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Disabled Children's Social Care Consultation Paper

Consultation Paper 265

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Disabled Children's Social Care: Consultation Paper

8 October 2024

This publication is available at: https://lawcom.gov.uk/project/disabled-childrens-social-care/.

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The Law Commission – how we consult

About the Law Commission: The Law Commission was set up by section 1 of the Law Commissions Act 1965 for the purpose of promoting the reform of the law. The Law Commissioners are: The Rt Hon Lord Justice Fraser (Chair), Professor Nicholas Hopkins, Professor Penney Lewis, and Professor Alison Young. Professor Sarah Green was also a Commissioner when this paper was approved for publication. The Chief Executives are Joanna Otterburn and Roshnee Patel.

Topic of this consultation: We are conducting a review of the legal framework governing social care for disabled children in England to ensure that the law is fair, modern and accessible, allowing children with disabilities to access the support they need. For our full terms of reference see: https://lawcom.gov.uk/project/disabled-childrens-social-care/.

Geographical scope: This consultation paper considers the law in England only.

Duration of the consultation: We invite responses from **8 October 2024** to **20 January 2025**.

Comments may be sent:

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Availability of materials: The consultation paper is available on our website at: https://lawcom.gov.uk/project/disabled-childrens-social-care/. We have also published a summary of the consultation paper, which is available as an audio file, in Easy Read and in large print. We are committed to providing accessible publications. If you require this consultation paper to be made available in a different format please email: dcsc@lawcommission.gov.uk.

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Glossary

We use the following terms within this Consultation Paper.

Adult social care: services provided by local authorities to adults in need of care and support. In England, the rules setting out when those services are available, and what services are provided, are set out in the Care Act 2014.

Autistic child: we explain why we use this term, rather than the term “child with autism”, in Chapter 1.

Child: any person under the age of 18. See our explanation on why we use this definition in Chapter 1.

Child in need: a child falling within one of the three categories provided for in section 17(10) of the Children Act 1989. The first is that they are unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision of services by a local authority under Part 3 of the Children Act 1989. The second is that their health or development is likely to be significantly impaired, or further impaired, without the provision for them of such services. The third is that they are disabled.

Children’s Commissioner for England: a non-departmental public body in England responsible for promoting and protecting the rights of children as set out in the United Nations Convention on the Rights of the Child, as well as other human rights legislation, such as the Human Rights Act 1998.

Children’s social care: services provided by social services to children and their families, to safeguard or promote their welfare.

Court of Appeal: appeals from the High Court and Upper Tribunal (see below) are heard by the Court of Appeal.

Court of Protection: the court which has oversight over matters falling within the scope of the Mental Capacity Act 2005.

Deprivation of liberty: a situation for which the state is either directly or indirectly responsible, where a person is confined, and either does not or cannot consent to their confinement. We discuss the concept of deprivation of liberty further in Chapter 8.

Direct payments: monetary payments made by local authorities directly to individuals who have been assessed as needing certain services, so that they can buy their own services directly.

Disabled children: we explain why we use this term, rather than the term “children with disabilities”, in Chapter 1. We explain our approach to the definition of disability in Chapter 19.

Disabled children’s social care: care and support provided by social services to meet the needs of disabled children and their families.

Disabled facilities grants: grants made by local housing authorities to carry out adaptations to the homes of disabled persons.

Education, health and care plan (EHCP): a plan made under the Children and Families Act 2014 setting out a child or young person’s special educational needs, together with related social care and health care needs. We discuss education, health and care plans in Chapter 13.

High Court: the High Court of Justice is divided into three sections or Divisions. For present purposes, the most important are the King’s Bench Division (which includes the Administrative Court) and the Family Division.

Judicial review: a legal challenge, brought in the Administrative Court, against the lawfulness of a decision taken by a public body. Judicial review challenges usually address the process by which a decision was reached, rather than the merits of the decision itself.

Legal aid: public money made available to fund legal advice and support people to bring or defend certain types of legal case.

Legal Aid Agency: the public body which administers the legal aid system, including deciding whether a particular person is eligible for public funding.

Maladministration: there is no statutory definition of maladministration, but in broad terms it can include flaws in policies or decision-making, poor administrative practice, failure to adhere to or consider properly statutory guidelines, failing to consider properly the exceptional circumstances of an individual or a situation, not properly considering statutory powers or duties or failing to give an adequate service. We discuss maladministration in Chapter 18.

Mental health tribunal: the common name for the First-tier Tribunal (Mental Health), which hears applications under the Mental Health Act 1983.

Ofsted: the Office for Standards in Education, Children's Services and Skills. Ofsted is the lead body for monitoring the performance by local authorities of their social services functions.

Ombudsman (plural ombudspersons): a person (supported by an office) who has the power to investigate complaints against companies, organisations or public bodies.

Parents and carers: we explain why we use this term in Chapter 1. In the context of disabled children, most parents are carers, but not all carers are parents.

Parental responsibility: this is defined in section 3(1) of Children Act 1989 as being “all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property”. The courts have made clear that the important aspect of parental responsibility are the duties that the parent owes to their child, rather than any rights that they might enjoy over them.

Personal budget: a sum of money allocated to a person receiving social care services by the local social services authority in order to meet their assessed eligible needs.

Practice guidance: government guidance which is not issued under section 7(1) of the Local Authority and Social Services Act 1970 or any other enactment. It is weaker in status than statutory guidance. We discuss the status of practice guidance in Chapter 23.

Safeguarding: measures taken to protect a child and keep them safe from harm. We explain in Chapter 1 why we use this term in this way, rather than the broader sense of protecting and promoting the welfare of children.

SEND Tribunal: the common name for the First-tier Tribunal (Special Educational Needs and Disability).

Short breaks: services to provide breaks for the benefit of disabled children and/or to assist individuals who provide care for disabled children to do so, or to do so more effectively, by giving them breaks from caring. We discuss short breaks in Chapter 17.

Social services: the part of the local authority children's services directorate that exercises its children's social care functions, as opposed to its education functions.

Special educational needs: section 20(1) of the Children and Families Act 2014 provides that a child has "special educational needs" if they have a "learning difficulty or disability" which requires "special educational provision" to be made for them. We discuss special educational needs in Chapter 13.

Statutory complaints procedures: procedures that local authorities must have in place for responding to complaints about the discharge of their functions.

Statutory guidance: guidance issued by the Secretary of State and the Welsh Ministers under section 7(1) of the Local Authority and Social Services Act 1970, or other legislation with similar effect. This guidance must be complied with unless there are good reasons for not doing so. We discuss statutory guidance further in Chapter 23.

Statutory principles: these are legislative provisions which set out how the legislation is to be applied to specific situations. We discuss our approach to statutory principles in Chapter 20.

Supreme Court: appeals from the Court of Appeal are heard by the Supreme Court.

Upper Tribunal: the appeal body (for almost all purposes) from the SEND Tribunal.

Working Together guidance: Working Together to Safeguard Children (which we refer to in this paper as the *Working Together* guidance) is statutory guidance for those working with children and their families, such as social workers or healthcare professionals. Such people have to have regard to this guidance and can only depart from it if they have cogent reasons to do so (see further Chapter 23). The Government have published several versions of this guidance, the most recent being the 2023 version.

Chapter 1: Introduction

THE PURPOSE OF THIS REVIEW

1.1 In this review, we have been asked to look at disabled children's social care law and consider whether it sufficiently meets the needs of disabled children and their families.[1]

1.2 When we talk about "disabled children's social care law" we are referring to the body of rules which determine:

(1) whether a disabled child can obtain help from social services to meet their needs;

(2) what help they can obtain; and

(3) how they go about obtaining it.

This help might take the form of personal care for a child provided in their own home by a carer. It could be a "short break", to give a child the chance to participate in activities in the community while their parent has some time off from their caring responsibilities. It could be an adaptation to their home to make it accessible for a wheelchair. Alternatively, it could be payments made directly to a child's parent, or the child themself if they are 16 or 17, so that they can purchase any of these things for themselves. A range of other services could also be provided.[2]

1.3 The children who have needed this kind of help from social services have changed over time as the needs of society have changed, and our awareness and understanding of particular conditions has developed. By way of example, one of the core elements of disabled children's social care law is the Chronically Sick and Disabled Persons Act 1970. At the time that Act came into force, autism, identified first in the 1940s, was recognised but was understood to be a form of "early childhood psychosis",[3] thought to affect only four to five school age children in 10,000.[4] In contrast, the equivalent figure now is around one in 100,[5] with autistic children[6] comprising over 40% of children who are recognised by social services as being "in need".[7]

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[1] See paras 1.17 to 1.22 below for our terms of reference.

[2] See ch 9.

[3] Chronically Sick and Disabled Persons Act 1970, s 26(1).

[4] A Morris and A Butler, *No feet to drag* (1972) p 48.

[5] British Medical Association, *Autism Spectrum Disorder* (June 2024).

[6] See para 1.16 below on our use of language.

[7] Department for Education, *Children in need data* (2023) data set B2. See para 3.6 for what it means to be a "child in need".

1.4 The children who need this help will often have serious and complex needs and face a greater risk of harm or abuse than other children.[8] Typically, at present, to access the specialist social services provided by a local authority's children with disabilities team, a child must have severe learning disabilities, complex physical disabilities, or the like.[9]

1.5 The person asking for the help will usually be the child's carer – in practice this is often their mother – who may be exhausted from juggling their caring responsibilities with work and looking after the child's siblings. The person deciding whether to provide help and, if so, what kind, will often be a busy social worker with a large case load to manage.

1.6 In these circumstances, it is self-evident that, if it is to be effective, disabled children's social care law should be up to date, easy to find and understand, and fair. Arguably, it is none of these things.

1.7 The law is out of date. The definition of disability in section 17(11) of the Children Act 1989 refers to any child who is "blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity".[10] This definition can be traced back to the creation of the welfare state.[11] It finds its roots in legislation intended to boost the employment prospects of servicemen injured during the second world war,[12] drafted at a time when our awareness of neurological conditions such as autism was in its infancy. It is very different to the more modern approaches contained in the Equality Act 2010 or the United Nations Convention on the Rights of Persons with Disabilities.

1.8 The law is inaccessible. It is spread across numerous statutes dating from 1970 onwards, which have to be read alongside an extensive body of regulations, case law and guidance. The Court of Appeal has described it as "a maze of interacting statutory provisions, which have been subject to frequent amendment".[13] The authors of the leading legal textbook on disabled children describe it as "a system of baffling complexity" the navigation of which amounts to "additional tiring and frustrating work".[14]

1.9 The law is also – potentially – unfair, in the sense that it permits children in similar circumstances to be treated differently. The law requires local authorities to make the arrangements necessary to meet the needs of disabled children. Those needs will depend on the nature of the child's disability: not where they live or how much money their local authority has left in its budget. But whether the child is able to access services to meet those needs depends on the eligibility criteria the local authority has

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[8] See para 23.20(2) below.

[9] See ch 7 on eligibility criteria.

[10] See ch 19 for the definition of disability.

[11] National Assistance Act 1948, s 29(1).

[12] Disabled Persons (Employment) Act 1944, s 1(1).

[13] *R (Spink) v Wandsworth London Borough Council* [2005] EWCA Civ 302, [2005] 1 WLR 2884 at [1] by Lord Phillips MR.

[14] S Broach and L Clements, *Disabled Children: A Legal Handbook* (3rd ed 2020) p 84, para 3.3.

adopted, taking into account their budgetary constraints. These criteria vary from authority to authority. This has the consequence that the same child might qualify to have their needs met in one area of the country but not another. This consequence was not intended.[15]

1.10 On top of these deficiencies, parents and carers from whom we have heard in the lead up to this consultation[16] have reported problems in the way the law is applied which make it difficult for their children to access the services they need. The recurrent concerns are that:

(1) there is too much focus on safeguarding disabled children from harm at the expense of meeting their needs;

(2) those assessing the needs of disabled children do not always have expertise in disability;

(3) the eligibility criteria for accessing services are too high;

(4) the needs of parents, carers and siblings are often overlooked; and

(5) the various teams, departments and bodies responsible for a child, operate in silos and do not communicate with each other.

