra.org.uk/>.

157 Also known, particularly in the health context, as 'respite care' although the term is not preferred from a disability rights perspective.

158 [2005] EWHC 2235 (Admin): (2006) 9 CCLR 58.

159 See, for example, DOH, *The national framework for NHS continuing healthcare and NHS funded nursing care in England*, October 2018, para 265.

It can do this by providing or funding the short break/respite care or working with the local authority to ensure that the service is available. In the *Haringey* case, the health body was responsible for the service by providing a respite care service in the children's home (or paying a private agency to do this).

5.87 Sometimes, however, the provision of short breaks will be a joint initiative under the 'working together' duties (see para 5.20 above). For example, a respite care centre run by a local authority may not have staff trained to deliver certain healthcare support (such as administering rectal valium) which as a consequence might make the service unavailable to children with certain disabling conditions. Such an impasse could be resolved, if a care assistant at the centre was willing to take on this role and be trained by the NHS in the procedure (and when administering the valium, he or she would be doing this as an agent of the NHS).

5.88 Short breaks have been identified as a key priority for NHS delivery and investment by the DOH with a clear expectation that both local authorities and health bodies will deliver additional and better quality short breaks services for disabled children and their families.¹⁶⁰ In 2013 DOH guidance, a best practice case study is set out in which the CCG and the local authority have formally integrated their commissioning for disabled children and have provided additional sessions of respite care.¹⁶¹

Continence services

5.89 Achieving continence is a central goal for many disabled children and their families. Yet even when continence assessments are available, parents report real problems in securing the supply of the right sort of continence products for their child, with many experiencing a 'one size fits all' service.¹⁶² NHS guidance in the Children's NSF recommended 'an integrated community based paediatric contin-

160 Department for Children Schools and Families/DOH, *Aiming high for disabled children: short breaks implementation guidance*, 2008; and DOH, *Healthy lives, brighter futures – The strategy for children and young people's health*, 2009.

161 DOH, Department of Education and others, *Improving Children and Young People's Health Outcomes: A system wide response*, 2013, p32.

162 See in this respect the Cerebra Legal Entitlements Research Project Digest, Digest of Opinions 2013, 'Jinny's Story', Cardiff Law School, 2014, which concerns a NHS body that operated an inflexible policy in relation to a disabled young person's continence needs.

ence service' in every area. In 2007, the DOH issued the Children's Contenance Exemplar to support the development of child-centred local delivery.¹⁶³

- 5.90 Detailed practice guidance concerning the organisation and range of continence services that should be made available has been issued by the DOH.¹⁶⁴ This advises that the nature and quantity of continence supplies made available should be determined as a result of an individual assessment of need in every case. Research suggests,¹⁶⁵ however, that despite the requirement for pads to be available on the basis of clinical need, almost 75 per cent of CCGs operate a fixed policy which stipulates a maximum number of continence pads that can be provided over a specified period. The research concerned older people but the experience of disabled children is similar: such policies are, however, contrary to the guidance, fetter the authorities' discretion and, where individual hardship results, constitute maladministration. If challenged through an application for judicial review, it is highly likely (in the opinion of the authors) that such a policy would be held to be unlawful.

Continuing care

- 5.91 Although (as noted above, see para 5.24) the local authority will generally be the lead agency in co-ordinating the support services for a disabled child, frequently the package will have funding support from the NHS and the education department (in relation to SEN needs – see chapter 4) as well as from the children's services department of the local authority. In some cases, however, the child's needs are such that the NHS may not only become the lead agency, but it may also assume sole responsibility for funding the child's health and social care needs. In such situations, the child is held to be eligible for 'NHS continuing care'.
- 5.92 *R (T, D and B) v Haringey LBC*¹⁶⁶ is an example of a case involving a disabled child with complex health needs. Her impairment meant

163 Despite these recommendations, the *Every disabled child matters* campaign describes integrated paediatric continence services as 'virtually non-existent': EDCM, 'Disabled children and health', 2009, p30.

164 DOH, *Good practice in continence services*, April 2000. See also NHS England, *Excellence in continence care*, July 2018.

165 Royal College of Physicians, *National audit of continence care for older people*, November 2006.

166 [2005] EWHC 2235 (Admin); (2006) 9 CCLR 58.

that she required a tracheostomy (a tube in the throat) which needed regular suctioning. The child was discharged from hospital and cared for at home, with her mother being trained to manage the tracheostomy with back-up from the district nursing service. The issue in the case was which authority – the health body or local authority – was responsible for providing the respite care that the mother required – since when she was attending to the tracheostomy she had to be awake through the night. The court held that in such a situation, the NHS was responsible – meaning that the same principles for NHS continuing healthcare eligibility as applied to adults, applied to children. In the judge’s opinion, the ‘scale and type of nursing care’ was such that it was outside that which could be provided by the local authority. What was required in this case was a night sitter who could replace the care provided by the mother – but who did not need to be a qualified nurse. In similar terms, in *R (Juttla) v Hertfordshire Valleys CCG*¹⁶⁷ a respite unit for children with complex health needs was held to be a health service even though it was accepted that much of the care provided could be delivered by trained social care staff.

5.93 The DOH has issued guidance specifically concerned with the assessment of children’s eligibility for NHS Continuing Care – *The National Framework for Children and Young People’s Continuing Care 2016*¹⁶⁸ (‘Continuing Care Framework’).

5.94 The framework sets out the process for arranging packages of continuing care for children and young people who have health needs that cannot be met by existing universal and specialist services. It requires that every child or young person referred to the NHS with possible continuing care needs should be offered an assessment¹⁶⁹ by a nominated children and young people’s health assessor.¹⁷⁰ There are four key areas of evidence that should be considered in the assessment:

- the preferences of the child or young person and their family;
- a holistic assessment of the needs of the child or young person and their family;

167 [2018] EWHC 267 (Admin); (2018) 21 CCLR 325.

168 The 2016 guidance has been the subject of trenchant criticism – see L Clements, *Means testing children’s healthcare by stealth* (2018) at: www.lukecllements.co.uk/means-testing-childrens-healthcare-by-stealth/

169 *Continuing Care Framework*, para 55.

170 *Continuing Care Framework*, para 7.

