Landmark Chambers Guide to NHS Continuing Care for Children in England[1]

Introduction

1. The rules relating to adults who are entitled to NHS Continuing Healthcare (**CHC**) and the statutory defined decision-making process to determine CHC eligibility for adults in need of care are set out in the separate guide; those rules only apply to adults (namely, persons over the age of 18). The position relating to children who need a level of health and social care support greater than that which can be provided by general services (ie those services available universally) commissioned by an integrated care board (**ICB**) or NHS England is subject to an entirely separate non-statutory decision-making process, as set out in the guidance *National Framework for Children and Young People's Continuing Care 2016*[2] (**CC guidance**). This guidance was issued in 2016 when the local NHS commissioning bodies were clinical commissioning groups (**CCGs**). It has not been reissued following the abolition of CCGs and their replacement with ICBs.[3] The guidance now needs to be read as if each reference to a CCG were a reference to the relevant ICB with commissioning responsibility for the child.

Who can be a 'child' or 'young person' under the CC guidance?

2. The nomenclature used in the CC guidance is potentially confusing because it refers separately to 'children' and 'young persons' but neither term is defined. The standard definition of the meaning of the term 'child' in legislation is in s105 Children Act 1989, which defines a child as a person under the age of 18. There is

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[2] See https://assets.publishing.service.gov.uk/media/5a80e998ed915d74e623126b/children_s_continuing_care_Fe_16.pdf.

[3] This chapter will refer to services being commissioned by an ICB. It is possible that some services for a disabled child will be commissioned by NHS England. Even where this is the case, where a child needs additional services, the package of additional services will need to be jointly funded by the relevant local authority and the ICB, not by NHS England.

a like meaning of the term ‘child’ in the Civil Procedure Rules[4] (**CPR**) (see CPR 21.1) and in the Family Procedure Rules[5] (**FPR**) (see FPR 2.35). Whilst there is no specific definition of the meaning of the term ‘child’ in Part 3 Children and Families Act 2014 (**CFA 2014**), the term ‘child’ is generally taken to refer to a person under the age of 18. In contrast, the CFA 2014 defines a ‘young person’ as a person ‘over compulsory school age but under 25’.[6] Thus a 16- or 17-year-old, who may be above the age of compulsory school age,[7] can be both a ‘*young person*’ and a child for the purposes of the CFA 2014. In contrast, a 23-year-old will no longer be a child but will still be a relevant ‘*young person*’ for the purposes of the CFA 2014.

3. The definitions under the CFA 2014 are not applied in the same way in the CC guidance. The CC guidance is only intended to apply to ‘*children and young persons*’ up to their 18th birthdays (see paras 1 and 5). Accordingly (and potentially confusingly), young people between the ages of 19 and 24 are ‘*young persons*’ for the purposes of the CFA 2014 but cannot be young persons for the purposes of the CC guidance. For the purposes of this chapter, we have sought to avoid this confusion by referring to a ‘*child*’ as a person under the age of 18. We have discarded entirely the term ‘*young person*’ when referring to the CC guidance because, within the meaning of the guidance, that term adds nothing because the CC guidance is only relevant to a young person who is also a child for the purposes of all the relevant statutory schemes, namely the CPR, the FPR and the Children Act 1989; it excludes all young persons who are not children.

The term ‘a child who requires care services’

4. In this Guide we have used the general term ‘*a child who requires care services*’ to mean a child who has a medical condition arising from an illness, accident or any other cause which leads to a need for a level of NHS or social care services over an extended period (that being the beginning of the test under the CC guidance). Any such child is highly likely to be classified as having a disability within the meaning of the Equality Act 2010 (**EA 2010**), although it is theoretically possible (although highly unlikely in practice) that a child who requires care services could

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[4] 1998 SI No 3132.

[5] 2010 SI No 2955.

[6] See s83 CFA 2014.

[7] See s8 Education Act 1996.

have such a medical condition (as a result of an accident or an illness) that is not of such severity or length, which means the child does not have a disability within the terms of the EA 2010.[8] However, irrespective as to whether a child who requires care services has a disability under the EA 2010, such a child may nonetheless be eligible for support under the CC guidance.

When is a child who requires NHS services eligible for a package of continuing care under the CC guidance?

5. The CC guidance is concerned with the provision of NHS and social care services for children who have a need for health or social care support which cannot be met by the NHS and social care services that are available generally to ill or disabled children. The CC guidance explains that a 'continuing care' package for a child or young person should be set up if the following test is met:

> *"A continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone"*

6. The 'services' referred to in this test will cover NHS services, social care services and educational services. Hence a child who requires care services may be eligible for a continuing care package if they have a need which cannot be met by existing universal or specialist NHS, social care or educational services. The CC guidance only applies to children and explains that, as the child reaches the age of 18, services will have to migrate to adult services, namely NHS services under the NHS CHC model (if the child is eligible, as explained in chapter 16) and/or adult social care services. The CC guidance states at para 5:

> *"This framework covers young people up to their 18th birthday. Thereafter, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care and the supporting guidance and tools should be used. There are significant differences between children and young people's continuing care and NHS Continuing Healthcare for adults. Although a child or young person may be in receipt of a package of continuing care, they may not be*

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[8] However, given the wide definitions of a 'disability' within s6 and Sch 1 EA 2010, there must be very few children who are within the scope of the CC guidance but do not have a disability within the terms of the EA 2010.

eligible for NHS Continuing Healthcare or NHS-funded Nursing Care once they turn 18. Further information on how to support transition is given below"

The relationship between the CC guidance and education, health and care plans under the CFA 2014.