1.11 The fact that there are problems with the law and the way it is applied does not diminish the legal and political significance of the existing legal framework governing social care for disabled children. The foundations of disabled children's social care law are found in section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 17 of the Children Act 1989. Both provisions were ground-breaking.

1.12 Initially, local authority support to meet the needs of disabled people in the welfare state was provided as a matter of discretion.[17] Section 2 of the Chronically Sick and Disabled Persons Act 1970, for the first time, made it a statutory requirement to provide this support. In the words of Alf Morris MP, the driving force behind the Act and the first Minister for Disabled People, "we were determined to make mandatory what was then permissive" and, in doing so, "ensure that everything humanly possible is done to normalise the lives of the long-term sick and disabled".[18]

1.13 As to section 17 of the Children Act 1989, this was meant to bring together various "scattered provisions" relating to services for disabled children and children in need of protection from harm, under the umbrella of a general power to provide services to promote the care and upbringing of children within their families.[19] In the words of

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[15] See ch 7 on eligibility criteria.

[16] See para 1.55 on pre-consultation engagement.

[17] National Assistance Act 1948, s 29(1).

[18] A Morris, *Needs before means – an exposition of the underlying purposes of the Chronically Sick and Disabled Persons Act 1970* (1971) pp 4 and 10.

[19] Department of Health and Social Security*, Review of Child Care Law, Report to Ministers of an Interdepartmental Working Party* (September 1985) paras 5.7 to 5.15.

Baroness Hale, one of the architects of the Act, "the hope was that all would be seen simply as children in need of help".[20]

1.14 It does no disservice to either of these pieces of legislation to observe that times have changed and that these objectives are no longer achieved. Once again, the law has become "scattered". Disabled children are often viewed as children in need of protection, rather than children in need of help. And it is open to question whether the law provides an adequate framework to support them.

1.15 Which brings us back to the purpose of this review. Does the law sufficiently meet the specific needs of disabled children and their families? If not, why not? And what can we do about it? These are the questions which this review is required to address. We would like consultees to help us answer them.

OUR USE OF LANGUAGE

1.16 A glossary of the key terms and concepts that we use in this consultation paper can be found at pages vi to viii. However, there are a number of these terms which we think need further explanation or justification, so that readers understand why and how we are using them.

(1) *Child*. This is the term used in our terms of reference and we use it in the sense it is used in the Children Act 1989 and the United Nations Convention on the Rights of the Child, to refer to any person under the age of 18.[21] This differs from the way the word is used in the Children and Families Act 2014, where a "child" is a person who is not over compulsory school age (which ends on the last Friday of June in the academic year in which they turned 16) and a "young person" is over compulsory school age but under 25.[22]

(2) *Disabled children*. This is the term used in our terms of reference[23] and we adopt it in preference to "children with disabilities" as it is the preferred term in the UK, encapsulating the idea that people are disabled by society, rather than by any inherent impairment. We try to avoid the use of the word "impairment" as much as possible, as we recognise some disabled people find this offensive as it may imply there is something wrong with them. Deaf people for example may see themselves as part of a minority group with their own culture and language – a language which many of us have not learned – rather than being "hearing impaired".[24] Similarly, those who are neurodivergent may see themselves as functioning differently to other people, without viewing themselves as having any kind of impairment. For those reasons we will try not to use the word impairment save, for the sake of accuracy, where we are referring to legislation (such as the Equality Act 2010) or statistics which use that specific

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[20] Baroness Hale, *30 Years of the Children Act 1989 - Scarman Lecture 2019* (November 2019) p 6.

[21] Children Act 1989, s 105(1); United Nations Convention on the Rights of the Child, art 1.

[22] Children and Families Act 2014, s 83(2) and (7); Education Act 1996, ss 8(3) and 579(1).

[23] See para 1.17 below for our terms of reference.

[24] T Shakespeare, *Disability: the basics* (2018) p 3.

classification. These various issues touch on the important question of how we should define disability which is discussed in Chapter 19.

(3) *Autistic children*. We use this in preference to “children with autism”, in line with the guidance of the National Autistic Society. They describe it as:

> “identity first” language which is preferred by most autistic people, because they see being autistic as integral to who they are, not as something they “have”.[25]

(4) *Parents and carers*. The term “parent carers” is often used to describe persons with caring responsibilities for disabled children. This term is defined in the Children Act 1989 as “a person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility”.[26] We have chosen to use the phrase “parents and carers” (or “parents or carers” as the context dictates) in this consultation paper as most parents are carers but not all carers are parents. In particular, there are around 121,000 children in England and Wales living in “kinship care”, with an adult relative (for example a sibling or grandparent) other than a parent. Nearly 12% of those children are disabled.[27] When we use the phrase “parents and carers”, we refer to anyone providing substantial care for a disabled child including biological, adoptive and foster parents and kinship carers. It is not meant to cover people providing care on a professional basis whether paid or voluntarily. The Law Commission will, in due course, be carrying out a separate review of kinship care. That review, like this one, arises from a recommendation made in the Independent Review of Children’s Social Care,[28] which we discuss at paragraphs 1.33 to 1.37 below. The aim of the review will be to reform the law to facilitate kinship care for children. The approach in this consultation paper is intended to be consistent with this objective.

(5) *Social services*. Within local authorities, the children’s services directorate has responsibility for the social services functions of the authority that relate to children as well as its education functions, among other things.[29] We use the term “social services” to refer to the part of children’s services that exercises the social services functions. We use the term “adult social services” to refer to the part of the authority with responsibility for the social services functions that relate to adults.[30]

(6) *Safeguarding*. This word is sometimes used in a narrow sense to refer to measures to protect a child and keep them safe from harm.[31] It is sometimes

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[25] National Autistic Society, *How to talk and write about autism.*

[26] Children Act 1989, s 17ZD(2).

[27] Office for National Statistics, *Kinship care in England and Wales: Census 2021* (September 2023).

[28] J MacAlister, *The independent review of children’s social care – Final report* (May 2022).

[29] Children Act 2004, s 18. For “social services functions” see Local Authority Social Services Act 1970, s 1A.

[30] Local Authority Social Services Act 1970, s 6.

[31] For example, Department for Education, *Children’s Social Care National Framework: Statutory guidance on the purpose, principles for practice and expected outcomes of children’s social care* (December 2023) p 64.

used in a wider sense to incorporate promoting the child's welfare, as well as keeping them safe.[32] The former sense accords better with the way the word is used in section 17 of the Children Act 1989 which distinguishes between safeguarding and promoting the welfare of children[33]. It also accords with the ordinary meaning of the word, and the way most parents and professionals we have spoken to use it. That is the sense in which we use it in this consultation paper, but we shall try to make it clear from the context that this is the sense in which it is being used.

THE SCOPE AND CONTEXT OF THE REVIEW

Scope

Terms of reference

1.17 The remit of this review is set out in the following terms of reference, which have been agreed between the Law Commission and the Department for Education.

> To review the laws relating to the provision of support and services for disabled children in England, and the wider legal frameworks in which they are contained; with a view to making recommendations aimed at simplifying and modernising them, and at promoting clarity and consistency of understanding as to entitlements.
>
> The review will focus on the provision of support and services in the context of family-based care. In particular, it will not extend to deprivation of liberty or secure accommodation of disabled children.
>
> The review will consider whether existing duties (specifically the inclusion of disabled children as children in need under section 17 of the Children Act 1989) and accompanying statutory guidance sufficiently meet the specific needs of disabled children and their families.
>
> In carrying out this review, the Law Commission will have regard to the Government's wider work on children's social care, and how the legislation relating to disabled children aligns with other parts of the statute book concerning social care, support for Special Educational Needs and children's rights more generally.

1.18 There are two exclusions contained in the second paragraph of the terms of reference:

(1) deprivation of liberty; and

(2) secure accommodation of disabled children.

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[32] For example, "safeguarding partners" under Children Act 2004, s 16E(1) are responsible for "safeguarding and promoting the welfare of children". See also Department for Education, *Children's Social Care National Framework* (December 2023) p 47.

[33] Section 17(1) talks of the local authority's duties to "safeguard and promote the welfare of children within their area in need", suggesting that there are two different obligations in play.

1.19 In relation to the first exclusion, we have, in the relatively recent past, carried out a review of the law on mental capacity and deprivation of liberty.[34] This review considered the existing procedural safeguards which apply when a person who lacks the mental capacity to take the relevant decisions needs to be deprived of their liberty in order to receive care or treatment in a hospital or care home. These are known as the Deprivation of Liberty Safeguards.[35] Our report recommended that the Deprivation of Liberty Safeguards should be overhauled and replaced with a new system applying to those aged 16 and over. The previous Government, in broad terms, accepted our recommendations, and Parliament passed the Mental Capacity (Amendment) Act 2019. However, before the 2024 general election, the previous Government had decided not to take further steps towards bringing the Act into force during the lifetime of the Parliament that ended in May 2024. The first exclusion in our terms of reference means that we will not be seeking to revisit our earlier work on the process for authorising a deprivation of liberty. Nevertheless, the subject matter of the review will affect children who are, or may become, deprived of their liberty. They too may (and often will) need help from social services to meet needs arising from a disability. For that reason, we have produced a separate research paper on deprivation of liberty for consultees who want to understand the subject better, as context to this consultation paper. You can find this research paper on the Law Commission's website.[36]

1.20 The second exclusion relates to secure accommodation of disabled children. It is well documented that there is a "long standing and chronic" lack of placements for the secure accommodation of children, whether disabled or not. This was how the situation was described in a 2023 case by the President of the Family Division, Sir Andrew McFarlane. He drew attention to the "very substantial deficit that exists nationally in the provision of facilities for the secure accommodation of children" and expressed the concerns of the senior judiciary about this situation.[37] The Government accepted in that case that collective action was required to address this problem and that steps were being taken to that end. The second exclusion in our terms of reference means that we will not be exploring this problem or making any recommendations for legal change to fix it. But the observations of the President of the Family Division speak for themselves and the fact we are not looking into this problem should not be taken to diminish its importance. That importance had been recognised by the establishment of the "improving cross-sector support for children in complex situations with multiple needs task and finish group".[38] Children who are deprived of their liberty because of the consequences of their disability are, almost by definition, those with the highest levels of need, requiring the most intensive supervision. The provisional proposals in this consultation paper which seek to make it easier for these children to get the support they need may not be effective if they do not have safe, suitable accommodation where they can receive that support.

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[34] Mental Capacity and Deprivation of Liberty (2017) Law Com No 372.

[35] Contained in the Mental Capacity Act 2005, sch A1.

[36] https://lawcom.gov.uk/project/disabled-childrens-social-care/.

[37] *Re X (Secure Accommodation: Lack of Provision)* [2023] EWHC 129 (Fam), [2023] 2 FLR 545 at [55] and [62] to [64].

[38] For further detail, see https://www.gov.uk/government/groups/improving-cross-sector-support-for-children-in-complex-situations-with-multiple-needs-task-and-finish-group.

1.21 We note that the terms of reference require us to focus on children in family-based care. We interpret the word "family" broadly in this context to encompass fostering and kinship arrangements as well as biological and adoptive families. But although family-based care is our focus, disabled children in other settings – for example children in the criminal justice system detained in secure children's homes, secure training centres or Young Offender Institutions – will still be affected by this review. The powers and duties of local authorities to support disabled children do not end just because those children are detained by the state.[39] Additionally, the need for disabled children to have proper access to local authority support while they are detained may be acute, not least because they do not have ready access to family support. Our initial view is that the proposals in this consultation paper should be of benefit to children in custody and in the community. At the end of this consultation paper we invite consultees' views on this.[40]

1.22 Finally, we highlight that our terms of reference neither require nor permit us to review the law on support for special educational needs. We need to consider whether our provisional proposals align with the system for supporting special educational needs. We will also have to delve into the system for meeting special educational needs to an extent, because social care is one element of that system. But this review will not look at the successes or failures of the special educational needs system in general, or make recommendations to change it. We emphasise this point because our pre-consultation work has shown that there is widespread, and entirely understandable, confusion among many parents and carers about the distinction between disabled children's social care and local authority support for special educational needs. Many – not unreasonably – conflate these two regimes under the general heading of "things that local authorities can do to help my disabled child". We take this as another indication that the law is too complicated, which is something we seek to address in so far as our terms of reference allow.