- reports and risk assessments from a multidisciplinary team or evidence collated during the Education, Health and Care plan assessment; and;
 - the Decision Support Tool for children and young people (see para 5.98 below).
- 5.95 The framework makes the not unreasonable point, that for children even if there is a primary health care need it is unrealistic for all commissioning responsibility to shift to the NHS:
- Children with complex needs may not only need support from health services. They may also have special educational needs, and need support from social care. Unless there is a good reason for this not to happen, continuing care should be part of a wider package of care, agreed and delivered by collaboration between health, education and social care.¹⁷¹
- 5.96 What is being asserted here is that from a policy perspective, social services and the education agencies should remain involved – even if a child has a primary care need. What the guidance cannot do is overrule or undermine the law, as detailed in the *Haringey* judgment. The legal position is, therefore, that once a child is eligible for NHS continuing care, funding, the children’s services department is unable to fund social care services which are related to a child’s medical needs – in the same way that the adult legislation (ie the Care Act 2014 s22) prohibits adult services funding services for adults. Services provided by the local authority must not turn the authority ‘into a substitute or additional NHS for children’.¹⁷² Children’s services do, however, retain responsibilities for safeguarding and associated social work functions eg:
- helping parents with the emotional problems of caring for disabled children;
 - providing carer support services ie services delivered solely to the parents/siblings – bearing in mind that respite care services are generally not of this nature since they are generally delivered to the child (eg a sitting service or overnight care);
 - giving information and so on.
- 5.97 So, for example, if a child’s behaviour became very challenging and a safeguarding issue arose then social services would have a role to fulfil. The safeguarding work undertaken by the local authority might

171 *Continuing Care Framework*, paras 15–16.

172 *R (T, D and B) v Haringey LBC* [2005] EWHC 2235 (Admin); (2006) 9 CCLR 58 at [68].

flag up that the mother was not coping and that she had a need to develop the skills to address the behaviour and also that the child needed short break care. It would be a health function to provide support to manage challenging behaviour (ie skilled assistants); it would be a health function to train the mother to acquire these skills; and the provision of the short break care too would be a NHS responsibility. This could be provided by skilled assistants coming to the home or the child going to a residential or overnight fostering placement – and, in this case, social services could seek to ensure this happened using its powers under Children Act 1989 s27.

Decision support tool

5.98 The framework contains a decision support tool which is based on a tool widely used for adults,¹⁷³ and brings together needs from across ten care domains:

- 1) challenging behaviour;
- 2) communication;
- 3) mobility;
- 4) eating and drinking;
- 5) continence and elimination;
- 6) skin and tissue viability;
- 7) breathing;
- 8) drug therapies and medicines;
- 9) psychological and emotional needs; and
- 10) seizures.

It describes five levels of need, from low to priority, and provides descriptors to assess the level of need for each of the care domains. The framework indicates that three ‘high’ ratings, one severe rating or one priority rating is likely to indicate that the child or young person has continuing care needs.¹⁷⁴

5.99 The framework stresses that the decision support tool is not prescriptive and the importance of exercising evidence-based professional judgment in all cases. Following assessment, the framework indicates that a decision as to whether or not the child has a continuing care need should be made by a multidisciplinary or multi-agency forum or panel and, where a decision is made regarding a package of continuing care, processes undertaken to put it in place.

173 For detailed consideration of these tools see L Clements, *Community care and the law*, 7th edn, LAG, 2019.

174 *Continuing Care Framework*, para 148.

- 5.100 The framework requires NHS bodies to have a local complaints procedure in place to respond to any disagreements voiced by the child or their family about any aspect of the continuing care process. In addition, once a continuing care package is put in place, regular reviews must be carried out. The framework recommends that a review takes place three months after initial assessment and then annually or more frequently depending on the specific case.

The continuing care pathway

- 5.101 Included in the 2016 framework is a continuing care pathway, which shows how the continuing care process should look from the perspective of child or young person and their family.¹⁷⁵ The pathway specifies:
- four phases – assessment, decision-making, arrangement of provision and ongoing;
 - seven discrete steps within these phases – identify, assess, recommend, decide, inform, deliver and review;
 - key actions to be undertaken at each stage; and
 - timescales, which should see the child and family informed of the continuing care service provision decision within six weeks of the referral.
- 5.102 The framework also contains detailed guidance on the continuing care process and pathway.¹⁷⁶

Continuing care and direct payments/personal budgets

Direct payments

- 5.103 Where a disabled child is deemed eligible for NHS continuing care funding it means that the care provided is subject to the provisions of the NHS Act 2006 and not the social services statutes (such as Children Act 1989 and CSDPA 1970, see chapter 3). Like social services authorities, NHS bodies are now able to make direct payments for the provision of certain types of healthcare services

¹⁷⁵ *Continuing Care Framework*, p13.

¹⁷⁶ *Continuing Care Framework*, paras 55–110.

under the NHS Acts, including for children.¹⁷⁷ Guidance from NHS England¹⁷⁸ sets out illustrative examples of why a CCG might decide not to provide someone with direct payments – for example, because ‘the benefit to that individual of having a direct payment for health-care does not represent value for money’.

5.104 Before providing direct payments, NHS bodies must prepare a care plan setting out the health services that are to be provided and must advise the patient, or their representative in the case of a child, of any potential risks arising out of the use of direct payments.¹⁷⁹ The direct payment must be set at a level to secure the agreed provision in any EHC plan (see para 5.47) and meet health needs agreed in the personal health budget care plan (see para 5.107 below for more on personal health budgets).¹⁸⁰ Guidance from NHS England states that ‘direct payments must be set at a level sufficient to cover the full cost of each of the services agreed in the care plan’.¹⁸¹ For each person receiving a direct payment, the CCG must name a care co-ordinator, and this must be recorded in the care plan.¹⁸² The role of the care co-ordinator includes undertaking or arranging for monitoring and review of the direct payment.

5.105 A health direct payment can only be used to pay an individual living in the same household, a close family member¹⁸³ or a friend

177 See NHS Act 2006 s12A and National Health Service (Direct Payments) Regulations 2013 SI No 1617 reg 4. Health direct payments for children under 16 must be made to a ‘representative’ who must act in accordance with reg 4(3); for example they must ‘act in the best interests of the patient when securing the provision of services in respect of which the direct payment is made’. See further NHS England, *Guidance on Direct Payments for Healthcare: Understanding the Regulations*, March 2014.