7. There can be a significant potential overlap between the non-statutory processes operated by the NHS and local authorities to put in place appropriate packages for support for children who require NHS services and the statutory education, health and care (**EHC**) plan processes required by the CFA 2014 for children who have special educational needs (**SEN**). Part 3 of the CFA 2014 is headed 'Children and young people in England with SEN or disabilities'. Although this Part sets out legal duties that are owed where a child has SEN, defined to include a disability,[9] it does not provide a comprehensive framework for making decisions on support packages for disabled children who require NHS services, because its primary focus is ensuring that such children have the support they need to enable them to access appropriate educational provision. This is because an SEN is only a need which calls for special educational provision, and special educational provision is provision which is educational or training provision.[10] Thus, NHS and social care bodies will need to provide a range of services to support such children that extend beyond those described in EHC plans.

Categories of children who require care services

8. As there is a considerable overlap between the duties owed by a local authority and the ICB under the CFA 2014 and the duties owed to children who require care services under the CC guidance, it may be helpful to classify such children into three different categories:

   (a) **Category 1:** Children who require care services and who (a) do not have an EHC plan and (b) do not need services beyond those that can be met by existing universal or specialist NHS services;

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[9] Section 20(1) of the CFA 2014.

[10] Sections 20(1) and 21(1) and (5) of the CFA 2014.

(b) **Category 2:** Children who require care services and who (a) have an EHC plan and (b) may need services beyond those that can be met by existing universal or specialist NHS services; and

(c) **Category 3:** Children who require care services and who (a) do not have an EHC plan and (b) may need services beyond those that can be met by existing universal or specialist NHS services.

Category 1: Children who (a) do not have an EHC plan and (b) do not need services beyond those that can be met by existing universal or specialist NHS services.

9. The vast majority of children living in England come within this category, regardless of the extent of their health needs. Where a child has health needs that can adequately be met by a combination of GP services, district nurses and hospital-based staff, they will fall outside the scope of the CC guidance.

10. Paragraph 55 of the CC guidance stresses that an assessment should be carried out if '*a child or young person may*[11] *have needs that require additional health service*'. The ICB should therefore proceed to undertake an assessment if there is any real possibility that a child has needs that are beyond universal or specialist NHS and/or social care services. Further, the CC guidance suggests that this decision should be taken quickly. Paragraph 63 provides:

> *"A decision on whether or not a child should proceed to a formal assessment has to be made quickly, and must be robust, fully documented and where necessary, agreed with the responsible executive in the CCG (an alternative might see such a decision delegated to a relevant member of staff). This pre-assessment should not take more than a day or two – and it is likely that a relatively quick paper-based assessment will give a suitable indication if a child or young person should proceed to a full assessment"*

11. However, if either the assessment concludes that such a child does not have needs that cannot be met by universal or specialist NHS services or the ICB decides that no assessment is needed, there are no further steps which need to

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[11] The threshold test is low as explained in the CHC chapter where the same language is used: see chapter 16 at para 16.58 and the discussion on *R v Bristol City Council ex p Penfold* (1997–98) 1 CCLR 315, QBD.

be taken beyond ensuring that the child continues to have access to universal and/or specialist NHS services.

Category 2: Children who have an EHC plan and may need NHS services beyond those that can be met by existing universal or specialist NHS services.

12. The CC guidance recognises that many children with complex healthcare needs will also have SEN. It provides at para 15:

> *"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"*

13. The CC guidance recommends that the continuing care process and the SEN process should be brought together in a single process. It provides at paras 22 and 23:

> *"22. Given the elements common to both the EHC plan assessment, and the continuing care process commissioners and local authorities should consider how the two processes can be brought together, to articulate a single set of needs and outcomes. There are many children and young people with special educational needs or disability without a continuing care need, and their health needs should of course be reflected in the EHC plan.*
>
> *23. Local authorities and CCGs must work together to make EHC plans work, and their joint arrangements should include an agreement as to how continuing care fits with the EHC process. Although the processes are different, the same information and professionals across disciplines should be involved, in order to result in a coherent package of care across health, education and social care for children and young people who are eligible for continuing care"*

14. Whilst ICBs and local authorities are not legally required to have a single needs assessment process for children, given the strong guidance above, as well as the duty on the local authority to co-operate with NHS bodies in exercising its

functions under the CFA 2014,[12] an ICB and a local authority would need to have formulated clear reasons why they were choosing to depart from the recommended course of having a single needs assessment process.