Geographical scope

1.23 The review extends to England only. Social care law is a devolved matter in Wales and was consolidated and updated by Senedd Cymru (known then as the National Assembly for Wales) in the relatively recent past in the form of the Social Services and Well-being (Wales) Act 2014. But we will consider the Welsh framework where there are relevant comparisons to be drawn to help identify and evaluate law reform options.

How many children will be affected by this review?

1.24 It is not possible to say exactly how many children will be affected by this review or what their needs are. This in itself is problematic and may demonstrate the need for law reform. Writing in 1972, Alf Morris MP noted that, unless we can "obtain full identification of the severely disabled in Britain… policy making is blind".[41] One of the problems they sought to address when the Private Members Bill that became the Chronically Sick and Disabled Persons Act 1970 was drafted, was that local authorities at that time were permitted, but not required, to maintain registers of the

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[39] *R (Howard League for Penal Reform) v Secretary of State for the Home Department (No.2)* [2002] EWHC 2497 (Admin).

[40] See consultation question 84.

[41] A Morris and A Butler, *No feet to drag* (1972) p 11.

disabled people they were helping.[42] That these registers were optional and included only people in the area *getting* help – as opposed to all of those in the area who *needed* help – meant that there were a large number of people who needed help who were not known to their local authority.

1.25 Section 1 of the Chronically Sick and Disabled Persons Act 1970, which required local authorities to find out how many disabled people were in the area and inform them of their rights and entitlements, was meant to change this. It was described as "the master key to the problem".[43] Equivalent provisions are now found in the Children Act 1989, which require local authorities to:[44]

(1) take reasonable steps to identify the extent to which there are children in need (including disabled children) within their area; and

(2) maintain a register of disabled children.

1.26 At the time of publishing this consultation paper, it is not clear to us whether and to what extent these duties are being carried out. Our impression is the duties are not always performed and local authorities do not always have a complete understanding or record of how many disabled children live in their area or the extent of their needs. We have undertaken a survey of local authorities to try and obtain a better understanding of national practice, but the results have been inconclusive. We discuss this issue further in Chapter 16.

1.27 In the absence of local authority level statistics showing the nature and extent of the social care needs of disabled children across the country, the best we can do at this stage is to look at other related statistics and try and draw some tentative conclusions. These statistics (which overlap to some extent) tell us the following.

(1) In 2022 to 2023, 11% of children in the UK had a disability.[45] This equates to around 1.38 million disabled children.[46] The most common reported "impairments" were social and behavioural (50%), learning (32%) and mental health (30%).

(2) In 2023, 9% of children had a "long-standing physical or mental impairment, illness or disability". Children in lone parent families are more likely to have a

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[42] National Assistance Act 1948, s 29(4)(g).

[43] A Morris, *Needs before means – an exposition of the underlying purposes of the Chronically Sick and Disabled Persons Act 1970* (1971) p 10.

[44] Children Act 1989, sch 2(1) to (2).

[45] Department for Work and Pensions, *Family Resources Survey: financial year 2022 to 2023* (March 2024) section 5.

[46] Based on the 2021 census data. Office for National Statistics, *Children in families in England and Wales: Census 2021* (March 2024). The Family Resources Survey does not estimate how many disabled children there were in England in 2022. The closest approximation is the number of disabled people aged 19 and under, which was around 1.7 million. See Department for Work and Pensions, *Family Resources Survey: financial year 2022 to 2023* (March 2024) table 4.3a.

long-standing physical or mental impairment, illness or disability (14%) than children in couple families (7%).[47]

(3) In 2023:[48]

(a) social services across the country received referrals for 566,960 children and completed 655,540 assessments;[49]

(b) as of 31 March, there were 403,090 children who were assessed as being "in need";[50]

(c) of these, 51,790 children (12.8%) had a disability recorded and for 32,790 of these children, disability was assessed as being their primary need;

(d) of the cohort of disabled children, the most prevalent conditions were grouped under the headings of autism (41.4%), learning (36.9%) and behaviour (19.4%);[51]

(e) of the cohort of children with disability assessed as their primary need, 67% were male and 33% were female and the average age bracket for both boys and girls was 10 to 15 years old.

(4) In 2022 to 2023 there were 1,183,384 pupils in schools in England receiving support for special educational needs, but without an education, health and care plan (EHCP). There were 389,171 pupils receiving support for special educational needs with an EHCP.[52]

1.28 At a bare minimum we can say that this review will affect the 51,790 disabled children assessed as being in need, together with their families. However, the real number affected is likely to be much higher. At present, all of the 1.38 million or so disabled children in England are legally classified as children in need and so may be affected to some extent by the outcome of this review. However, not all of these children want or need help from social services. Based on the special educational needs statistics, the numbers affected could be around 390,000. As we discuss in Chapter 13, the fact that a child requires support to meet their special educational needs does not automatically mean that they have a disability or that they require social care. Conversely, the fact that a disabled child has social care needs does not inevitably mean they have special educational needs. Nevertheless, experts we have heard from in the lead up to this consultation consider that there is substantial overlap between those disabled children with social care needs and those children with

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[47] Department for Education, *Childcare and early years survey of parents* (July 2024) table B11.

[48] Department for Education, *Children in need data* (2023) data sets A3, B1 to B3 and C1 to C2.

[49] Some assessments may have started in the previous year, which may explain why there were more assessments than referrals.

[50] See para 3.6 for what it means to be a "child in need".

[51] Some children may be affected by more than one of these conditions.

[52] Department for Education*, Special educational needs in England* (2022 to 2023).

special educational needs. And so there is likely to be a correlation between the numbers of children affected.

The relationship between law reform and politics

1.29 The subject of this review is inherently political, in the sense that it raises questions about the role of the state in the lives of disabled children, that might ordinarily be thought of as the preserve of democratically elected representatives in local and central government. Moreover, we are not purely considering the legal procedures by which disabled children access social care in this review. We are looking at the much wider question of whether current law and guidance sufficiently meets the specific needs of disabled children and their families. Answering this question entails making a value judgement. This value judgement, in turn, gives rise to other value judgements such as which disabled children should be entitled to state support. That leads on to questions such as how much should the state spend on helping disabled children? This is an especially difficult and politicised question given the challenging financial climate in which local authorities currently operate.[53]

1.30 This means that, in carrying out this review, we have constantly to ask ourselves which of the questions that arise are appropriate for the Law Commission to answer and which should be left to the Government. This is not an easy task, but it is the same task which the Law Commission had to undertake in relation to adult social care in 2008 to 2011. In that consultation paper we observed that:

> 1.9 Fundamental to this project is the delineation of the respective roles of the Law Commission and Government. The Law Commission undertakes law reform. We have a statutory function to review the law with a view to its systematic development and reform. Political policy, on the other hand, is a matter for Government. It is Government that must make political judgements about the setting of spending priorities and the making of value judgements about rights and responsibilities.
>
> 1.10 Drawing a clear distinction between law reform, on the one hand, and political policy on the other is not always easy. Political policy works through and influences law. The form of legal structures can enable or limit both the delivery of policy and its development. Some things are clearly law reform, others are clearly political policy. But where the two meet it can be difficult to disentangle them. Indeed, the nature of the distinction can vary from one law reform project to another. There are some factors which, of course, tend to distinguish the two. Paradigmatically, a decision involving the expenditure of substantial resources falls on the political side of the dividing line. The big decisions about how much of a welfare state we should have and how it should be funded are not decisions for us.
>
> 1.11 However, these are not bright-line distinctions. Any law reform will necessarily involve some expenditure, if only to implement it. In the context of adult social care, if we declined to make any proposals with resource implications, the utility of the project would be seriously compromised. We have sought to make our proposals broadly resource neutral. But some proposals may have implications in terms of how any given level of resources are deployed within adult social care. On the other hand, not everything the Government has a view about is necessarily a matter of

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[53] See paras 1.45 to 1.46 below.

> politics. Perfectly properly, the Government may take a view about whether certain rules should appear in legislation or in some other form; but we are entitled, by virtue of our expertise and our statutory functions, to take a different view.
>
> 1.12 In a specific context, these are difficult judgements to make and we might not have got them right. We are interested in your views on whether we have drawn the correct line in this consultation paper between areas for politics and areas appropriate for law reform.[54]

1.31 We endorse these observations, which apply with equal force to disabled children's social care law. To these we would add that there are numerous places where the law that we review in this project already reflects political judgements. A political judgement has been made about what constitutes disability. A judgement has been made that support should not be restricted to disabled children but can be provided to their parents and family members too. Judgements have been made that local authorities should be required to make arrangements to meet the needs of disabled children, and that short breaks are one service that should be made available for that purpose. Where such policy objectives have been embodied in legal provisions and those objectives are not being met, we regard it as entirely appropriate to make recommendations as to how the law needs to be changed to achieve them, and to facilitate the effective provision of support to disabled children. On this, and all of the provisional positions taken in this consultation paper, we welcome views on whether we have appropriately drawn the line between political judgements and matters of law reform.

Context

The policy context

1.32 In carrying out this review it is important to keep in mind the policy context in which it takes place and our terms of reference require us to do so. There are two principal reasons for this. First, because policy developments in disabled children's social care, and related areas like special educational needs or adult social care, may change – or even resolve – some of the problems we are coming across in the review. Second, as much as we can, we want to try and make sure the review aligns with current policy. This is not the overriding objective of the review. After all, policy can change. For example, the 2024 general election occurred during the pre-consultation stage of our work. We cannot presume that all the policy initiatives will remain the same and unchanged. This review needs to make recommendations for law reform that will help meet the needs of disabled children whatever the current policy is. Nevertheless, if – without compromising that objective – we can make recommendations that are consistent with what we understand the likely direction of travel of such policy to be, then we view that as beneficial. We do not want the recommendations in the review to undermine the wider children's social care policy agenda or vice versa.

1.33 By way of background to the policy context within which we started our work, this review was the product of a recommendation made by Josh MacAlister (now Josh MacAlister MP) in the report of the independent review of children's social care that he led. This was a wide-ranging review looking at the entirety of children's social care. It

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[54] Adult Social Care (2010) Law Commission Consultation Paper No 192 pp 2 to 3.

made a series of important recommendations with a view to effecting “a radical reset of our children’s social care system”.[55] One of these recommendations was that the Law Commission should carry out a review of disabled children’s social care law. The purpose of the recommendation was to remedy the “patchwork of duties” owed to disabled children spanning various pieces of legislation, as well as the outdated definitions, the poor alignment with adult social care and the difficulties families have in understanding what support they are entitled to.[56] The Department for Education acted on this recommendation and asked the Law Commission to undertake this review, with the terms of reference set out above at paragraph 1.17.

1.34 A number of the other recommendations from the independent review of children’s social care were also being taken forward by the previous Government before the 2024 general election, pursuant to the children’s social care implementation strategy.[57] These may well have a direct effect on some of the problems we are considering. For example, in the lead up to this consultation we have been told that there is a tendency for the various teams in social services to operate in silos, not communicating effectively with each other and requiring families to retell their stories each time their case is transferred between teams. We have also been told that local authorities focus too much on safeguarding disabled children from harm – in instances where there is no evidence that the child faces any risk of harm – at the expense of meeting their needs.[58] To help alleviate both of these issues the independent review of children’s social care recommended a new “Family Help” service combining different types of work currently undertaken by social services and delivering it to families with a “non-stigmatising approach”.[59] Prior to the 2024 general election the previous Government began to trial this in a number of local authorities as part of the “Families First for Children pathfinder programme”.[60] The new Government is continuing to test Family Help in these pathfinders, with funding currently confirmed until the end of March 2025.