178 NHS England, *Guidance on Direct Payments for Healthcare: Understanding the Regulations*, March 2014, para 33.

179 National Health Service (Direct Payments) Regulations 2013 reg 8. The requirements of the care plan are set out in NHS England, *Guidance on direct payments for healthcare: Understanding the regulations*, March 2014, para 97. See the SEND Code at para 9.124 for how sections G and J of an EHC plan can be modified to fulfil the requirements of a care plan for health direct payments.

180 SEND Code, para 9.120.

181 NHS England, *Guidance on Direct Payments for Healthcare: Understanding the Regulations*, March 2014, para 117. The guidance goes on to emphasise (para 118) that ‘hidden costs’ such as National Insurance and pension contributions and training costs must be recognised in this calculation.

182 NHS England, *Guidance on Direct Payments for Healthcare: Understanding the Regulations*, March 2014, para 114.

183 The definition of ‘close family member’ is provided in box 3 at para 154 of NHS England, *Guidance on Direct Payments for Healthcare: Understanding the Regulations*, March 2014.

if the CCG is satisfied that to secure a service from that person is necessary in order to satisfactorily meet the person receiving care's need for that service; or to promote the welfare of a child for whom direct payments are being made.¹⁸⁴

- 5.106 Where the CCG or commissioning health body declines a request for a direct payment pursuant to a personal health budget, they must set out their reasons for doing so in writing and provide the individual with the opportunity for a formal review.¹⁸⁵

Personal health budgets

- 5.107 Since October 2014, disabled children and young people who are eligible for continuing care have had a right to have a 'personal health budget'.¹⁸⁶ Guidance from NHS England¹⁸⁷ describes personal health budgets as 'an amount of money to support a person's identified health and well-being needs the application of which is planned and agreed between the individual, their representative, or, in the case of children, their families or carers and the local NHS team'. Although slightly different terms are used in each, the guidance¹⁸⁸ and the Continuing Care Framework¹⁸⁹ make clear that a personal budget can be paid in one of three ways:

- A notional budget – where the commissioner spends the budget following discussion with the child or young person, and their family (or other representative).
- A third party budget – where a person or organisation independent of the individual and the NHS manages the budget on behalf of the child or young person.

184 NHS England, *Guidance on Direct Payments for Healthcare: Understanding the Regulations*, March 2014, para 153.

185 SEND Code, para 9.109, p181.

186 See the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) (No 3) Regulations 2014 SI No 1611.

187 NHS England, *Guidance on the 'right to have' a personal health budget in adult NHS continuing healthcare and children and young people's continuing care*, September 2014, pp8 and 10. The relevant guidance (see below) states (p11) that: 'In the case of children this refers to the element of their care package that would normally be provided by the NHS once they become CC eligible and not the elements of their package provided by social care or education.'

188 NHS England, *Guidance on the 'right to have' a personal health budget in adult NHS continuing healthcare and children and young people's continuing care*, September 2014, p10.

189 *Continuing Care Framework*, para 37.

- A direct payment to the young person or their family (see para 5.103 above).
- 5.108 The framework states that ‘CCGs must publicise and promote the availability of personal health budgets and provide information, advice and support to those eligible.’ The guidance also states that ‘CCGs should ensure all three options are available to enable people to make a choice about the level of control they feel comfortable with’. There may be ‘exceptional circumstances’ where a personal health budget can be refused; the guidance suggests this could be ‘due to the specialised clinical care required or because a personal health budget would not represent value for money as any additional benefits to the individual would not outweigh the extra cost to the NHS’.¹⁹⁰
- 5.109 Since 2015, the NHS has been implementing personal health budgets as part of a wider drive to make health more personalised, in line with the NHS Five Year Forward View¹⁹¹, and they are now mentioned in many other key strategies¹⁹². Evidence taken from the pilot of individual budgets for families with disabled children suggests that children, young people and their families are benefiting from the control that personal health budgets give. In 2016/17 more than 1,500 children had a personal health budget, a number which is expected to increase rapidly over the next few years.¹⁹³

Child and Adolescent Mental Health Services

- 5.110 Many disabled children will experience episodes of mental ill-health. Many will need support from CAMHS: support designed to promote the mental health and psychological well-being of children and young people. The intention of CAMHS is ‘to provide high quality, multi-disciplinary mental health services to all children and young people with mental health problems and disorders to ensure effective assessment, treatment and support, for them and their

190 NHS England, *Guidance on the ‘right to have’ a personal health budget in adult NHS continuing healthcare and children and young people’s continuing care*, September 2014, p15.

191 NHS England, *NHS Five Year Forward View*, 2015.

192 Including: SEND Code of Practice, 2015; NHS England, *Five Year Forward View for mental health*, 2016; *Transforming care for people with learning disabilities – next steps*.

193 NHS England, *Personal health budgets and Integrated Personal Commissioning quick guide: children and young people*, June 2017.

families'.¹⁹⁴ In February 2011, the government published a mental health strategy for people of all ages, which identified the following objectives:¹⁹⁵

- More people will have good mental health.
- More people with mental health problems will recover.
- More people with mental health problems will have good physical health.
- More people will have a positive experience of care and support.
- Fewer people will suffer avoidable harm.
- Fewer people will experience stigma and discrimination.

5.111 This strategy was followed, in October 2011, by the government committing £32 million to expanding the availability of talking therapies for children and young people.

5.112 The central importance of mental health provision has been highlighted by the events at the Winterbourne View hospital, where vulnerable people were subjected to terrible abuse. The report into what happened was produced by the DOH in December 2012. It addresses important issues relating to mental health care for children and young people, as well as adults:¹⁹⁶

- Children and young people have a right to be given the support and care that they need in a community-based setting, near to family and friends.
- Each area should have a locally agreed joint plan to ensure high quality care and support services for children with mental health problems, learning disabilities or autism.
- The norm should be that children and young people live in their own homes with the support they need for independent living within a safe environment.

5.113 Unfortunately, CAMHS provision is widely criticised as being disjointed, poor quality and difficult to access. In July 2014, NHS England revealed major problems with CAMHS, including finding that many children and young people were placed in hospitals hundreds of miles away from home or were inappropriately placed

194 Department for Children Schools and Families, *Services supporting the emotional wellbeing and mental health of children and young people*, 2010.

195 *No health without mental health: a cross-government outcomes strategy for people of all ages*, February 2011.