15. The CC guidance can be divided up into six separate stages[13] that an ICB and its partner local authority should follow where a disabled child may have a need for a continuing care package of support, namely:

    (a) **Stage 1**: The ICB and the local authority both have duties to identify any child who may be disabled or may require care services for whom the ICB and/or the local authority have commissioning responsibility;

    (b) **Stage 2**: The ICB has to undertake an assessment process to determine any such child's needs and to make a recommendation as to whether the child has a need for NHS and social care services that are greater than universal and/or specialist services;

    (c) **Stage 3:** The ICB and the local authority have to work together to follow a decision-making process through a multi-agency forum to make a decision whether the child has a need for services which are greater than universal and/or specialist NHS and social care services (ie whether the child had a need for a continuing care package of support);

    (d) **Stage 4**: If the multi-agency meeting decides that the child has a continuing care need, the ICB and the local authority together are required to commission and fund a package of NHS, social care and educational services designed to the meet the child's eligible needs;

    (e) **Stage 5:** Where a continuing care package is in place, the ICB and the local authority then have to regularly review and reassess the package of services to ensure that it is continuing to meet the eligible needs of the child;

    (f) **Stage 6**: As the child approaches the age of 18, the ICB and the local authority must engage in transition care planning, including an assessment of the

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[12] Section 28 of the CFA 2014.

[13] These stages seem to the authors to be the real stages in a decision-making process. The CC guidance describes extra stages but they do not appear to the authors to be significant.

child’s entitlement to adult CHC or funded nursing care, in order to ensure that the young person’s needs are appropriately met once they reach the age of 18.

Stage 1: Identifying relevant children and young people

16. The CC guidance explains the importance of the ICB and local authority proactively seeking to identify children who may require NHS services beyond those universally provided. Section 22 of the CFA 2014 provides that a local authority ‘*must exercise its functions with a view to securing that it identifies … all the children and young people in its area who have a disability*’.[14] Hence, there is a positive duty on each local authority to identify all disabled children in the local authority area. There is also a duty on each ICB, each NHS trust and each NHS foundation trust to inform the relevant local authority if that NHS body ‘form[s] the opinion that the child has (or probably has) special educational needs or a disability’.

17. If the local authority considers that the child may have SEN, the local authority has a duty to assess the educational, healthcare and social care needs of the child: see s36 CFA 2014. As the CC guidance recognises, many disabled children will also have SEN, but some disabled children may be able to be supported within the provision ordinarily available in mainstream schools and therefore would not need an EHC plan. Such children may, nonetheless, have substantial health or social care needs.

18. In order to identify children who are or may be disabled or have a need for care services, the ICB will need to seek information about the child, usually from their parents. Paragraphs 55–67 of the CC guidance refer to the importance of seeking consent from the child or their parents in order to undertake this identification process. Consent can be sought from the child in the case of a child who has *Gillick* competency[15] or the parents in the case of a child who lacks *Gillick*

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[14] A child or young person has a disability for the purposes of Part 3 CFA 2014 if they have a disability for the purposes of the EA 2010. Disability is defined in s6 EA 2010 as having a physical or mental impairment which has substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities. There are supplementary provisions about the meaning of a disability in Sch 1 EA 2010.

[15] Namely, the right of the child to make their own medical treatment decisions based on the maturity and level of understanding of the child, as explained in *Gillick v West Norfolk and*

competency. Following *AB v CD and others*,[16] the law seems reasonably clear that the fact that a child may gain competency does not remove all parental rights to consent, but does mean that such rights cannot be exercised so as to override any refusal of consent by the child. Thus, unless the child objects, consent can be sought from parents even if the child has *Gillick* competency. Further, where a child is living in their parent's accommodation, the support of the parents is almost always practically essential if any package is to be delivered to benefit the child.

19. There can be cases where an ICB is concerned that a child has health or care needs which mean that it would be in the best interests of the child to have a package of support, but where the parents are blocking the provision of any support by refusing to engage with the assessment process or are otherwise preventing the ICB or the local authority delivering support to the child. ICBs should seek legal advice in such circumstances because, absent any form of negotiated way forward, the ICB or the local authority may need to apply to the High Court to exercise its *parens patriae* powers under the inherent jurisdiction so as to require the parents to accept a care package or other medical support for the child.[17] Alternatively, a local authority may need to consider whether to exercise its powers under the Children Act 1989 by inviting the court to make a care order for the child.

Stage 2: Undertaking an assessment process to determine the child's needs

20. Having identified a child who may be entitled to continuing care support, and after obtaining appropriate consent, a children's health assessor nominated by the ICB should lead the assessment phase of the continuing care process on behalf of the ICB and the local authority.[18] Details about who the assessor should be and how

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Wisbech AHA [1986] AC 112, HL and in *AB v CD and others* [2021] EWHC 741 (Fam). *AB v CD* was approved by the Court of Appeal in *Bell another v Tavistock and Portman NHS Foundation Trust* [2021] EWCA Civ 1363.

[16] [2021] EWHC 741 (Fam).

[17] The authors have been involved in such cases and, to say the least, they are complex to navigate, especially where the parents have property rights in the family home and are refusing access. However, the High Court does have the power to enforce a package of support by way of injunctions following *Re G (Court of Protection: Injunction)* [2022] EWCA Civ 1312. That case concerned a Court of Protection case, but the reasoning must apply equally to a case in the inherent jurisdiction of the High Court.