1.35 Another recommendation that the previous Government had been trialling prior to the 2024 general election was the introduction of regional care cooperatives.[61] These are regional bodies, spanning and run by a number of local authorities, that are responsible for planning, commissioning and running particular social care services such as children’s homes. If these bodies are effective they may alleviate a number of problems that have been brought to our attention in the lead up to this consultation such as the lack of sufficient social care services to meet the needs of disabled children in many areas. This issue is discussed further in Chapter 16.

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[55] J MacAlister, *The independent review of children’s social care – Final Report* (May 2022) p 15.

[56] J MacAlister, *The independent review of children’s social care – Final Report* (May 2022) p 86.

[57] Children's Social Care: Stable Homes, Built on Love (2023) CP 933.

[58] This is discussed further in paras 4.14 to 4.18.

[59] J MacAlister, *The independent review of children’s social care – Final Report* (May 2022) ch 2.

[60] Children's Social Care: Stable Homes, Built on Love (2023) CP 933 p 20.

[61] J MacAlister, *The independent review of children’s social care – Final Report* (May 2022) ch 5; Children's Social Care: Stable Homes, Built on Love (2023) CP 933 p 41.

1.36 The recommendations of the independent review of children’s social care that relate to the workforce[62] are relevant to the important concerns that we have come across repeatedly in the lead up to this consultation, that the social care workforce is overstretched and undervalued, and that there is too much reliance on agency staff.

1.37 Finally, the recently adopted *Children’s Social Care National Framework* (the Framework) implemented one of the key proposals of the independent review of children’s social care, intended to give direction and purpose to the children’s social care system.[63] This framework sets out the views of the Government in 2023 on the purpose of children’s social care, the principles which should be applied in providing social care and on the outcomes that should be achieved.[64]

1.38 According to the Framework, the purpose of children’s social care is to:

> Support children, young people and families, to protect them by intervening decisively when they are at risk of harm and to provide care for those who need it so that they grow up and thrive with safety, stability and love.

1.39 The principles which should be applied in providing social care are that:

(1) children’s welfare is paramount;

(2) children’s wishes and feelings are sought, heard, and responded to;

(3) children’s social care works in partnership with whole families;

(4) children are raised by their families, with their family networks, or in family environments wherever possible;

(5) local authorities work with other agencies to effectively identify and meet the needs of children, young people, and families; and

(6) local authorities consider the economic and social circumstances which may impact children, young people, and families.

1.40 The first two of these principles are, the Framework acknowledges, drawn from the United Nations Convention on the Rights of the Child. They are intended to be considered in parallel with that Convention.[65] Consistently with this, we proceed on the basis that this review should also, in so far as it is relevant, have regard to and draw on this Convention.

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[62] J MacAlister, *The independent review of children’s social care – Final Report* (May 2022) ch 7; Children's Social Care: Stable Homes, Built on Love (2023) CP 933 p 49.

[63] J MacAlister, *The independent review of children’s social care – Final Report* (May 2022) ch 7; Children's Social Care: Stable Homes, Built on Love (2023) CP 933 p 8.

[64] Department for Education, *Children’s Social Care National Framework: Statutory guidance on the purpose, principles for practice and expected outcomes of children’s social care* (December 2023) p 13.

[65] Department for Education, *Children’s Social Care National Framework: Statutory guidance on the purpose, principles for practice and expected outcomes of children’s social care* (December 2023) p 14.

1.41 The outcomes that should be achieved are that:

(1) children, young people, and families stay together and get the help they need;

(2) children and young people are supported by their family network;

(3) children and young people are safe in and outside of their homes; and

(4) children in care and care leavers have stable, loving homes.

1.42 The purpose, principles and objectives of the Framework are relevant to the entirety of this consultation paper. Our preliminary view is that the analysis and provisional proposals in this consultation paper are consistent with them.

1.43 The summary above provides an overview of some of the core elements of the children's social care policy which are relevant to this review. But in addition to this, the previous Government's special educational needs and disability (SEND) strategy, which was set in motion before the 2024 general election, may provide context to the review.[66] This strategy contains a number of policy actions and objectives which are relevant to proposals in this consultation paper relating to assessments, service provision and remedies, as well as the intersection between education and social care.[67] The most pertinent parts of the strategy are as follows.

(1) There should be a new system for SEND with national standards setting out what is available, who provides it and who pays for it.

(2) There should be better early identification of needs.

(3) There should be clarity over what support is available.

(4) Improved provision for special educational needs in mainstream schools should reduce the need for EHCPs.

(5) The success of the new system should be measured by parental satisfaction and fewer appeals to the SEND Tribunal will be an indicator of this.

(6) Increased funding is to be made available for short breaks, encouraging innovation in provision, and leading to the development of a national policy.

(7) There should be a greater supply of occupational therapists and speech and language therapists.

(8) Local SEND and alternative provision partnerships should be established and given the responsibility for joint assessments of need in the local area covering education, health and care. This is with a view to ensuring appropriate services are made available locally.

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[66] Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan: Right Support, Right Place, Right Time (2023) CP 800.

[67] See chs 3 to 6, 10 to 13 and 18.

(9) There should be multi-agency advisory panels spanning education, health and care to advise local authorities at points in the SEND decision making process to improve integration of services.

1.44 The policies and strategies above are those that we have identified as being of principal relevance to this review, that have influenced our approach and that we think readers should be aware of.

The financial context

1.45 A central issue in any discussion about disabled children's social care is money. Specifically, the lack of it. The overwhelming majority of those we have spoken to in the lead up to this consultation – including social workers, managers and leaders in local authorities – support the idea of making it easier for disabled children to access the services they need. Many, however, have expressed concern that there is insufficient funding for this to happen. At present, the financial situation for many local authorities in England is very difficult. A survey undertaken by the Local Government Association in 2023 suggested that nearly one in five local authorities will need to issue a report under section 114(3) of the Local Government and Finance Act 1988 – sometimes referred to as a section 114 notice – within the next year because it appears that the authority's expenditure in a financial year will exceed its resources. The Local Government Association also estimates that local authorities in England will face a £4 billion funding gap over the next two years.[68] Spending on children's social care has been recognised as one of the drivers behind the financial pressures faced by some authorities.[69]

1.46 We think it is important to acknowledge this financial context at the outset and to make clear that we are aware of it. The question of how much to spend on social care for disabled children is for central Government. However, this does not mean that we can ignore the financial context. Quite the opposite. In order to inform the decisions that will ultimately need to be made by central Government about whether and how to implement our recommendations, it is important for us to provide a realistic idea of how much they will cost. We address this further in our draft impact assessment which we discuss in Chapter 2.

The historical context

1.47 This review is concerned with the entirety of disabled children's social care law. That body of law is spread across a bewildering array of statutes, case law and guidance. But the foundations of disabled children's social care law rest on two provisions in two statutes: section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 17 of the Children Act 1989. As we observed at paragraph 1.11, both of these provisions, and these pieces of legislation, were ground-breaking in what they set out to achieve for disabled children. It is important to keep this in mind. Although we think there is a need for law reform in this area, that reform should build on the positive aspects and objectives of the current system. It would be misguided for us to propose

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[68] Local Government Association, *Section 114 fear for almost 1 in 5 council leaders and chief executives after cashless Autumn Statement* (December 2023).

[69] Financial distress in local authorities, Report of the House of Commons Levelling Up, Housing and Communities Committee (2023-24) HC 56 pp 21 to 24.

reforms that reintroduced problems which section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 17 of the Children Act 1989 sought to solve simply because those provisions are not currently delivering the services that disabled children need.

1.48 Prior to 1948, help for disabled children – and disabled people generally – was provided, if it was provided at all, under the poor laws: the system that had existed in one form or another for helping those in need, since the dissolution of the Monasteries by Henry VIII removed one of the main sources of alms for the poor.[70] There had been some legislative measures prior to 1948 directed at the specific circumstances of disabled people, for example the Blind Persons Act 1920 and the Disabled Persons (Employment) Act 1944. But these were exceptional.

1.49 The implementation of the National Assistance Act 1948 swept away the poor laws.[71] In their place, the Act introduced, among other things, a power for local authorities to:

> …make arrangements for promoting the welfare of persons to whom this section applies, that is to say persons who are blind, deaf or dumb, and other persons who are substantially and permanently handicapped by illness, injury, or congenital deformity or such other disabilities as may be prescribed by the Minister.[72]

1.50 The problem with this, as Alf Morris MP saw it, was that the services were discretionary. The intention behind section 2 of the Chronically Sick and Disabled Persons Act 1970 was to change this power into a duty and standardise provision across the country.[73]

1.51 One of the most significant problems which that Act sought to deal with was the difficulties faced by those with mobility problems in physically accessing buildings and public spaces, which made disabled people "feel like a race apart".[74] In relation to children specifically, the provision of services under section 2 was intended to help alleviate the plight of young children placed in geriatric wards, and missing out on things like holidays, places to store their toys and the opportunity to bathe and use the toilet in private, and with dignity.[75] The provision of such services was not intended to be limited by local authority resources. The services set out in section 2 were considered to be essential lifelines to disabled people and were not to be restricted, by means of local authority policies, to only those with the most significant needs.[76]

1.52 The context in which the Chronically Sick and Disabled Persons Act 1970 was enacted has shifted. Access to public spaces for those with limited mobility is,

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[70] B Inglis, *Poverty and the Industrial Revolution* (1972) p 43.

[71] National Assistance Act 1948, s 1.

[72] National Assistance Act 1948, s 29(1).

[73] *Hansard* (HC), 5 December 1969, vol 792, col 1856.

[74] A Morris and A Butler, *No feet to drag* (1972) p 10; Chronically Sick and Disabled Persons Act 1970, ss 4 to 8.

[75] A Morris and A Butler, *No feet to drag* (1972) p 10.

[76] A Morris, *Needs before means – an exposition of the underlying purposes of the Chronically Sick and Disabled Persons Act 1970* (1971) pp 11 and 16 to 17.

although still far from perfect, significantly improved from 1970 and is protected under the Equality Act 2010. Likewise, disabled children are no longer placed in geriatric wards. Modern legislation for disabled children's social care does not need to be directed toward these problems. However, the role that local authority resources have to play in deciding what provision is to be made for disabled children remains a pressing current issue. The intention that local authorities could not and should not adopt policies to limit the provision of services to the most serious of cases has not been achieved. This issue is discussed further in Chapter 7.

1.53 As to the Children Act 1989, this was intended to unify child care law with a hotchpotch of legal provisions starting with section 29 of the National Assistance Act 1948, which governed local authority support for the health and welfare of ill, disabled and vulnerable children. Part of the rationale for doing so was that the latter framework, unlike the former, did not distinguish children from adults and so did not recognise the particular circumstances and needs of children.[77] The intention behind section 17 of the Children Act 1989 was to bring together the various "scattered provisions" providing help to families with children alongside "a broad power to provide services to promote the care and upbringing of children within their families".[78] Doing this meant bringing together the law relating to services for disabled children with the law relating to services for children in need of protection from harm. In the words of Baroness Hale, as noted at paragraph 1.13 above, "the hope was that all would be seen simply as children in need of help".[79]

1.54 These are important contextual points to keep in mind. Our terms of reference require us to consider whether disabled children should be taken out of section 17 of the Children Act 1989. There are strong arguments for doing so. But, if we were to go down that route, would we be adding to the mass of "scattered provisions" on the statute book relating to disabled children? And would we be segregating disabled children from other children in need of help, and undermining the ability of local authorities to view the child holistically and meet all of their needs? These issues are discussed in Chapter 23.

OVERVIEW OF THE REVIEW PROCESS

1.55 This review commenced in September 2023. Since then, we have met with a range of individuals and groups with an interest in, or experience of, disabled children's social care. These have included disabled children and young people, parents and carers, social workers, managers and directors at local authorities, charities, academics, lawyers and judges. We are extremely grateful to all those who have given up their time to meet with us. We have not met with everybody who is affected by this review. Those we have met with do not comprehensively represent the views and experiences of those we have not. Nevertheless, this pre-consultation engagement has helped us form preliminary views about what is, and is not, working with the current system and

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[77] Department of Health and Social Security*, Review of Child Care Law, Report to Ministers of an Interdepartmental Working Party* (September 1985) paras 4.2 to 4.4.