196 DOH, *Transforming care: A national response to Winterbourne View Hospital*, 2012.

on adult wards.¹⁹⁷ In October 2014, the House of Commons Health Committee published a report into CAMHS.¹⁹⁸ The report found that there are ‘serious and deeply ingrained problems with the commissioning and provision of children’s and adolescents’ mental health services’ that ‘run through the whole system from prevention and early intervention through to in-patient services for the most vulnerable young people’.¹⁹⁹

5.114 In its latest report in 2015, the Children and Young People’s Mental Health and Wellbeing Taskforce recognised that there are a number of challenges facing CAMHS, including difficulties accessing mental health services generally, and crisis services in particular. The taskforce’s key proposals include delivering a joined-up approach between health and social care bodies, simplifying commissioning structures and arrangements and improving access to services.²⁰⁰

5.115 In 2017, the government published its green paper for transforming children and young people’s mental health, which detailed proposals for expanding access to mental health care for children and young people. Following a 13-week public consultation, during which the government received more than 2,700 responses, in June 2018 the Department of Health and Social Care (DHSC) and the Department for Education published its *Response to the Children and Young People’s Mental Health Green Paper Consultation*. The three core proposals were:

1. To incentivise and support all schools and colleges to identify and train a Designated Senior Lead for mental health.
2. To fund new Mental Health Support Teams, which will be supervised by NHS children and young people’s mental health staff.
3. To pilot a four-week waiting time for access to specialist NHS children and young people’s mental health services.

The response also stated that the government would make available £300 million of funding to implement the proposals.

5.116 NHS England is leading the delivery of two of the programme’s main commitments, establishing new Mental Health Support Teams

197 NHS England, *Child and Adolescent Mental Health Services (CAMHS) Tier 4 Report*, July 2014.

198 House of Commons Health Committee, *Children’s and adolescents’ mental health and CAMHS*, third report of session 2014–15.

199 House of Commons Health Committee, *Children’s and adolescents’ mental health and CAMHS*, third report of session 2014–15, at p3.

200 Children and Young People’s Mental Health and Well-being Taskforce, *Future in Mind: Promoting, protecting and improving our children and young people’s mental health and wellbeing*, 2015.

and trialling a four-week waiting time (2 and 3 above). NHS England is also supporting the Mental Health Services and Schools and Colleges Link Programme, which will be rolled out over four years. Under the programme, every school, college and alternative provision will be trained through a series of workshops to pool their understanding and resources and to draw up long-term plans, co-ordinated by CCGs.

- 5.117 The term ‘CAMHS’ can be used widely to refer to all services which play a part in promoting children’s mental well-being, or narrowly to refer to specialist mental health services for children. The narrow meaning of the term is used in the remainder of this section, while recognising the critical importance of wider health and other services in achieving good mental health for disabled children – and their families.
- 5.118 There is no specific statutory framework for CAMHS. Accordingly, CAMH services are provided under the general obligations created by the NHS Act 2006 and the Mental Health Act (MHA) 1983. Provisions in relation to detention in hospital and compulsory treatment will be found in the MHA 1983, for children as for adults. All issues in relation to mental health treatment should be informed by the 2015 Mental Health Act Code of Practice (‘MHA Code’) which has statutory force.²⁰¹ Particular regard should be had to chapter 19 ‘Children and young people under the age of 18’.
- 5.119 Input into CAMHS from children’s services within local authorities will be governed by the Children Acts 1989 and 2004, the Chronically Sick and Disabled Persons Act 1970 s2 (see chapter 3 at para 3.66) and MHA 1983 s117 (see para 5.136).
- 5.120 CAMH services are in large part shaped by government policy initiatives and targets. These targets and policies are relevant in that they give an indication of the nature and quality of services that disabled children and their families should expect to receive if they need the help of a specialist mental health service. It is for this reason that the following paragraphs provide a brief overview of the structure of local CAMH services, their guiding principles and the services that they should be able to provide.
- 5.121 Many disabled children will require input from CAMHS, whether because their primary need is a mental health need or because of secondary mental health problems associated with their disabilities, which may sadly emerge as a result of their needs not being addressed properly. The expectation is that all such children will have ‘access to

201 *R (Munjaz) v Mersey Care NHS Trust* [2006] 2 AC 148.

timely, integrated, high quality, multi-disciplinary mental health services to ensure effective assessment, treatment and support'²⁰² and that CAMHS will provide for four levels of service:

- Tier 1: A primary level of care.
- Tier 2: A service provided by specialist individual professionals relating to workers in primary care.
- Tier 3: A specialised multi-disciplinary service for more severe, complex or persistent disorders.
- Tier 4: Essential tertiary level services such as day units, highly specialised out-patient teams and in-patient units.

5.122 Responsibility for commissioning the first three tiers of CAMHS lies with CCGs. NHS England has responsibility for commissioning Tier 4 of CAMHS.

A comprehensive CAMHS

5.123 A 2003 *Department of Health policy paper*²⁰³ set the expectation that a comprehensive CAMHS would be available in each locality in England by 2006. This has proved to be aspirational, and recent reports suggest that such a service has yet to be achieved.²⁰⁴

5.124 In 2004, a specific Children's NSF Standard was published to address the 'Mental Health and Psychological Well-being of Children and Young People'²⁰⁵ which required that CAMHS should ensure, as part of their underpinning principles:

- access for all children and young people regardless of their age, gender, race, religion, ability, culture, ethnicity or sexuality;²⁰⁶
- multi-agency commissioning and delivery of services;²⁰⁷ and

202 DOH/DfES, *National service framework for children young people and maternity services: the mental health and psychological well-being of children and young people: Standard 9, 2004* ('NSF Standard 9'), p4.

203 DOH, *Improvement, expansion and reform: the next 3 years, priorities and planning framework 2003–2006*, 2003.

204 For analysis of what is meant by a 'Comprehensive CAMHS' and whether it has been achieved, see 11 Million, *Out of the shadows?* Children's Commissioner for England, 2008, p42 and the 2008 UK Children's Commissioners' *Report to UN Committee on the rights of the child*, p23. See also House of Commons Health Committee, *The Government's Green Paper on mental health: failing a generation*, sixth report of session 2017–19; and Children's Commissioner for England, *Early access to mental health support*, April 2019.