[18] See CC guidance at para 68.

the assessor should collate evidence from multiple different sources is set out at paras 68–78 of the CC guidance.

21. There are four recommended ‘Areas of Assessment’ identified in the CC guidance, as follows:

> ***“The Four Areas of Assessment***
>
> ***1. The preferences of the child or young person and their family***
> *The child or young person and their family should be supported to be partners in the assessment process; this might include siblings and any family members involved in supporting the child or young person. Care is often highly invasive of the family home and the preferences of all family members should be sought as far as possible. This area corresponds to section A in the Education, Health and Care plan, which captures the views, interests and aspirations of the child or young person, and their parents.*
>
> ***2. Holistic assessment of the child or young person***
> *The nominated children and young person’s health assessor undertakes a health assessment, collating existing assessments, including for social care. Where social and educational assessments have not been undertaken, the assessor should liaise with the appropriate professionals.*
> *The health needs of other family members and the proposed environment of care should also be considered. The Decision Support Tool for children and young people provides some prompts to help shape this part of the assessment.*
>
> ***3. Reports and risk assessments from the professionals in the child’s multidisciplinary team***
> *The nominated children and young people’s health assessor is responsible for collating the evidence from professionals who are involved in the care of the child or young person (across health, social and education), particularly risks assessments and reports. There may also be a need to commission healthcare risk assessments that have not already been undertaken. As in all elements of the assessment, the health assessor may need to get expert advice on this, and is not expected to act as a specialist in all areas of the*

> *child or young person's care. This again is similar to the co-ordinated assessment of the EHC process. In many cases, the assessor will be able to receive a written report and / or risk assessment from the relevant professionals based on their notes (and often, a copy of the relevant section of the notes will suffice).*
>
> ***4. The Decision Support Tool for children and young people***
> *The fourth area provides a means of making a summative judgement of a child or young person's needs, drawing on evidence from the other parts of the assessment. It is not a stand-alone tool and is designed to ensure that relevant needs are assessed, captured and described in a consistent way"*

22. The CC guidance has a specific Children's Continuing Care Decision Support Tool (**CCC DST**), which is separate from the DST used for CHC applications. However, unlike the CHC process, the outcome of the CCC DST is only part of the overall assessment process and does not have the centrality that the DST has within CHC assessments.

23. The CCC DST is at Part 3 of the CC guidance. It is similar in structure to the CHC DST, but is tailored to the needs of children and young people. The CC guidance explains at paras 133 and 134:

> *"133. The Decision Support Tool sets out children's needs across 10 care domains, divided into different levels of need:*
>
> - *breathing*
> - *eating and drinking*
> - *mobility*
> - *continence and elimination*
> - *skin and tissue viability*
> - *communication*
> - *drug therapies and medicines*
> - *psychological and emotional needs*
> - *seizures*
> - *challenging behaviour*

> *134. The nominated children and young people's health assessors will use their clinical skill, expertise and evidence-based professional judgement to consider what, for each care domain, is over and above what would be expected for a child or young person of that age. For example, incontinence would only become recognised as an issue when a child or young person has continence needs beyond those typical for their age"*

24. However, the CC guidance recognises that there may be needs that arises outside these domains which need to be taken into consideration. It states at paras 136 and 137:

> *"136. There may be circumstances where a child or young person may have particular needs which do not fall within the 10 care domains described in the Tool (an example might be a child who is unable to regulate their body temperature, or who has an unstable cardiac condition). Information on these needs should of course be included as evidence in the assessment if considered significant, usually drawn from risk assessments or professional reports. Some significant health needs may not of course result in a need for continuing care, if they are already supported by outpatient or other services routinely commissioned.*
>
> *137. The assessment of the level of need must recognise that where a child or young person requires constant supervision or care which is largely provided by family members, there will be a need for professional support to allow the family time off from their caring responsibilities, and this may require a social care assessment, and agreement, between the CCG and the local authority (which is usually the commissioner of respite care), of the respective contribution"*

25. The assessment process is required to produce a recommendation as to whether the child has needs '*arising from disability, accident or illness that cannot be met by existing universal or specialist services alone*'. There is guidance about scoring the CCC DST at paras 144–151 of the CC guidance, of which the key paragraph is para 148, which provides:

> *“A child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in three domains of care”*

Stage 3: Decision-making process in a multi-agency forum to decide whether the child or young person has a continuing care need.

26. The decision-making process under the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012[19] (‘**RSR Regs 2012**’) provides that a decision whether an adult is eligible for CHC is to be taken by the ICB alone.[20] That is understandable because the ICB has sole responsibility[21] for funding a care package for any adult who is eligible for CHC. The position is different for children because any package is required to be funded by a combination of the ICB and the local authority, with relative levels of contribution depending on the precise needs of the child. The CC guidance thus provides that the decision as to whether a child is eligible for a package of continuing care support should be taken by a ‘*multi-agency forum or panel*’.[22]

27. The CC guidance does not provide any detail about how ICBs and local authorities are recommended to work together to set up decision-making panels for children’s continuing care cases. ICBs and local authorities thus have considerable discretion to decide how to set up local panel or committee arrangements that work for them (but it is likely to be unlawful not to have any joint decision-making arrangements). The key decision that the local joint ICB/local authority panel or committee has to make is whether the child has ‘*needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone*’.[23] If the child has such needs, the CC guidance recommends that the ICB and local authority are required to accept that the child should be provided with a continuing care package. If that point is reached, the next step is to for the ICB and the local authority to plan how jointly to commission services to meet those needs. Section 26 of the CFA 2014 places a

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[19] SI No 2996.