[78] Department of Health and Social Security*, Review of Child Care Law, Report to Ministers of an Interdepartmental Working Party* (September 1985) paras 5.7 to 5.15.

[79] Baroness Hale, *30 Years of the Children Act 1989 - Scarman Lecture 2019* (November 2019).

an initial idea of what might be done to fix that. This will enable us to consult more widely on an informed basis.

1.56 That is the purpose of this consultation paper. In this paper we make a number of provisional proposals for law reform. We also ask a number of open questions designed to gather further information where we have not yet reached a provisional view. We emphasise that, at this stage, any proposals are only provisional. They represent our initial view about how the law should be reformed. The purpose of this consultation paper is to seek views on the content of these provisional proposals, and whether they should be modified and taken forward into our final report or abandoned. We will be undertaking a wide consultation process in order to gather many different views and as much information as possible. We welcome responses from any person or group interested in, or affected by, this review. Details of how to respond can be found on the inside front page of this consultation paper.

1.57 The consultation period will run from 8 October 2024 to 20 January 2025. During this period we will host and attend a number of consultation events to give people the chance to talk to us directly, as well as responding to the consultation paper.

1.58 After the consultation period we will analyse all the responses we receive and, based on this, form a final view on which proposals to take forward and in what form. These will then be published in a final report setting out our recommendations for reform. We aim to publish this report in mid-2025. The Government is required to provide an interim response within six months of publication and a full response within one year.

THE STRUCTURE OF THIS CONSULTATION PAPER

1.59 The remainder of this consultation paper is divided into six parts, each containing a number of chapters grouped thematically.

(1) Part 1 discusses assessments. This covers the assessment of the needs of individual disabled children, their parents, carers and siblings. This is the first step in the process of identifying and meeting the needs of a disabled child and their family.

(2) Part 2 looks at eligibility. This refers to the rules which determine whether a person is eligible for disabled children’s social care. Having assessed the needs of a disabled child and their family, a local authority will apply these rules to decide whether or not to provide services.

(3) Part 3 considers service provision. The subject of this part is the range of services that are available and the methods by which they are provided. These are the matters which a local authority will need to consider next, if a disabled child or their family has been assessed as having eligible needs requiring the provision of services.

(4) Part 4 covers systemic issues such as joint working between local authorities and other public bodies, and the processes for identifying overall levels of need in the local area and commissioning sufficient services. It also looks at the boundaries between disabled children’s social care, special educational needs and disability, health care and adult social care, as well as the legal remedies

that are available in disabled children's social care, such as complaints and appeals.

(5) Part 5 deals with wider issues that are relevant to all of the other issues and topics under consideration in the review, such as the definition of disability, mental capacity, statutory principles and advocacy.

(6) Part 6 considers, in light of the analysis in the earlier parts of the consultation paper, whether a new legal framework is required. The paper concludes with our provisional view that a new legal framework governing disabled children's social care – accompanied by dedicated guidance for both local authorities and for families – is required. Such a framework, we suggest, is needed to address the problems and implement the proposals discussed in the rest of the paper.

1.60 In each chapter we will follow the same structure, setting out the current law, the case for reform, the various reform options and our provisional proposals. We are consulting on all of these proposals: they are no more than provisional at this stage. We also seek information relevant to the assessment of these proposals and ask a number of questions designed to gather further evidence and data. The proposals and consultation questions are summarised at the end of this paper.

WEB LINKS AND REFERENCES

1.61 All web links and references to documents have been checked and are accurate as of 30 September 2024.

ACKNOWLEDGEMENTS AND THANKS

1.62 We start by reiterating our thanks to the children and young people, parents and carers, social workers, managers and directors at local authorities, charities, academics, health and education professionals, lawyers and judges who have given up their time to speak to us and lend us their expertise in the lead up to this consultation.

THE TEAM WORKING ON THIS PROJECT

1.63 The following members of the Public Law and Law in Wales Team have contributed to this project: Henni Ouahes (team manager); Connor Johnston (team lawyer); Professor Alex Ruck Keene KC (Hon) (consultant lawyer); and Efa Jones (research assistant).

Chapter 2: The impact of this review

INTRODUCTION

2.1 We have been asked to review the law because it is complicated, out of date and does not sufficiently meet the needs of disabled children. We set out in this consultation paper our provisional proposals for making it simpler, more modern and effective. The law should be simple, so it is accessible to those who use it. It should also be modern so that it reflects society's current understanding of disability. Finally, it needs to be effective, otherwise Parliament's intentions in legislating are frustrated.

2.2 This paper's provisional proposals and questions are therefore aimed at identifying reforms that are valuable in and of themselves. However, as important as it is, meeting the needs of disabled children is one political goal amongst many. Assessing and meeting the social care needs of disabled children is not free of financial cost. At heart, the reason we have legislation in this area is to set out the circumstances in which the state will allocate resources to meet the social care needs of disabled children. As we explained in the preceding chapter, how much money should be spent in this area is a political judgement rather than a law reform issue (see further paragraphs 1.29 to 1.31). However, in order to inform the decisions that will ultimately need to be made by central Government about whether and how to implement our recommendations, it is important for us to provide a realistic idea of how much they will cost. To that end we seek consultees' help. We have published a draft impact assessment to accompany this consultation paper. That impact assessment sets out our initial, provisional estimates of the costs of implementing our provisional proposals and gives consultees the opportunity to identify the areas where our estimates need refining.

2.3 We also need to make sure that we have understood the potential equality impacts of our provisional proposals, not least because we recognise that many disabled children will have other protected characteristics. Any future law reform to improve the lives of disabled children needs to ensure that this does not inadvertently lead to the exclusion of those with other protected characteristics.

DRAFT IMPACT ASSESSMENT

2.4 When reading and responding to the draft impact assessment, it is important to have in mind the timeframes over which costs may be incurred. In some cases, spending money on providing support to a disabled child at an early stage can reduce the amount of money that might need to be spent further down the line. For example, support to help a young autistic child develop their social and communication skills may reduce the need for a costly residential placement during their teenage years, when their communication difficulties result in their behaviour becoming too challenging for their parent or carer to deal with. There will, however, always be up-front costs. This is inherent in the idea that spending money now can save money later.

2.5 There will also be other up-front costs associated with law reform, for example providing training to local authority staff on changes to the law where this goes beyond what would be expected as a part of routine continuing professional development. This needs to be acknowledged and costed.

2.6 We invite views on the costs of our proposals and whether consultees agree with the provisional analysis in our draft impact assessment. But we would encourage those who respond to this consultation paper and the draft impact assessment to also engage with the substance of the proposals and whether they will improve access to social care for disabled children. Whether our proposals will work and how much they will cost are both important questions. But they are distinct, and we need to ask both.

Consultation Question 1.

2.7 We invite consultees' views on the provisional analysis of the costs set out in the draft impact assessment. In particular, please highlight any assumptions we have made that you consider may be incorrect and explain why.

EQUALITY IMPACTS

2.8 As part of the law reform process, we need to consider how our provisional proposals could affect particular groups, or people with particular characteristics.

2.9 Many of the disabled children and their families who fall within the scope of this review will have other needs and protected characteristics, in addition to the child being disabled. This may mean that, under the current system, they are treated differently to others who do not share these characteristics. Or that they have different needs. Or that the outcomes for them if they do or do not receive the right support are different.

2.10 We highlight here a few examples that have emerged from the data and from our pre-consultation work.

(1) There are higher proportions of disabled children in the most deprived areas of the country.[1] Pupils with special educational needs are more likely to be eligible for free school meals than those without.[2] Although having special educational needs is not an exact proxy for having a disability that gives rise to social care needs, there is a correlation.[3]

(2) Children of Black Caribbean, and mixed white and Black Caribbean heritage are more likely to be permanently excluded from school than most other ethnic groups.[4] But the exclusion rate among older children in these groups is lower in

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[1] Office for National Statistics, *Disability by age, sex and deprivation*, England and Wales: Census 2021 (February 2023) section 7, figure 9.

[2] Department for Education, *Special educational needs and disability: an analysis and summary of data sources* (August 2024) p 16.

[3] See para 1.27.

[4] Department for Education, *Permanent exclusions* (February 2024) section 3.

cases where the child has been referred for or received support from social services.[5]

(3) Moderate and severe learning difficulties are more common among children from Gypsy, Roma and Traveller communities.[6] Children in this cohort are most likely to have an education, health and care plan.[7] More generally, members of the Gypsy, Roma and Traveller communities who struggle with literacy skills can face particular barriers accessing public services.[8]

(4) Research suggests that families from Black and Asian ethnic backgrounds face significant additional barriers in accessing social care support.[9] These may be attributable to a range of factors, including a lack of trust of professional services, stigma around health or disability, language barriers, services not being culturally appropriate, limited staff, education and training and previous experience of racist treatment.[10]

(5) Around 60% of unpaid carers in England and Wales are women.[11] Both male and female parents and carers we have spoken to in the lead up to this consultation have reported that women are not always listened to or accorded a level of respect appropriate to their experience, expertise and knowledge of their own child, when they seek support from social services for their disabled child. In addition, if they seek to challenge local authority decision-making, they may be labelled as “difficult”. We have heard that both of these trends may be more acute for Black women.

(6) There is a higher proportion of disabled unpaid carers in England than the proportion of disabled non-carers.[12] This can present particular problems for disabled parents and carers trying to access social care for their disabled children. For example, autistic parents struggling to access and navigate the

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[5] R Hood and others, *Studying the outcomes of children’s social care provision for different types of demand* (January 2024) p 91.

[6] T Shakespeare, *Disability: the basics* (2018) p 10.

[7] Department for Education, *Special educational needs and disability: an analysis and summary of data sources* (August 2024) p 12.

[8] Tackling inequalities faced by Gypsy, Roma and Traveller communities, Report of the Women and Equalities Committee (2017-19) HC 360.

[9] Disabled Children’s Partnership, *Support not Suspicion: Social Care, Ethnicity, Disabled Children and Their Families* (September 2024).

[10] Disabled Children’s Partnership, *Support not Suspicion: Social Care, Ethnicity, Disabled Children and Their Families* (September 2024) p 14.

[11] Office for National Statistics, *Unpaid care by age, sex and deprivation, England and Wales: Census 2021* (February 2023) section 3.

[12] Office for National Statistics, *Unpaid care and protected characteristics, England and Wales: Census 2021* (April 2023) section 3.

system may be characterised as themselves being difficult rather than finding the process difficult.[13]

(7) Research has identified "astonishing levels of discrimination based on the triad of minority statuses: being young, being LGBT+ and being disabled".[14]

2.11 It is important for us to be alive to these, and other, intersections so that we can make sure that our final recommendations benefit everyone and, in so far as possible, redress inequalities in the system. We invite views on the different intersections and inequalities that arise in this area of law, and how these impact on our provisional recommendations and vice versa.

Consultation Question 2.

2.12 We invite consultees' views and/or evidence as to whether our provisional proposals could result in advantages or disadvantages to particular groups or to individuals with particular characteristics?

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[13] S Radev, M Freeth and A Thompson, "'I'm not just being difficult . . . I'm finding it difficult': A qualitative approach to understanding experiences of autistic parents when interacting with statutory services regarding their autistic child" (2023) 28 *Autism* 1394.

[14] A Toft and A Franklin, "Sexuality and gender identity in the lives of young, disabled LGBT+ persons Initiating a dialogue", in A Toft and A Franklin (eds), *Young, Disabled and LGBT+ Voices, Identities and Intersections* (2020) p 6.