205 NSF Standard 9, p49.

206 NSF Standard 9, p49.

207 NSF Standard 9, p49.

- participation of children and young people and their families at all levels of service provision.²⁰⁸
- 5.125 The NSF placed great emphasis on early intervention,²⁰⁹ by (among other things) requiring that health bodies and local authorities ensure CAMH workers are available and accessible within community settings²¹⁰ and that all localities have specialist multidisciplinary teams with the resources and skills to provide:
- specialist assessment and treatment services;
 - services for the full range of mental disorders in conjunction with other agencies as appropriate;
 - a mix of short-term and long-term interventions and care;
 - a full range of evidence-based treatments; and
 - specialist services that are commissioned on a regional or multi-district basis, including in-patient care.²¹¹
- 5.126 Adequate services must be in place for emergencies, including policies that clarify the level of service provided and the criteria for referral. Arrangements need to be in place to ensure that 24-hour cover is provided to meet children's urgent needs and that a specialist mental health assessment is undertaken within 24 hours or during the next working day where indicated.²¹²
- 5.127 Health bodies and local authorities are also required to develop a long-term strategy to ensure that young people²¹³ are provided with services which meet their developmental needs. This includes ensuring there are no gaps in service provision and that there is a smooth transition to adult services.
- 5.128 Adults who receive help from 'secondary mental health services' (for example from community mental health teams (CMHTs), early intervention teams etc) are assessed and supported under a system known as the care programme approach (CPA)²¹⁴ and the CPA should also be used on transition from child to adult services

208 NSF Standard 9, p13.

209 NSF Standard 9, eg pp8–9.

210 NSF Standard 9, p11–12.

211 NSF Standard 9, p50.

212 NSF Standard 9, p19.

213 The Mental Health Act Code refers to 'child' or 'children' as under 16s and 'young person' or 'young people' in relation to those aged 16 or 17.

214 DOH, *Refocusing the care programme approach policy and positive practice guidance*, 2008, although the CPA is capable of being adapted to meet the needs of children in touch with CAMHS – see Annex B: CPA and Child and Adolescent Mental Health Services. See further the Mental Health Act Code at chapter 34.

(see para 5.156 below for more on transition to adult health services).²¹⁵

5.129 It is the responsibility of health bodies and local authorities to ensure that children and young people with learning disabilities receive equal access to mental health services at all tiers of CAMHS. This includes:

- adequately resourced Tiers 2 and 3 learning disability specialist CAMHS with staff with the necessary competencies to address mental health difficulties in children and young people with learning disabilities; and
- access to Tier 4 services providing in-patient, day-patient and outreach units for children and adolescents with learning disabilities and severe and complex neuro-psychiatric problems.²¹⁶

5.130 For more detail on CAMHS, see Dr Camilla Parker, *Adolescent Mental Health Law* (forthcoming 2020, LAG).

Admission to hospital for treatment of a mental disorder

5.131 The law relating to the admission and treatment of a child or young person with a mental health issue (whether ‘informally’, with parental consent or under the MHA 1983) is complex and is explained in chapter 19 of the MHA Code.²¹⁷ A key complicating factor is the difficult relationship that exists between the detention and treatment powers under the 1983 Act, the Mental Capacity Act (MCA) 2005 (which is of primary relevance for persons aged 16 and over) and the common law as it relates to children’s powers to make their own decisions.

5.132 Detailed guidance on assessment and applications for detention in hospital under the MHA 1983 is set out in chapter 14 of the MHA Code²¹⁸ which in addition, at chapter 19, provides guidance on particular issues arising in relation to children and young people. An application is usually made by the approved mental health professional (AMHP) and, save in cases of emergency, must be supported by two medical recommendations. Those with parental responsibility (see chapter 2 at para 2.58) should be consulted about decisions to

215 NSF Standard 9, p22.

216 NSF Standard 9, p24.

217 See further DOH, *The legal aspects of the care and treatment of children and young people with mental disorder*, 2009.

218 DOH, *Code of Practice: Mental Health Act 1983*, TSO, 2015.

admit/treat their child.²¹⁹ The person identified as the ‘nearest relative’²²⁰ will have additional rights.

Ensuring an age appropriate environment for CAMHS

- 5.133 MHA 1983 s131A requires that for mental health purposes the hospital environment in which a child or young person is to be accommodated is age appropriate. The requirement applies regardless of whether the admission is informal or formal and its primary purpose is to ensure that children and young people are not admitted inappropriately on to adult psychiatric wards. A detailed briefing published in 2010 by Young Minds²²¹ explains the nature of the obligation created by section 131A and the very limited circumstance when an admission to an adult psychiatric ward would be permitted – and the obligations that are placed on the hospital in such cases.²²²

Hospital discharge

- 5.134 The Children’s NSF Standard for Hospital Services²²³ provides general advice concerning the discharge of children from hospital care – including the need (where appropriate) for effective liaison with social services – to ensure (for example) that equipment is available and ‘that rehabilitation programmes can be continued at home’.²²⁴

- 5.135 Good practice guidance is given in the Children’s NSF Standard for Mental Health and Psychological Well-being of Children and Young People²²⁵ where the discharge follows a period in an NHS mental health setting (or CAMHS arranged setting). The advice includes:

The in-patient unit needs to be able to hand over to an appropriately equipped community service. There needs to be a shared understand-

219 See MHA Code, para 19.38.

220 See MHA Code at chapter 5 for the definition of ‘nearest relative’. See also MHA Code, paras 14.57–14.65.

221 C Parker, *Young Minds briefing on the responsibilities of NHS Trust Boards under section 131A of the Mental Health Act 1983*, Young Minds, 2010.

222 See the MHA Code, paras 19.90–19.104.

223 DOH, *Getting the right start: national service framework for children: standard for hospital services*, 2003, see para 3.27 onwards.

224 DOH, *Getting the right start: national service framework for children: standard for hospital services*, 2003, see paras 3.27 and 3.30.

225 NSF Standard 9, para 9.13 onwards.

ing of the level of care required on discharge from inpatient services and if the appropriate resources are not available in community services, shared aftercare arrangements should be considered; there may be a continuing role for the in-patient team in the provision of outreach and after-care services.

- 5.136 Where the discharge of the child or young person follows their formal detention under either section 3 or one of the criminal provisions of the MHA 1983, then they will be entitled to support services, not under the Children Act 1989 or the Chronically Sick and Disabled Persons Act 1970 (see chapter 3 above) but under MHA 1983 s117 ('section 117 services'). The fact that these services are provided under a distinct statutory provision should not in practice make any material difference to the child, young person or his or her family. Section 117 services do have certain distinct legal characteristics, for example, they are the joint responsibility of both the NHS and the local authority,²²⁶ they must be provided free of charge²²⁷ and can cover a wide spectrum of supports – both health and social care – albeit that they must be required because of a mental health need.²²⁸ A detailed consideration of section 117 services is provided by the MHA 1983 Code of Practice.²²⁹

Consent to mental health treatment

- 5.137 In all areas of healthcare, including mental health care and treatment, it will be unlawful to treat a disabled child unless the appropriate consent has been obtained or the treatment is otherwise authorised. A general overview of the law relating to mental capacity and decision-making is provided at chapter 7. Issues of capacity to consent to treatment are dealt with below.