[20] Albeit that local authority colleagues can be invited to be part of the CHC decision-making panel.

[21] There will be occasional CHC packages that are funded by NHS England as opposed to being funded by an ICB, including, for example, packages of care for disabled armed forces personnel.

[22] See CC guidance at para 10.

[23] This is the test in para 1 of the CC guidance.

duty on the local authority and partner NHS commissioning bodies to make joint commissioning arrangements in respect of children who have SEN or a disability.

Stage 4: Commissioning and funding a package of care to the meet the child or young person's needs

28. If a decision is made that the child has care needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone, the ICB and the local authority have to work together to commission and fund a package of services to meet those needs. Such a child may need a range of health and social care services, but there are limits on the type of specifically medical services that can be lawfully provided by a local authority.

29. The CC guidance provides the following at para 100 concerning the areas that should be covered as part of any commissioning process:

> *"100. Care planning should begin early, consider discharge needs where appropriate, and be simplified to enable community-based services to provide home-based care wherever possible. Planning of the package of care should consider:*
>
> - *the skill mix of staff (e.g. the complement of nurses/carers within the package), since this is a critical aspect of the care package in terms of quality and outcomes;*
> - *how continuing care integrates with SEND provision, and universal and specialist health provision;*
> - *sustainability and long-term outcomes (see below for transition);*
> - *a multi-professional approach, rather than one which focuses on venues of care;*
> - *the child or young person's home as the focus of care;*
> - *out of hours support;*
> - *staff competency and training of parents, staff and foster carers (including training costs);*
> - *equipment.*

30. However, although the essence of a continuing care package is a jointly commissioned package between an ICB and a local authority, both the ICB and

the local authority must carefully bear in mind the limits on the *vires* of local authorities to commission medical services. The dividing line between care that a local authority can and cannot lawfully provide was discussed in *R v North and East Devon HA ex p Coughlan*[24] and is now, to an extent, codified in s22 Care Act 2014 and in reg 22(7) RSR Regs 2012. This issue is discussed in detail in chapter 16 on NHS CHC at paras 16.119 to 124 onwards for adults, and it appears that largely the same division should be applied between NHS and social care services for children as for adults. The divide between NHS and social care services was specifically considered in the context of disabled children by Mr Justice Ouseley in *R (T and others) v Haringey LBC and another*.[25] The judge said at para 60:

> *"I accept, first, that there is a broad distinction to be drawn between health and social care provision which illustrates the true interpretation of those provisions. It does so even though there may be an overlap between the two in any given case. The discussion in Coughlan is helpful as to the indicators relevant here: the provisions of the Children Act are not to be regarded in general as reducing or replacing the important public obligations, with their qualifications and their target nature, set out in the 1977 NHS Act"*[26]

31. A key finding in that case is at para 70, where the judge said:

> *"The fact that a need has been assessed by the local authority pursuant to Schedule 2 paragraph 1*[27] *does not create a duty on the local authority to meet that need. The task of assessment involved looking at the whole spectrum of needs, social, health, educational and others, which could not properly then fall upon the social services authority. The assessment of the child's needs, which has to be comprehensive, can properly include the availability of medical provision under the provision of the NHS Act. I reject the suggestion of Mr Bowen that the local authority was the 'default provider' for those needs which it assessed, even those which fell primarily into the province of other bodies, but which those others might not meet"*

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[24] [2001] QB 213, CA.

[25] [2005] EWHC 2235 (Admin). Annex C to the CC guidance summarises the findings in that case.

[26] Now the NHSA 2006.

[27] Of the Children Act 1989.

32. It follows that, when planning a joint package for a child (absent funding coming from a joint fund established under s75 National Health Service Act 2006 (**NHSA 2006**)), the ICB needs to be mindful of the need to identify any services which cannot lawfully be provided by the local authority, and thus cannot be commissioned or paid for by the local authority. Those services will include services that need to be delivered by a registered nurse or fall within s22 Care Act 2014 which, although that section does not directly apply to children's services, identifies those services that are sufficiently medical that they lie beyond the *vires* of a local authority.

33. Aside from cases where the child has medical needs which can only be funded by the NHS, a continuing care package will contain elements of services that can either wholly or very substantially be lawfully commissioned by either a local authority or an ICB, as both would lawfully be able to fund the services. Many local authorities and ICBs have set up pooled funds under s75 NHSA 2006 to meet the costs of children's packages. In such a case the entire package will be funded from the pooled fund. In other cases, the ICB and the local authority will have to agree a division between them of the cost of the services to be provided to the child and their family.