PART 1 – ASSESSMENTS

Chapter 3: Assessing the child's needs – obtaining an assessment

INTRODUCTION

3.1 The law requires local authorities to assess the needs of children in need – which includes disabled children – who are within the area. When we use the word "assessment" in this context, we are referring to the process of identifying the child's needs by collecting information and evidence. The purpose of the assessment is to decide whether a child needs, and qualifies for, extra help to meet their needs. As we said in our adult social care consultation paper, an assessment by the local authority "can be a service in its own right and can help an individual identify their needs, inform them as to the support available and discuss the support they want".[1]

3.2 This chapter considers the circumstances in which a disabled child is entitled to an assessment of their social care needs. That assessment is likely to be the first sustained contact that a disabled child and their parent or carer has with their local authority about their social care needs. The assessment forms the basis of the subsequent decisions which the local authority is required to make about whether to provide services, what services to provide and how to provide them. These questions are discussed in Chapters 7 to 10.

3.3 It is important to note at the outset that an assessment can be carried out in a variety of ways and may be more or less complex or time consuming depending on the nature and degree of a child's needs. The assessment, in many cases, will involve meeting with the child and their family and discussing their needs. It may also involve obtaining and considering materials from other relevant contexts – for example documents or assessments relating to the child's special educational needs – or seeking new information from third parties such as the child's GP. We discuss these matters further in Chapter 4 which covers the process and content of assessments.

3.4 Assessments in this field are not limited to looking at the needs of the child. Where a disabled child lives at home, the needs of the whole family may require assessment. We discuss assessing parents', carers' and siblings' needs in Chapters 5 and 6.

THE CURRENT LAW

3.5 In this section, we set out the multiple routes to obtain an assessment of a disabled child's social care needs. The section is necessarily detailed and technical, because the routes to obtaining an assessment are complicated, a matter which we return to in paragraphs 3.29 to 3.30 below.

Assessment under section 17 of the Children Act 1989

3.6 The two key provisions at the heart of disabled children's social care law are section 17 of the Children Act 1989 and section 2 of the Chronically Sick and Disabled

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[1] Adult Social Care (2010) Law Commission Consultation Paper No 192 para 4.16.

Persons Act 1970. Services for disabled children are generally provided pursuant to these provisions. We discuss the nature of these duties in detail at paragraphs 7.3 to 7.11. In outline, section 17 of the Children Act 1989 places local authorities under a "general duty" to safeguard and promote the welfare of children within their area who are in need by providing a range of services appropriate to those needs.[2] A child is in need if:

(1) they are unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision of services by a local authority under Part 3 of the Children Act;

(2) their health or development is likely to be significantly impaired, or further impaired, without the provision for them of such services; or

(3) they are disabled.[3]

3.7 In order to perform the general duty owed to children in need in the area, local authorities have a discretion to provide services to any individual child who is in need.[4] In relation to disabled children, the exercise of this discretion is directed by section 2(4) of the Chronically Sick and Disabled Persons Act 1970. This requires a local authority that has functions under Part 3 of the Children Act 1989 in relation to a disabled child who is ordinarily resident in their area, to exercise those functions to "make any arrangements within subsection (6) that they are satisfied it is necessary for them to make in order to meet the needs of the child". Subsection (6) then sets out an exhaustive list of "arrangements", such as "the provision of practical assistance for the child in the child's home" and the provision of "wireless, television, library or similar recreational facilities". These services are discussed in Chapter 9.

3.8 In order to decide whether to provide services to a disabled child under the provisions set out above, a local authority will need to carry out an assessment of the child's needs. The first route to such an assessment is set out below.

(1) Section 17 of the Children Act 1989 does not contain an express duty to carry out an assessment. In other words, it does not say that "local authorities must assess any child in need in its area". The courts have, however, implied a specific duty to undertake such assessments into the legislation. They have, further, made clear that the threshold for the duty to assess is low, namely that the child should *appear* to be in need.[5]

(2) Disabled children are deemed to be children in need for purposes of section 17 of the Children Act 1989.[6]

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[2] Children Act 1989, s 17(1).

[3] Children Act 1989, s 17(10) and (11). See ch 19 on the definition of disability.

[4] *R (G) v Barnet London Borough Council* [2003] UKHL 57, [2004] 2 AC 208; *R (HC) v Secretary of State for Work and Pensions* [2017] UKSC 73, [2017] 3 WLR 1486 at [43] by Baroness Hale.

[5] *R (G) v Barnet London Borough Council* [2003] UKHL 57, [2004] 2 AC 208 at [32] by Lord Nicholls.

[6] Children Act 1989, s 17(10).

(3) Any child within a local authority's area who appears to have a disability is therefore entitled to an assessment of their needs. Importantly, a child does not need a diagnosis of a specific medical or other condition in order for the assessment duty to arise.

3.9 The duty to assess under section 17 of the Children Act 1989 applies to any child who is "within [the] area" of the local authority.[7] This is not a technical legal test, in contrast with the concepts of "ordinary" or "habitual" residence which are used in adult social care and social security contexts.[8] It requires only physical presence in the area of the authority. This may mean that the duty is owed simultaneously by several authorities, for example where a child is living in one area but attending school in another.[9] The focus on physical presence, as opposed to any more elaborate concept of residence, was described by Baroness Hale in a related context as being "an important innovation in the forerunner provision in the Children Act 1948".[10] It means that "there should be no more passing the child from pillar to post while the authorities argue about where he comes from".[11]

3.10 The potential cost of the care that might be required should not be a matter that is taken into account during an assessment under section 17 of the Children Act 1989.[12]

3.11 A second route to an assessment under section 17 of the Children Act 1989 arises by operation of the Chronically Sick and Disabled Persons Act 1970 read together with the Disabled Persons (Services, Consultation and Representation) Act 1986.

(1) Section 4 of the Disabled Persons (Services, Consultation and Representation) Act 1986 requires a local authority, upon request by a disabled child[13] or their representative, to decide "whether the needs of disabled persons call for services" under section 2(4) of the Chronically Sick and Disabled Persons Act 1970.[14]

(2) That, in turn, requires the local authority to be satisfied whether services under section 17 (or some other provision of Part 3 of the Children Act 1989) are necessary to meet the child's needs.

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[7] Children Act 1989, s 17(1)(a).

[8] See ch 7 for a further discussion of the concepts of "ordinary" or "habitual" residence.

[9] *R (Stewart) v Wandsworth London Borough Council, Hammersmith and Fulham London Borough Council and Lambeth London Borough Council* [2001] EWHC Admin 709, [2002] FLR 469 at [23] by Jack Beatson QC sitting as a Deputy High Court Judge; *R (AM) v Havering London Borough Council* [2015] EWHC 1004, [2015] PTSR 1242 at [33(xii)] by Cobb J. Note that the same phrase has recently been interpreted differently in the special educational needs and disability context as meaning "ordinarily resident": *Hampshire County Council v GC* [2024] UKUT 128 (AAC) at [199] to [228] by Upper Tribunal Judge West.

[10] *R (G) v Southwark London Borough Council* [2009] UKHL 26, [2009] 1 WLR 1299 at [28] by Baroness Hale.

[11] *R (G) v Southwark London Borough Council* [2009] UKHL 26, [2009] 1 WLR 1299 at [28] by Baroness Hale.

[12] *R (G) v Barnet London Borough Council* [2003] UKHL 57, [2004] 2 AC 208 at [35] by Lord Nicholls.

[13] Section 4 originally applied to both adults and children but was repealed in relation to adults by the Care Act 2014 and Children and Families Act 2014 (Consequential Amendments) Order 2015/914 sch 1, para 39.

[14] Disabled Persons (Services, Consultation and Representation) Act 1986, s 4.

(3) Indirectly, therefore, section 4 of the Disabled Persons (Services, Consultation and Representation) Act 1986 triggers a duty to assess under section 17 of the Children Act 1989. It is, however, a duty which only arises where a request has been made.

3.12 A third route to an assessment under section 17 of the Children Act 1989 is where a local authority owes obligations under section 117 of the Mental Health Act 1983 following detention under that Act.[15]

(1) The appearance of a need for services under section 117 of the Mental Health Act 1983 will trigger a duty to assess the child under section 47(1) of the National Health Service and Community Care Act 1990.

(2) Where the child appears to be disabled, section 47(2) of the National Health Service and Community Care Act 1990 then requires the local authority to make a decision under section 4 of the Disabled Persons (Services, Consultation and Representation) Act 1986 whether services need to be provided under section 2 of the Chronically Sick and Disabled Persons Act 1970.

(3) That, in turn, requires the local authority to be satisfied whether services under section 17 (or some other provision of Part 3) of the Children Act 1989 are necessary to meet the child's needs.

(4) That, in turn, requires the local authority to carry out an assessment under section 17 of the Children Act 1989.

Short breaks assessments

3.13 Many local authorities offer and carry out what they call "short breaks assessments". By way of example, one local authority's website refers to this as "a non-statutory light touch assessment from the short break review team or integrated keywork team". However, in law, a short breaks assessment is not a distinct type of assessment. As we discuss further in Chapter 8, short breaks are one kind of service that can be provided to disabled children under section 17 of the Children Act 1989 and section 2 of the Chronically Sick and Disabled Persons Act 1970. The process for identifying a child's need for a short break is therefore the same as if they were seeking any other kind of services under section 17 or section 2.

3.14 A local authority that carries out a "light touch assessment" for a disabled child to decide whether to provide them with a short break is therefore not carrying out a "non-statutory" assessment. Local authorities are statutory bodies, so they can only exercise powers conferred by statute. They do not have non-statutory or common law powers.[16] In assessing the child to decide whether to provide a short break, the local authority is most likely, as a matter of law, fulfilling its duty under section 17 of the Children Act 1989. But the assessment in this situation may be "light touch" because the local authority takes the view that it does not require very much information about

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[15] See further paras 14.22 to 14.27.

[16] *R (Ncube) v Brighton and Hove City Council* [2021] EWHC 578 (Admin) [2021] 1 WLR 4762 at [43] by Freedman J. See also para 23.14.

the child's needs in order to provide them with a short break. We discuss this approach in Chapter 4 when we consider the process and content of an assessment.

Needs assessments under other provisions of the Children Act 1989 and subordinate legislation[17]

3.15 A "looked after child" is a child in the care of the local authority or who is accommodated under the provisions of the Children Act 1989, except for sections 17, 23B and 24B, for more than 24 hours.[18] The Care Planning, Placement and Case Review (England) Regulations 2010[19] place local authorities under a duty to assess a "looked after" child's needs for services to achieve or maintain a reasonable standard of health or development, for the purposes of preparing a care plan.[20] The duty to assess under these regulations only applies where the child is not in the care of the local authority and a care plan has not already been prepared.[21] This assessment duty is not explicitly focused on needs arising from any disability the child might have and it applies to any child who is looked after by the local authority and not just disabled children. Nevertheless, a disabled child who is provided with accommodation by their local authority may be entitled to an assessment under this duty. The assessment, in considering the child's health or development needs, will need to look at the needs arising from the child's disability. In many cases those needs will have been identified by the local authority already in an assessment carried out previously under section 17 of the Children Act 1989.

3.16 A further assessment duty is found in paragraph 19B of schedule 2 to the Children Act 1989. This imposes a duty on a local authority to assess the needs of an "eligible child". An "eligible child" is a child who has been looked after by a local authority for a total period of 13 weeks or more, beginning on or after their 14th birthday and ending on or after their 16th birthday.[22] The purpose of the assessment is to determine what advice, assistance and support it would be appropriate for the local authority to provide under the Children Act 1989 while the child continues to be looked after, and after the local authority ceases to look after them.[23] Again, this duty is not limited to disabled children, it applies to any child who has been looked after by their local authority for the requisite period of time, and it is not expressly focused on disability. But some of the children owed this duty will be disabled and the assessment will necessarily touch on the needs arising from their disability. Those needs may well have been identified previously under a section 17 assessment.

3.17 A child is only classed as an "eligible child" while they continue to be looked after by their local authority. If the local authority stops accommodating them, they are known

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[17] See ch 8 for a further discussion of the duties owed to "looked after", "eligible" and "relevant" children.

[18] Children Act 1989, s 22(1).

[19] SI 2010 No 959.

[20] SI 2010 No 959, reg 4(1).

[21] SI 2010 No 959, reg 4(1).