Consent to treatment

Children (under 16s)

- 5.138 Consent to treatment is a difficult issue for disabled children, as it can be for all children. Consent should be sought for each aspect of

226 *R v Mental Health Review Tribunal ex p Hall* (1999) 2 CCLR 361.

227 *R (Stennett) v Manchester CC* [2002] UKHL 34; (2002) 5 CCLR 500.

228 MHA 1983 s117(6) and *R (Mwanza) v Greenwich LBC and Bromley LBC* [2010] EWHC 1462 (Admin); (2010) 13 CCLR 454.

229 DOH, *Code of Practice: Mental Health Act 1983*, 2015, chapter 33.

the child or young person's treatment as and when it arises, even if the treatment proposed could be given without consent under the MHA 1983.²³⁰ In relation to mental health treatments, reference should be made to the MHA Code at chapter 19 and the DOH publication *The legal aspects of the care and treatment of children and young people with mental disorder*.²³¹

5.139 Detailed guidance has been issued by the DOH concerning treatment decisions relating to children.²³² Children's capacity to consent to treatment is determined by individual assessment. Children who are able to make decisions about their admission to hospital or treatment are referred to as being 'Gillick competent', a reference to the leading House of Lords case.²³³ A 'Gillick competent' child is a child who has attained sufficient understanding and intelligence to be able to understand fully what is involved in the proposed intervention. Such a child will be regarded as competent to consent to a particular intervention, such as admission to hospital or proposed treatment.²³⁴

5.140 If a child is not 'Gillick competent', those with parental responsibility may, as a general rule, consent if the decision falls within the 'scope of parental responsibility'. This relatively difficult concept is discussed in detail in chapter 7 at para 7.11. The parent's consent should be sought for each aspect of the child or young person's care and treatment as it arises.²³⁵

5.141 The 'inherent jurisdiction' of the High Court can be invoked to make treatment decisions on behalf of all children, whether competent or otherwise and the court may override treatment consents or refusals if it considers it necessary to do so in the child's 'best interests'.²³⁶ This jurisdiction has no limits other than the requirement

230 DOH, *The legal aspects of the care and treatment of children and young people with mental disorder*, 2009, p56 at 4.3.

231 DOH, *The legal aspects of the care and treatment of children and young people with mental disorder*, 2009.

232 DOH, *Reference guide to consent for examination or treatment*, 2nd edn, 2009.

233 *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112.

234 DOH, *The legal aspects of the care and treatment of children and young people with mental disorder*, 2009, p18 at 2.10.

235 See the MHA Code, chapter 19.

236 *Re W (a minor) (medical treatment: court's jurisdiction)* [1993] Fam 64 and P Bowen, *Blackstone's guide to the Mental Health Act 2007*, OUP, 2007, para 9.33. See further *Re JM (a child)* [2015] EWHC 2832 (Fam), where the court approved life-saving invasive surgery to treat cancer in relation to a ten-year-old child whose parents did not consent to the treatment. The court gave guidance that in these cases an application should be made for a specific issue order under the Children Act 1989 s8 as well as under the inherent jurisdiction, see [20]–[28].

to act in the child's best interests, although the House of Lords has held that the Family Division cannot compel a public authority to exercise its public law functions.²³⁷

Young people (16- and 17-year-olds)

- 5.142 The law on consent to treatment, including treatment for mental disorder, for young people (aged 16–17 years) is governed by the MCA 2005 and Family Law Reform Act (FLRA) 1969 s8. The MCA 2005 creates a rebuttable presumption that all individuals aged 16 or over have capacity to make decisions for themselves, see further chapter 7. FLRA 1969 s8 provides that persons of this age can consent to any surgical, medical or dental treatment.
- 5.143 MCA 2005 s3 provides that a person is deemed to be incapable of making a specific decision if they cannot understand the information about the decision, retain the relevant information in their mind, use or weigh the information as part of the decision-making process or communicate their decision.²³⁸ A person may be incapable of 'understanding' relevant information due to a particularly severe intellectual impairment or because they have a completely distorted sense of reality – for example, a belief that they are obese, when they are in fact emaciated. Likewise, a person's inability to weigh information in their mind as part of the decision-making process, might stem, not from profound cognitive impairment but from an obsessional or compulsive disorder – for example, an uncontrollable phobia.²³⁹
- 5.144 The courts have held that, in certain cases, a court (or even a parent) can override a refusal by a competent child or a young person with capacity.²⁴⁰ While the courts, in the exercise of their inherent jurisdiction, can override certain treatment refusal decisions of even 16- and

237 *A v Liverpool CC* [1982] AC 363. In addition to the High Court's inherent jurisdiction, courts also have jurisdiction under section 8 of the Children Act 1989 to make a 'specific issue order' for the purposes of determining a specific question, including a question relating to medical treatment. See P Bowen, *Blackstone's guide to the Mental Health Act 2007*, OUP, 2007, para 9.35.

238 MCA 2005 s3.

239 See, for example, *Re MB (Caesarean section)* [1997] 2 FLR 426; (1997–98) 38 BMLR 175.

240 See, for example, *Re R (a minor) (wardship: medical treatment)* [1991] 4 All ER 177 and *Re W (a minor) (medical treatment: court's jurisdiction)* [1992] 4 All ER 627. In *Re W*, the court also emphasised that the child or young person's refusal is a very important consideration when deciding whether treatment should be given, despite the child or young person's refusal, noting that its importance increases with their age and maturity; see the MHA Code at para 9.23.