34. However, when undertaking planning for services to meet the needs of children who are eligible for a continuing care package, an important qualification was identified in *R (T and others) v Haringey LBC and another*,[28] namely that the existence of a 'need' for a service does not impose any form of absolute duty on the ICB to meet that need. NHS-funded care services for children as part of a continuing care package are services by NHS bodies delivered under the target duty imposed by s3 NHSA 2006, and accordingly they are subject to the general limitations on all NHS services, namely that the ICB is undertaking a resources-based rationing decision and does not have an absolute obligation to provide a service to meet every need. It follows that, where the ICB undertakes a care planning process, it also has to perform a lawful administrative exercise in coming to decisions about what services to provide. If the ICB fails properly to understand the medical evidence, any decision to limit the extent of a care package based on

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[28] [2005] EWHC 2235 (Admin).

that misunderstanding could be quashed in a judicial review: see *R (Juttla) v Hertfordshire Valleys Clinical Commissioning Group and others*.[29]

35. Where a child has an EHC plan, any health or social care provision which educates or trains a child is special educational provision. If it is reasonably required[30] (which is a judgment for the local authority, and a tribunal on appeal), then the local authority is under a mandatory duty to secure that provision.[31]

36. Health or social care provision that does not educate or train the child, but which is reasonably required by the child's SEN, should also be included in the EHC plan:

> *"(d) any health care provision reasonably required by the learning difficulties and disabilities which result in him or her having special educational needs;*
>
> *(e) in the case of a child or a young person aged under 18, any social care provision which must be made for him or her by the local authority as a result of section 2 of the Chronically Sick and Disabled Persons Act 1970; …*
>
> *(f) any social care provision reasonably required by the learning difficulties and disabilities which result in the child or young person having special educational needs, to the extent that the provision is not already specified in the plan under paragraph (e)"*[32]

37. The SEN Code of Practice explains how health services should be provided to SEN children and their families, as follows:

> ***"Health services for children and young people with SEN and disabilities and their families***
>
> *3.59 Health services for children and young people with SEN or disabilities provide early identification, assessment and diagnosis, intervention and*

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[29] [2018] EWHC 267 (Admin).

[30] *A v Hertfordshire CC* [2006] EWHC 3428 (Admin) at para 25.

[31] Section 42 of the CFA 2014.

[32] Section 37(2) of the CFA 2014.

review for children and young people with long-term conditions and disabilities, for example chronic fatigue syndrome, anxiety disorders or life-threatening conditions such as inoperable heart disease. Services are delivered by health professionals including paediatricians, psychiatrists, nurses and allied health professionals such as occupational therapists, speech and language therapists, habilitation trainers, physiotherapists and psychologists. In addition, public health services for children ensure a whole population approach to health and wellbeing including preventative services such as immunisation for the whole population and targeted immunisation for the most vulnerable.

3.60 Health services support early identification of young children who may have SEN, through neonatal screening programmes, the Healthy Child Programme, and specialist health and developmental assessment where concerns have been raised. Community paediatricians in conjunction with other health professionals, particularly therapists, are often the first people to notify young children with SEN to local authorities. They provide diagnostic services and health reports for EHC needs assessments. CCGs, NHS Trusts, and NHS Foundation Trusts must inform the appropriate local authority if they identify a child under compulsory school age as having, or probably having, a disability or SEN (Section 23 of the Children and Families Act 2014).

3.61 The multi-disciplinary child health team, including paediatricians, therapists, clinical psychologists, dieticians and specialist nurses such as health visitors, school nurses and community children's nursing teams, provide intervention and review for children and young people with SEN and disabilities and should contribute to supporting key transition points, including to adulthood. They aim to provide optimum health care for the children, addressing the impact of their conditions, managing consequences for the families and preventing further complications.

3.62 Health professionals advise education services on managing health conditions such as epilepsy and diabetes, and health technologies such as tube feeding, tracheostomy care and ventilation in schools. They are able to provide an ongoing overview of health and wellbeing. They seek advice from

> *paediatric specialists when necessary and facilitate training for education staff.*
>
> *3.63 Therapists have important and specific roles in supporting children and young people with SEN or disabilities, working directly with children and young people, advising and training education staff and setting programmes for implementation at home and in school"*

38. Special educational provision, which as explained above includes health or social care provision that educates or trains a child, is set out in section F of an EHC plan. The local authority's mandatory duty to secure applies to this provision. Section C of the EHC plan should list the child or young person's health needs that are related to their SEN, and section D should list the child or young person's social care needs that are related to their SEN or to a disability. Section G should set out the healthcare provision reasonably required, and section H should set out the social care provision reasonably required (this excludes the provision that educates and trains, as that belongs in section F).[33]

39. Section 42(3) of the CFA 2014 then provides:

> *"If the plan specifies health care provision, the responsible commissioning body must arrange the specified health care provision for the child or young person"*

40. If a parent is dissatisfied with the content of the EHC plan, they can appeal to the First-tier Tribunal (**FTT**) in respect of the SEN or a provision set out in the EHC plan.[34] On such an appeal the FTT can make an order in respect of SEN or the provision, and the FTT can effectively rewrite the EHC plan. This includes healthcare provision that educates or trains the child.