[22] Children Act 1989, sch 2, para 19B(2); Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, reg 40(1).

[23] Children Act 1989, sch 4, para 19B.

as a “relevant child” until they reach the age of 18.[24] Under section 23B(3)(a) of the Children Act 1989, local authorities are required, unless they have done so already, to carry out an assessment of the needs of a relevant child with a view to determining what advice, assistance and support it would be appropriate to provide.[25] This mirrors the assessment duty owed to eligible children: it is not limited to disabled children but it will cover the child’s disability-related needs where relevant, and those needs may well have been identified in an earlier assessment under section 17.

Early Help assessments

3.18 Not all disabled children will immediately be assessed under the processes set up within local authorities to carry out assessments under section 17 of the Children Act 1989. Many are first referred to Early Help teams within local authorities for Early Help assessments. This raises the question of the basis upon which such assessments are carried out and, in turn, the basis upon which Early Help is provided.

3.19 The *Working Together* guidance[26] describes Early Help as “a system of support which aims to support children and families as soon as problems emerge”.[27] It seems to us that the legal basis for Early Help is not clear or well understood. The *Working Together* guidance says that support and services offered under Early Help “may be provided before and/or after statutory intervention".[28] This might be read as suggesting it is a non-statutory intervention. We do not consider that is right for the reasons set out at paragraph 3.14: local authorities do not have non-statutory powers.

3.20 Some researchers consider that Early Help is provided under section 17 of the Children Act 1989.[29] The charity Cerebra, by contrast, expressly contrasts Early Help provision with the provision of services under section 17.[30] Some stakeholders have suggested to us that Early Help may be provided under section 10(5A) of the Children Act 2004. The *Working Together* guidance also suggests at one point that sections 10 and 11 of the Children Act 2004 are the relevant powers.[31] We doubt, however, that this can be correct. Section 10(5A) of the Children Act 2004 allows local authorities to provide staff, goods, services, accommodation or other resources to another authority or public body. It also allows a local authority to contribute to a fund out of which payments can be made to cover the costs incurred by the other authority or body in exercising its functions. Section 10 is not, however, a general power to provide services to help children and their families. It is a power that can only be used for the

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[24] Children Act 1989, s 23A(2) and (3); Care Leavers (England) Regulations 2010, SI No 2571, reg 3(1) and (2).

[25] Children Act 1989, ss 23A(1) and 23B(3).

[26] See Glossary at p viii.

[27] HM Government, *Working Together to Safeguard Children 2023* (December 2023) p 43, fn 40.

[28] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 118.

[29] Research in practice, *What is early help? Concepts, policy directions and multi-agency perspectives A scoping study on the purpose, provision and potential of early help for children and families in England* (February 2022) p 49.

[30] L Clements and A L Aiello, *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children’s services departments* (July 2021) p 17, para 2.25.

[31] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 117.

specific purpose of making arrangements to promote co-operation between the local authority and other authorities and public bodies. Moreover, the powers do not allow the local authority to provide services directly to families; rather, the services or payments are provided to the authority or body with which the first local authority is working.[32] Section 11 of the Children Act 2004, in turn, requires local authorities (amongst others) to make arrangements for ensuring that their functions, and those of partner bodies, are discharged having regard to the need to safeguard and promote the welfare of children.

3.21 We note that there was a dispute in a case, albeit one not resolved by the court, in February 2024, as to the basis upon which Early Help was being delivered.[33] In that case, reference was also made to the potential for Early Help to be delivered under section 1(1) of the Localism Act 2011, which gives a local authority a power (subject to certain limits) to do anything that individuals generally may do.

3.22 We do not seek to resolve the question of the legal basis upon which Early Help is provided. For present purposes, the important point is that there is no clear legal framework for Early Help. This means that the law does not explain what an Early Help assessment is, when exactly a duty to assess arises, what it covers, or how it relates to other assessments. There are, however, guidance documents which address some of these points.

(1) The *Special Educational Needs and Disability Code of Practice* defines an Early Help assessment as:

> A social care assessment of a child and his or her family, designed to identify needs at an early stage and enable suitable interventions to be put in place to support the family.[34]

(2) The *Working Together* guidance, under the heading “Early Help”, provides that, “where a child and family would benefit from co-ordinated support from more than one organisation or agency (for example, education, health, housing) there should be a multi-agency assessment”.[35] It states that Early Help assessments should take account of the needs of all members of the family as individuals and consider how their needs impact on one another and identify what help the child and family require to prevent needs escalating.[36] The assessment can then provide the basis for any future assessments if they are needed, for example, under sections 17 and 47 of the Children Act 1989.

3.23 Over the years, a number of good practice guidance documents have encouraged local authorities to move away from detailed assessments of children in need towards

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[32] Children Act 2004, s 10(1) and (5A).

[33] *R (TW) v Essex County Council* [2024] EWHC 264 (Admin) at [34] by Upper Tribunal Judge Ward, sitting as a High Court judge.

[34] Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years* (January 2015) p 279.

[35] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 131.

[36] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 131. Footnotes omitted.

a more flexible approach. The key tool is the "Common Assessment Framework" (CAF). The CAF was fully implemented across all local authorities in 2008 as part of policy moves towards early intervention and preventative services. It can be described as a:

> … standardised approach for the assessment of children and their families, to facilitate the early identification of additional needs and to promote a coordinated service response. CAF is underpinned by an integrated approach to support and has been designed for use by all professionals working with children and families with additional needs, but who do not meet the threshold for more intensive interventions such as those associated with children's social care or safeguarding.[37]

3.24 In 2015, in *R (L and P) v Warwickshire County Council*,[38] the High Court considered the relationship between an Early Help assessment of a disabled child using the CAF and an assessment carried out by a social worker under section 17 of the Children Act 1989. Mr Justice Mostyn took the view that a "full-blown social worker assessment" under section 17 was not required in every case involving a disabled child and that disabled children with lower-level needs could properly be assessed under the CAF.[39] In the view of the authors of the leading textbook on this area: "this case leaves open the question of the threshold at which a local authority must offer a social work assessment rather than an 'Early Help' assessment".[40]

3.25 As noted at paragraph 1.34, the Independent Review of Children's Social Care recommended that a new umbrella of "Family Help" should combine some Early Help assessments and services with work carried out under section 17 of the Children Act 1989.[41] This is being trialled in a number of local authorities as part of the "Families First for Children pathfinder programme", with funding currently confirmed until the end of March 2025.

Child protection enquiries

3.26 In the process of assessing a child under any of the provisions set out above, the local authority may have reasonable cause to suspect that the child is suffering or is likely to suffer significant harm. At that point, section 47 of the Children Act 1989 is engaged. This places the local authority under a duty to investigate by making such enquiries as they consider necessary to enable them to decide whether they should take any action to safeguard or promote the child's welfare.[42] Not least as they appear in two different sections of the Children Act 1989, a child protection enquiry is conceptually separate from an assessment under section 17 of the Children Act 1989 (the most relevant needs assessment duty for our purposes). But the subject matter and timing of the two processes may overlap.

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[37] L Holmes, S McDermid, M Padley, J Soper, *Exploration of the costs and impact of the Common Assessment Framework* (2012) p 7.

[38] *R (L and P) v Warwickshire CC* [2015] EWHC 203 (Admin), (2015) 18 CCLR 458.

[39] *R (L and P) v Warwickshire CC* [2015] EWHC 203 (Admin), (2015) 18 CCLR 458 at [70] to [72].

[40] S Broach and L Clements, *Disabled Children: A Legal Handbook* (3rd ed 2020) p 101, para 3.39.

[41] J MacAlister, *The independent review of children's social care – Final Report* (May 2022) p 55.

[42] Children Act 1989, s 47(1).

Education, health and care needs assessments

3.27 A proportion of disabled children with social care needs will also have special educational needs and require an education, health and care plan (EHCP) under the Children and Families Act 2014.[43] The first step to obtaining an EHCP is an education, health and care needs assessment. A local authority is required to assess the education, health and social care needs of a child if it is of the opinion that:

(1) the child has, or may have, special educational needs; and

(2) it may be necessary for special educational provision to be made for the child in accordance with an EHCP.

This assessment is referred to as an EHC needs assessment and may be requested by the child's parent, or the child (if they are 16 or over) or their school or other educational institution.[44]

3.28 Any social care provision which must be made for the child under section 2 of the Chronically Sick and Disabled Persons Act 1970 or which is reasonably required under section 17 Children Act 1989 should be specified in section H of the EHCP.[45] Identifying that provision will require the local authority's education department to seek advice and information from social services.[46] A request for advice and information which provides sufficient information to indicate that the child may have a disability should be enough to trigger the section 17 assessment duty.[47] As the authors of the leading textbook on this area note:

> … it will not be sufficient for children's services to discharge the advice-giving duty in relation to an EHC assessment by simply stating that a child is 'not known' to social care. The request for advice must constitute a referral for the purposes of Children Act 1989 s17 and so the proper response where a child is not previously known to social care will be to carry out an assessment in accordance with the Working Together guidance […] so that there can be meaningful input to the EHC assessment process. Where a new or revised social care assessment is necessary, this should be carried out alongside the overall EHC assessment process.[48]

THE CASE FOR REFORM

The complexity of the duties to assess needs

3.29 As explained in paragraphs 3.5 to 3.17 there is a complex series of legal duties to assess disabled children's social care needs. The law is unclear, fragmented,

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[43] See ch 13 for a detailed discussion of the requirements of the Children and Families Act 2014.

[44] Children and Families Act 2014, s 36(1), (2) and (8).

[45] Special Educational Needs and Disability Regulations 2014, SI No 1530 reg 12(1)(h); Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years* (January 2015) para 9.62. See also para 13.11.

[46] Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years* para 9.49.

[47] See paras 3.6 to 3.7 above.

[48] S Broach and L Clements, *Disabled Children: A Legal Handbook* (3rd ed 2020) p 96, para 3.32.

overlapping and unnecessarily complex. It is unclear because it is explicit in at the legislation that local authorities are required to assess the needs of disabled children. Instead, it has been decided by the courts that the duty is implicit in the legislation. This means that families and professionals need to be aware of this case law to realise such a duty exists. The law is fragmented because there are various duties to assess contained in different statutory provisions, or which are not contained in statute at all, but are derived from secondary legislation (regulations), case law interpreting legislation, or guidance setting out how law should be applied. But those provisions overlap, and a disabled child may be entitled to have the needs arising from their disability assessed under more than one of the provisions. The requirements that have to be satisfied for the various assessment duties to arise are different. Despite that, some ultimately reach the same end point – section 17 of the Children Act 1989 – by a convoluted route.

3.30 The most convoluted of these routes is the route discussed at paragraph 3.12, where a child is identified as requiring after-care services under section 117 of the Mental Health Act 1983. Much of the complexity noted above has been stripped away for adults: the Care Act 2014 repealed sections 4 of the Disabled Persons (Services, Consultation and Representation) Act 1986 and section 47(2) of the National Health Service and Community Act 1990 in respect of adults. It is difficult to see any justification for the continuing complexity in relation to children.

Assessments being refused or not carried out

3.31 The lack of a clear legal right to assessment appears to be causing difficulties in obtaining assessments, including in circumstances when the child (objectively) should be seen as satisfying the low threshold set for an assessment of needs under section 17 of the Children Act 1989. We have heard the following from stakeholders.

(1) Social care assessments under section 17 are not always carried out during the EHC needs assessment process. In particular, where a child is not previously known to social care, a request for information in relation to Section H (social care provision) of the EHCP for a disabled child will not necessarily be treated as a request for an assessment under section 17.