17-year-olds,²⁴¹ great caution should be exercised in relying on parental consent in relation to a competent child or a young person with capacity. In this context, the MHA Code states at para 19.39 that where a child under 16 has competence or a young person has capacity then it would be inadvisable to rely on parental consent. In such cases, legal advice should be sought and an application made to the relevant court, if necessary on an emergency basis. See, further, the 2009 DOH guidance concerning treatment decisions relating to children.²⁴²

Emergency treatment

- 5.145 If there is no other lawful basis on which to give the treatment and if the failure to treat is likely to lead to the child or young person's death or to severe injury, it may be possible to treat without consent or formal authorisation.²⁴³ In this context, the 2009 DOH guidance concerning treatment decisions relating to children²⁴⁴ advises:

A life-threatening emergency may arise when consultation with either a person with parental responsibility or the court is impossible, or the person with parental responsibility refuses consent despite such emergency treatment appearing to be in the best interests of the child. In such cases, the courts have stated that doubt should be resolved in favour of the preservation of life, and it will be acceptable to undertake treatment to preserve life or prevent serious damage to health.

Palliative care

- 5.146 A group of disabled children whose needs must be given the highest priority are those with life-limiting conditions who require palliative care services. In accordance with Standard 8 of the Children's NSF, high quality palliative care services should be available for all children

241 See, for example, *Re P (a child)* [2014] EWHC 1650 (Fam); [2014] Fam Law 1249, where the court granted a declaration overriding the wishes of a 17-year-old girl who had refused to consent to urgent life-saving treatment following a drug overdose.

242 DOH, *Reference guide to consent for examination or treatment*, 2nd edn, 2009, pp34–35.

243 In the mental health context, see the MHA Code at paras 19.71–19.72. The MHA Code suggests: 'If the failure to treat the child or young person would be likely to lead to their death or to severe permanent injury, treatment may be given without their consent, even if this means overriding their refusal when they have the competence (children) or the capacity (young people and those with parental responsibility), to make this treatment decision.'

244 DOH, *Reference guide to consent for examination or treatment*, 2nd edn, 2009, p35, para 18. This guidance is relevant to all under 18s.

and young people who need them. As with CAMHS, there is no specific statutory basis for palliative care services, which are provided under the NHS Acts. Palliative care provision for children has been criticised. A 2011 DOH report, for example, found that although children and families overwhelmingly wanted a child in the terminal phase of an illness to die at home, 74 per cent of children requiring palliative care died in hospital.²⁴⁵

5.147 Since the publication of the Children's NSF in England, local authorities, CCGs and NHS Trusts have been required to ensure that:

- palliative care services provide high quality, sensitive support that takes account of the physical, emotional and practical needs of the child and their family, including siblings. Services are sensitive to the cultural and spiritual needs of the child and family;
- services maximise choice, independence and creativity to promote quality of life;
- services are delivered where the child and family want;
- services include the prompt availability of equipment to support care, access to appropriate translation services, and workers skilled in using communication aids;
- services are regularly reviewed with parents or carers, children and young people, and gaps in provision identified and addressed;
- services are planned in partnership with voluntary sector providers and children and young people's hospices in localities where these exist;
- provision of services includes, where appropriate:
 - a) 24-hour access to expertise in paediatric and family care (often provided by local community children and young people's services to enable continuity of care);
 - b) 24-hour expertise in paediatric palliative care (provided by those with specialist palliative care training);
 - c) pain and symptom control;
 - d) psychological and social support;
 - e) spiritual support which takes account of the needs of the whole family;
 - f) where required, formal counselling or therapy;
 - g) arrangements to avoid unnecessary emergency admission to hospital;
 - h) protocols for immediate access to hospital, if needed; and
 - i) a process for keeping the general practitioner informed.²⁴⁶

245 DOH, *NHS at Home: Community children's nursing services*, 2011, p31.

246 Disabled Child Standard, Children's NSF, pp33–34.

- 5.148 In recognition of the ongoing problems in children's palliative care, the government strategy document *Better care: better lives*²⁴⁷ provides best practice guidance on children's palliative care services in England. The vision of the guidance is that every child with a life-limiting and life-threatening condition has equitable access to high quality, family-centred care with services built around a philosophy of 'children first'.²⁴⁸ In order to achieve this, the guidance requires a fully integrated approach among key delivery partners and for all services to be designed around the needs of children and their families.²⁴⁹
- 5.149 The guidance recognises that all children need to experience life as a child and as such all children with palliative care needs should have equal access to universal and generic services. These universal services should also be able to inform children and their families about what other support is available and work in partnership to ensure support is timely, accessible and effective. A flexible approach should be adopted with recognition that traditional methods of service delivery may need to be reviewed and, in some cases, services may have to be taken to the child.²⁵⁰ To achieve this, there should be joint assessment and planning, joint funding or aligned budgets and an agreed decision-making formula such as the decision support tool in the National Framework for the Assessment of Children's Continuing Care (see para 5.91 above).²⁵¹
- 5.150 The guidance also aims to ensure that all children have a choice of location of care, 24-hour access to multidisciplinary community teams and, when needed, specialist care advice and services.²⁵² The independent review of children's palliative care services demonstrated that there is an overreliance on hospital-based care and that there needs to be an increased amount of community-based support through the use of multidisciplinary children's community teams.²⁵³ Access to specialist end of life care is highlighted as a key component of palliative care services. At this stage families need access to the multidisciplinary community team working seven days a week as

247 DOH, *Better care: better lives: improving outcomes and experiences for children and young people and their families living with life-limiting and life-threatening conditions*, 2009.

248 *Better care: better lives*, p11.

249 *Better care: better lives*, p12.

250 *Better care: better lives*, p26.

251 *Continuing Care Framework*, p13.

252 *Better care: better lives*, p30.

253 *Better care: better lives*, p31.

well as 24-hour specialist support and advice and specialist psychological, emotional and spiritual care and bereavement support.²⁵⁴

5.151 Co-ordination of transition between children's and adult services is as critical in palliative care as in every other aspect of disabled children's service provision. A transition support worker or named key worker should ideally be identified for each young person to oversee their transition, ensuring links with a counterpart within the receiving adult service.²⁵⁵ Concerns have been raised about young adults being able to access services during the transition period,²⁵⁶ although the Choice in End of Life Care Programme Board has now been commissioned to provide advice to the government on the quality and experience of end of life care.

5.152 In December 2016, the National Institute for Health and Care Excellence (NICE) developed the first Guidelines on *End of life care for children and young people with life-limiting conditions*, setting out recommendations about what children and families should expect to receive from the point at which their needs are identified until the end of their lives. This includes around bereavement support, highlighting the need to discuss and plan in advance the arrangements that may be needed and ensuring parents and carers can access that support both before and after the death of a child and young person.