41. On such an appeal, a parent can also appeal against the healthcare needs and provision in sections C and G of the EHC plan (ie healthcare provision that does not educate or train). In respect of these sections, the FTT has a power to make recommendations which the responsible commissioning body (usually the ICB,

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[33] Regulation 12 of the Special Educational Needs and Disability Regulations 2014 SI No 1530.

[34] Section 51(2)(c) of the CFA 2014.

which has commissioning responsibility for the child) is under a duty either to implement or to explain in writing why it is not implementing.[35] The responsible commissioning body is mandated to follow the procedure of considering the recommendation rather than under a duty to implement recommended provision.[36] For this reason, there is no right for the responsible commissioning body to be joined as a party to the FTT proceedings.[37]

42. Where a child has a need for health or social care services that go beyond universal services but are not related to the child's SEN provision, the ICB and the local authority are sole decision-makers about the nature and extent of the services to be provided to the child as part of any continuing care package, and that part of the package cannot be the subject of an appeal to the tribunal.

Stage 5: The ICB and the local authority review and reassess the package to ensure that they are continuing to meet the needs of the child or young person.

43. The CC guidance makes it clear that, once a continuing care package is put in place, it should be reviewed regularly by the ICB and the local authority. Paragraphs 105–107 provide:

> *"105. The child or young person's continuing care needs should be reviewed three months after the package of care has commenced, and then annually thereafter, or when a child or young person's health or function is known to have changed. Clearly, if there is a significant change, a full reassessment may be necessary.*
>
> *106. The child or young person and their family should be able to request a review. As with any commissioned service, the CCGs is responsible for regular contract review to ensure that service specifications are being met and that the service being provided is of the required level.*

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[35] Section 51(4) of the CFA 2014 and regs 4–7 Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations 2017 SI No 1306.

[36] *VS and RS v Hampshire CC* [2021] UKUT 187 (AAC) at para 41.

[37] *NHS West Berkshire Clinical Commissioning Group v First-Tier Tribunal (Health, Education and Social Care Chamber)* [2019] UKUT 44 (AAC) at paras 90–96.

> *107. Reviews of a child or young person's continuing care should be an opportunity for assessment of needs and how they are being addressed by the care package. It should be made clear to the child or young person and their family that reviews are designed to ensure that the child or young person's continuing care needs are being met on an ongoing basis and that they are not financially motivated. Where a child or young person has SEND, the continuing care package review, and the regular review of an EHC plan, should ideally be synchronized"*

44. The ICB and the local authority should both involve the child and parents and keep proper records of any review of a continuing care package.

Stage 6: Transition planning as the child approaches the age of 18.

45. As the child approaches the age of 18, the CC guidance recommends that the ICB and the local authority engage in transition care planning, including an assessment of the child's entitlement to adult CHC, in order to ensure that their needs are appropriately met once they reach the age of 18. The CC guidance makes it clear that it cannot be assumed that a child who is eligible for a continuing care package will automatically become eligible for CHC funding. It states at para 5:

> *"This framework covers young people up to their 18th birthday. Thereafter, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care and the supporting guidance and tools should be used.2 There are significant differences between children and young people's continuing care and NHS Continuing Healthcare for adults. Although a child or young person may be in receipt of a package of continuing care, they may not be eligible for NHS Continuing Healthcare or NHS-funded Nursing Care once they turn 18. Further information on how to support transition is given below.*

46. The CC guidance at paras 111–116 explains the steps that should be to transition a child from children's to adult services. The process is summarised at para 117, which provides:

- *At **14** years of age, the young person should be brought to the attention of the CCG as likely to need an assessment for NHS Continuing Healthcare.*
- *At **16-17** years of age, screening for NHS Continuing Healthcare should be undertaken using the adult screening tool, and an agreement in principle that the young person has a primary health need, and is therefore likely to need NHS Continuing Healthcare.*
- *At **18** years of age, full transition to adult NHS Continuing Healthcare or to universal and specialist health services should have been made, except in instances where this is not appropriate.*

47. The process should be relatively straightforward for children found eligible for CHC, with the only major change being that commissioning responsibility will transfer entirely to the ICB. The CC guidance explains the steps that should be taken where a child in receipt of a continuing care package is found not to be eligible for CHC as follows:

> *"122. If a young person who receives children and young people's continuing care has been determined by the relevant CCG*[38] *not to be eligible for a package of NHS Continuing Healthcare in respect of when they reach the age of 18, they should be advised of their non-eligibility and of their right to request an independent review, on the same basis as NHS continuing healthcare eligibility decisions regarding adults. Although these young people will cease to have a 'right to have' a personal health budget, CCGs can continue to offer services via a personal health budget on a discretionary basis, to support the transition to adult services.*
>
> *123. The CCG should continue to participate in the transition process, in order to ensure an appropriate transfer of responsibilities, including consideration of whether they should be commissioning, funding or providing services towards a joint package of care (for example, to deliver an EHC plan). Transition should be planned and agreed with the young person and their family or carers in good time to avoid any disruption or delay to implementing a package of care.*

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[38] References to a CCG should now be read as referring to an ICB.