5.153 The associated NICE Quality Standard consists of six quality statements, with the aim of helping those who provide palliative care for children and their families to: identify gaps and areas for improvement; measure the quality of care; understand how to improve care; and demonstrate they are providing quality care.²⁵⁷

5.154 In July 2016, the DOH published its response to the Independent Review of Choice in End of Life Care ('the Choice Review').²⁵⁸ The government's response to the Choice Review²⁵⁹ included a 'note on palliative and end of life care for children and young people', which stated that:

254 *Better care: better lives*, p33.

255 *Better care: better lives*, p40.

256 *Report of the Long Term Conditions, Disability and Palliative Care Sub-Group*, Children and Young People's Health Outcomes Forum, 2012; *Making a Difference for Young Adult Patients – Research Briefing*, York University, 2013.

257 National Institute for Health and Care Excellence, *End of life care for infants, children and young people with life-limiting conditions: Quality Standard [QS160] 2017*.

258 The Choice in End of Life Care Programme Board, *What's important to me: A Review of Choice in End of Life Care*, February 2015.

259 DOH, *Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care*, July 2016.

It is essential that the voices of children and young people are heard so that they are involved in their care, able to express their needs and preferences and make informed choices about their care.

- 5.155 In September 2017, the DOH published a further report setting out the progress of its response to the Choice Review, one year on.²⁶⁰ The DOH confirmed that NHS England is working with the children's charity *Together for Short Lives* to promote the implementation of the NICE Guidelines on 'End of life care for children and young people with life-limiting conditions', referred to above at para 5.152. It also confirmed that it is working closely with the Paediatric Bereavement Network as they develop standards for bereavement services in paediatric tertiary centres and guidelines for children bereavement.

Transition from child to adult services

- 5.156 As set out in detail in chapter 10, the guidance (and in some contexts, the legislation) concerning the respective responsibilities of the NHS, social care and other services differ between children's and adult services. By way of example, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care and the supporting guidance only applies to people aged 18 or over. The terms 'continuing care' (in relation to children's services) and 'NHS continuing healthcare' (in relation to adults) also have different meanings, as explained above. It is important that young people and their families are helped to understand this difference and its implications from the start of transition planning. *Transition: moving on well*²⁶¹ sets out good practice for health professionals and their partners in transition planning for young people with complex health needs or disabilities and *A transition guide for all services*²⁶² explains how all relevant services should work together with a young person to identify how they can best support them to help achieve their desired outcomes.

260 DOH, *One Year On: The Government Response to the Review of Choice in End of Life Care*, September 2017.

261 Department for Children Schools and Families/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.

262 Department for Children Schools and Families/DOH, *A transition guide for all services: key information for professionals about the transition process for disabled young people*, 2007.

- 5.157 The Continuing Care Framework states 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 or to a more appropriate specialised or NHS Continuing Healthcare pathway, and that there should be a single key contact for families of a young person approaching transition.²⁶³ The 2014 *From the pond into the sea: Children's transition to adult health services* report sets out the CQC's assessment of transition services. Unfortunately, the report found that there is a significant difference between policy and practice, with many young people falling between the gaps of child and adult service provision.²⁶⁴
- 5.158 The SEND Code sets out general guidance about what children and young people are entitled to when they transition to adult health services:
- Health service and other professionals should work with the young person and, where appropriate, the young person's family.
 - Health professionals should gain a good understanding of the young person's individual needs, including his or her learning difficulties or disabilities, to co-ordinate health care around those needs and to ensure continuity and best outcomes for the young person. This means working with the young person to develop a transition plan, which identifies who will take the lead in co-ordinating care and referrals to other services.
 - The young person should know who is taking the lead and how to contact them.
 - The CCG must co-operate with the local authority in supporting the transition to adult services and must jointly commission services that will help to meet the EHC plan outcomes.
 - In supporting the transition from CAMHS to adult mental health services, CCGs and local authorities should refer to *The Mental Health Action Plan, Closing the Gap: Priorities for Essential Change in Mental Health*.²⁶⁵
- 5.159 Children's continuing care teams should identify those young people for whom it is likely that adult NHS continuing healthcare will be necessary and notify the relevant CCG that will hold adult responsibility for them. Such young people should be identified when they reach the age of 14. This should be followed up by a formal referral

263 *Continuing Care Framework*, paras 113–114.

264 CQC, *From the pond into the sea: children's transition to adult health services*, 2014.

265 DOH, 2014.

for screening at age 16 to the adult NHS continuing healthcare team. By the age of 17, an individual's eligibility for adult NHS continuing healthcare should be decided in principle by the relevant CCG in order that, where applicable, effective packages of care can be commissioned in time for the individual's 18th birthday.²⁶⁶

- 5.160 Entitlement for adult NHS continuing healthcare should initially be established through use of the decision-making process set out in the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. If a young person receiving children's continuing care has been determined by the relevant CCG not to be eligible for adult NHS continuing healthcare, they should be advised of their non-eligibility and of their rights to request an independent review on the same basis as NHS continuing healthcare eligibility decisions regarding adults.²⁶⁷ Even where a young person is not entitled to adult NHS continuing healthcare, they may have some health needs that fall within the responsibilities of the NHS. In such circumstances, CCGs should continue to play a full role in transition planning for the young person.²⁶⁸

- 5.161 Guidance from NHS England²⁶⁹ highlights (at para 88) the abrupt transition at 16 for a child who has previously been receiving health direct payments:

When a child on whose behalf a representative has consented to direct payments reaches 16, the CCG may continue to make direct payments to the representative or their nominee in accordance with the care plan, providing the child who has reached 16 and the representative and, where applicable the nominee, consent. If the child who has reached 16 does not consent the CCG must stop making direct payments. In either case, the CCG must as soon as reasonably possible review the making of direct payments.

- 5.162 There is specific guidance relating to the transition from children's to adult health services in different service areas. For example, guidance on the transition from CAMHS to adult mental health services can be found in the MHA Code of Practice.²⁷⁰
- 5.163 Further information on the issues for disabled young people in transition to adult health services can be found in chapter 10.

266 *Continuing Care Framework*, paras 118–120.

267 *Continuing Care Framework*, para 122.

268 *Continuing Care Framework*, para 124.

269 NHS England, *Guidance on Direct Payments for Healthcare: Understanding the Regulations*, March 2014, at para 88.

270 *Mental Health Act 1983: Code of Practice*, paras 19.119–18.120.