> *124. Even if a young person is not entitled to adult NHS continuing healthcare, they may have certain health needs that are the responsibility of the NHS. In such circumstances, CCGs should continue to play a full role in transition planning for the young person, and should ensure that appropriate arrangements are in place for services that meet these needs to be commissioned or provided. The focus should always be on the individual's desired outcomes and the support needed to achieve these"*

48. A child in receipt of a continuing care package who is not found to be eligible for CHC may have eligible social care needs, and thus a social care assessment under the Care Act 2014 may be appropriate (albeit those services will be means-tested whereas NHS services are free at the point of use).

Category 3: Children who require NHS services and who (a) do not have an EHC plan and (b) need services beyond those that can be met by existing universal or specialist NHS services.

49. Where a child does not have an EHC plan because they do not have SEN, all of the above steps identified for Category 2 children will need to be followed save that, as the child will not have an EHC plan, the only document setting out the services to be provided to them will be the continuing care package. The decision-makers relating to the content of the continuing care package will be the ICB and the local authority. Any such decision cannot be the subject of an appeal to the tribunal.

Disputes between a child/parents and an ICB/local authority.

50. In general, there are two types of disputes between a child or their parents and an ICB or local authority concerning continuing care packages, namely (a) disputes about a child's entitlement to a continuing care package and (b) disputes about the nature or extent of services to be provided under the continuing care package. The CC guidance explains that these disputes should be mediated through a specific complaints process. It provides:

> *"88. Where a child or young person is found not to have a need for continuing care, a clear written explanation of the rationale for the decision should be*

> *provided to the child or young person and family following verbal notification as above.*
>
> *89. The child or young person and their family should be informed of their rights and of the complaints procedure in the case of a decision which does not meet their preferences and/or expectations. This should ideally form part of any public documentation on the continuing care process, and must be included within the published Local Offer of services for children with SEND.*
>
> *90. CCGs must have complaints procedures in place to respond promptly to any request to review disagreements voiced by the child or young person or their family or carer about any aspect of the continuing care process.*
> *91. CCGs will already have a system for reviewing assessments or decisions by a senior panel and/or by referral to an out-of-area continuing care team to provide greater patient confidence in the impartiality in decision-making. Any dispute with a child or young person and their family should go through this process. Any package of care should remain in place whilst a dispute is ongoing"*

51. This guidance recommends a bespoke complaints process, but it cannot remove the right of the child or a parent to use the complaints procedure under the Local Authority, Social Services and National Health Service Complaint Regulations 2009.[39] Unlike CHC eligibility disputes, there is no provision for complaints about a child's entitlement to a continuing care package to be referred to an NHS England-arranged independent review panel.

Disputes between an ICB and a local authority.

52. There is considerable potential for ICBs and local authorities to disagree about (a) whether a child is entitled to a continuing care package, (b) what services should be commissioned as part of a continuing care package and (c) how the costs of a continuing care package should be divided as between an ICB and a local authority. It is also possible for ICBs and local authorities to disagree about which ICB or which local authority has commissioning responsibility for a child. The CC

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[39] SI No 309. See chapter 21 for the law concerning the making and consideration of complaints against NHS bodies.

guidance provides that ICBs and local authorities should have dispute resolution arrangements, as follows:

> *"92. CCGs and local authorities should agree a local dispute resolution process to resolve cases where there is a dispute between NHS organisations, or between a health commissioner and a local authority, over a child or young person's continuing care needs and/or over responsibility for the funding of a package of continuing care, in a robust and timely manner. Disputes should not delay the provision of the care package, and the arrangements should be clear on how funding will be provided pending resolution of the dispute and arrangements for reimbursement to the agencies involved once the dispute is resolved.*
>
> *93. Given the requirement on CCGs and local authorities to have, as part of their joint arrangements for SEND, arrangements for resolving disputes, it would be sensible for such arrangements to also cover disputes relating to continuing care. Working with the child or young person and their family on the content of their package, as with their EHC plan, is the strongest means of ensuring a plan meets the child's needs and expectations"*

53. Where there is a dispute, the ICB and the local authority should agree that funding should be provided by one or the other party to put a continuing care package in place on a 'without prejudice' basis, with both parties agreeing that adjustments and reimbursement could be made depending on the outcome of the dispute resolution process.

Personal health budgets and direct payments

54. The CC guidance explains at para 35 that, under Part 6A RSR Regs 2012,[40] the families of a child or young person eligible for continuing care have a 'right to have' a personal health budget (**PHB**), covering the part of the child's care package that is funded by the NHS. Thus, although the grant of a continuing care package is governed by an entirely non-statutory framework, once an ICB has

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[40] Strangely, the CC guidance refers to the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations 2013 SI No 2891, which are the regulations that amended the RSR Regs 2012, but not the RSR Regs 2012 themselves.

agreed to provide a continuing care package for a child, the parent gets a statutory right to a PHB in relation to NHS-funded services.

55. A PHB can only cover that part of the overall package which is funded by the ICB. Although this is not explained in the CC guidance, a separate application can be made under the Care and Support (Direct Payments) Regulations 2014[41] to the local authority for a direct payment for the social care elements of any jointly funded package.

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[41] SI No 2871.