(2) Certain groups have difficulty accessing section 17 assessments, or are being refused them, as local authorities say that they will not assess the needs of a child with a specific condition. We have heard of this happening in respect of autistic children in particular. It is linked to the issues with eligibility criteria explained in Chapter 7.[49] We have heard from parents and carers that the reason some local authorities refuse to assess is because of a perception that there is no point in assessing a child who does not have a real prospect of being eligible for services at the end of the assessment. However, unless the

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[49] See also P Bahri, L Clements, A L Aiello and T Hutchinson, *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (July 2020) section 3.

child does not appear to be disabled, we cannot identify a lawful basis upon which a local authority can refuse to carry out an assessment.[50]

(3) Bringing a disabled child to the attention of social services and asking for help or services does not always trigger an assessment of the child's needs. We have heard this in particular from adoptive parents of disabled children where the child's background and trauma are already known to social services. They have explained to us that requests for help may not trigger any action at all or trigger a referral to Early Help and then signposting to mainstream services only. It is difficult, on the face of it, to see how such actions comply with the duty to assess on the basis of appearance of disability.

Complex intersections with other types of assessments

3.32 The interaction of the duty to assess under section 17 of the Children Act 1989 with the powers and duties to carry out assessments of the needs of looked after, eligible and relevant children, EHC needs assessments, Early Help assessments and short breaks assessments, is complex and can be confusing to professionals, children, parents and carers. In addition, it is not always clear if and when these assessments can be combined. This may result in the duplication of work if two separate assessments which cover the same material are undertaken, requiring families to tell their stories or share the same information repeatedly.

3.33 In particular, the intersection between disabled children's social care and the Early Help framework is not clear. This is partly because the legislative basis for the latter is unclear.[51] It is also because it is unclear whether and when a local authority can offer an Early Help assessment rather than a full social care assessment under section 17 of the Children Act 1989, and there has been no detailed consideration of this since the judgment in *R (L and P) v Warwickshire County Council,*[52] which we discuss at paragraph 3.24 above.

3.34 In practice, this means that parents and carers of disabled children do not necessarily understand what they are entitled to. For example, oral testimony collected by the University of Kent's Living Assessment project shows that some families are not clear what Early Help is and what the difference is to "conventional" social services support. For example, one parent carer said that:

> I didn't actually understand that it was early social care, or that it would involve an assessment, because they present it to you as a family conversation. You're not actually aware that it's an assessment framework… .[53]

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[50] *R (G) v Barnet London Borough Council* [2003] UKHL 57, [2004] 2 AC 208. See also P Bahri, L Clements, A L Aiello and T Hutchinson, *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (July 2020) section 4.

[51] See paras 3.18 to 3.25 above.

[52] *R (L and P) v Warwickshire CC* [2015] EWHC 203 (Admin), (2015) 18 CCLR 458.

[53] Interview FCA21.02.B, The Living Assessments Project, shared with us by Professor Julie Anderson, the principal investigator on the Wellcome Trust-funded Living Assessments Project. The project website is https://research.kent.ac.uk/living-assessment/.

3.35 We have also heard that offering a disabled child an Early Help assessment instead of a child in need assessment means that they end up waiting longer for appropriate services, as Early Help practitioners may not have access to the social care support required. The child's parents or carers will then have to repeat their stories and information again in a child in need assessment. Although the policy intention is that Early Help assessments are supposed to feed into full social care assessments under section 17, we have heard that this does not always happen.

OPTIONS FOR REFORM

The duty to assess

Option 1: clearer guidance, but no change to the law

3.36 It would be possible for the law to remain as it is, namely with the duty implied, rather than expressly set out in the legislation, but with dedicated statutory guidance to make the duty clearer. However, our provisional view is that the statutory guidance has been clear on this point for a significant period of time, and yet problems still arise, as we have set out above. This option would also do nothing to address the complexity of the different routes into assessment that we have set out at paragraphs 3.29 to 3.30 above.

Option 2: a single express duty to assess

3.37 The second option would be for legislation to set out a single, express duty to assess. The main benefits of moving to such a duty are as follows.

(1) Having a single, express duty would clarify the law and offer a more streamlined route to services.

(2) It would bring disabled children's social care law closer in line with other similar legislation. Our terms of reference require us to consider the alignment of legislation relating to disabled children with the other parts of the statute book concerning social care. In England, there is an express duty to assess the social care needs of adults and an express duty to assess the special educational needs of children. In addition, in Wales, there is an express duty to assess the social care needs of children. The legal framework for disabled children's social care in England is an outlier in not having an express duty to assess.

(3) It would, some stakeholders have suggested, require local authorities to document their decision-making as to what, if any, support is necessary to meet the child's needs.

3.38 The main argument of principle against having an express duty is that it would only apply to disabled children, but not other children who may be in need for the purposes of section 17 of the Children Act 1989. This could lead to further inconsistency in the law, and an inconsistency we cannot make proposals to address, as it falls outside of our terms of reference.

3.39 The other arguments against having an express duty are pragmatic ones that were made to us by some stakeholders in the lead up to this consultation. The first is that it will not be possible for local authorities to carry out the increased number of assessments that are likely to be required upon the clarification of the duty. The second is that having an express duty would open the floodgates to unnecessary assessments being required in circumstances where there was no realistic prospect that the child will be eligible for services. This would be expensive and could also create false hope among families.

3.40 At one level, the response to both arguments might be that, if we are proposing no more than codifying an implicit duty, we would only be spelling out expressly that which local authorities should be doing already. That response is, however, overly simplistic. It assumes that assessments are, at present, always done when the law requires it. But we have been told that this may often not be the case. So, we must work on the basis that there will be an increase in the number of assessments. In our draft impact assessment we seek to identify the additional number of assessments that may be required. This will depend upon a number of factors, including:

(1) the precise threshold at which the duty to assess is engaged;[54] and

(2) the clarity of the eligibility criteria for being provided with services, which will help families decide whether they have a realistic chance of accessing services and hence whether there is any purpose served by seeking an assessment.[55]

3.41 As the potential increase in the number of assessments will represent one of the most important practical implications of any legislative change in this area, it is particularly important for us to have consultees' views on the assumptions that we have made in our draft impact assessment. This will allow us to come up with final recommendations in this regard which are based on the best possible evidential basis.[56]

The threshold for assessment

3.42 Any duty to assess must contain a threshold for that duty to arise. We have identified five possible options for the threshold, drawing from other jurisdictions and legislative frameworks.

Option 1: where the child appears to be disabled

3.43 The first option is to keep the threshold as it currently stands. As developed by the courts, the duty to assess will arise where the child appears to the local authority to be disabled and is thus a child in need under section 17 of the Children Act 1989. The advantages of this option are as follows.

(1) It is a low threshold. A child does not need a diagnosis of a specific condition or illness to have access to an assessment, and we believe it is important to retain this feature. This threshold will depend on the definition of disability, which would, itself, be made clearer if our provisional proposals discussed in Chapter 19 are adopted.

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[54] See paras 3.42 to 3.56 and 3.63.

[55] See chs 7 and 8.

[56] See ch 2.

(2) It is a threshold which is easy to understand and apply.

(3) Because it is a low threshold and one which is easy (and therefore quick) to apply, it could arguably better reflect the social model of disability, by ensuring that the local authority was considering at the earliest possible stage whether it was required to take steps to respond to the child's needs to enable them to flourish.

3.44 The disadvantages include the following.

(1) The threshold might be said to be too low. It could lead to an unnecessary drain on local authority resources if they were required to assess all children in the area who appeared to be disabled even if they have no social care needs. This is a concern that a number of local authority stakeholders have raised with us in the lead up to this consultation.

(2) Further, such a low threshold could also mean that families' expectations are raised unnecessarily, with more children being assessed but not then meeting the criteria for services. The extent of that gap would depend on the threshold at which local authorities are required to provide services, a matter we discuss further in Chapter 7.

Option 2: where it appears the child may have needs for care and support

3.45 The second option is to have a threshold similar to that which applies to adult social care. Under the Care Act 2014, if it appears to a local authority that an adult may have needs for care and support, the local authority must assess whether they do, and, if so, what those needs are.[57] This threshold stems from our review of adult social care law. In that review, we explained our reasoning:

> …consultation has confirmed our view of the importance of having a single and clear assessment duty, which has a low qualifying threshold and applies to all service users… Although we did not replicate its precise wording, the clear intention behind our proposal was to establish the same threshold for assessment as section 47 of the NHS and Community Care Act 1990. However, we also remain convinced that the trigger for the assessment should be amended to refer to needs that can be met by services, rather than needs for services.[58]

3.46 In the consultation which preceded our final report, consultees who supported that wording identified that it made clear that a local authority should only decide whether a person has needs after carrying out an assessment and should not screen people out by pre-empting the results of the assessment. We observed in our adult social care report that "authorities cannot decide if a person 'has needs' without first undertaking an assessment".[59] To implement that objective, section 9(3) of the Care Act 2014 now provides that the duty to carry out a needs assessment applies regardless of the local authority's view of (a) the level of the adult's needs for care and support, or (b) the

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[57] Care Act 2014, s 9(1).

[58] Adult Social Care Law (2011) Law Com No 326 para 5.23.

[59] Law Commission, *Adult Social Care: Consultation Analysis* (2011) p 71, para 4.8.

level of the adult's financial resources.[60] We consider that the same logic and approach could apply to the assessment of children. The level of care and support required, and the family's resources could come into play at the later stage of deciding whether the child is eligible for support (see Chapters 7 and 8) and whether the family should contribute toward the cost (see Chapter 12). But those factors should not be a barrier to an assessment taking place. Aligning the assessment thresholds for children and adults would fulfil the goal set out in our terms of reference of aligning (where possible) children's social care with other parts of the statute book concerning social care. Substantively, this threshold would be similar to the threshold for other children in need under section 17 of the Children Act 1989 (see paragraph 3.6 above).[61]

3.47 This threshold might go some way to meeting the concerns of local authority stakeholders that having an express duty would significantly increase the number of assessments needing to be carried out. While this threshold is still set relatively low, it will mean that only those disabled children who may have needs for care and support are assessed. In addition, as we observed in our adult social care report:

> it may be that the additional cost of assessing those who may subsequently be found not to be eligible for services could be met by the reduction in challenges to refusals of support, the reduced administration involved in identifying whether to assess, and the ability to meet needs when they are simple, rather than refusing support until those same needs become more complex and may become more expensive to meet.[62]

3.48 Conversely, we recognise that the threshold could be interpreted as higher than that currently provided for in section 17 in respect of disabled children. However, that would only be because disabled children who do not (or do not appear) to have any care and support needs would no longer be entitled to an assessment. Our provisional view is that there is no benefit to that group in having such an entitlement.

Option 3: where it appears the child may be eligible for care and support

3.49 The third option for a threshold would be to model it on the threshold for obtaining an EHC needs assessment.[63] Section 36 of the Children and Families Act 2014 requires a local authority to assess the education, health and social care needs of a child or young person if it is of the opinion that:[64]

(1) the child or young person has, or may have, special educational needs; and

(2) it may be necessary for special educational provision to be made for the child or young person in accordance with an EHCP.

3.50 The second part of this test is based on the threshold for obtaining an EHCP. The local authority is required to secure the preparation of an EHCP if it is necessary for

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[60] Care Act 2014, s 9(3).

[61] Children Act 1989, s 17(10)(a) and (b).

[62] Law Commission, *Adult Social Care: Consultation Analysis* (2011) p 71, para 4.12.

[63] See ch 13 for a detailed discussion of the requirements of the Children and Families Act 2014.

[64] Children and Families Act 2014, s 36(8).

special educational provision to be made for the child in accordance with an EHCP.[65] In effect, the assessment for obtaining an EHC needs assessment is based on the likelihood that the child will be eligible for an EHCP: a child is entitled to an EHC needs assessment if they “may” be eligible for an EHCP. Adopting an equivalent threshold in the context of disabled children’s social care would mean that a disabled child should be entitled to an assessment of their social care needs where it appears that they “may” be eligible for social care provision.

3.51 This is a higher threshold than currently applies and may be objectionable on that basis. It is also, potentially, more complex than options one or two. Options one and two, respectively, require local authorities to consider the child’s disability and needs. Whereas this third option requires the local authority to consider both these things and then go further and consider whether they may meet the eligibility criteria[66] for providing support. That is a more involved process and runs the risk either that the process of determining whether a child is entitled to an assessment becomes quite onerous – in effect, requiring a pre-assessment assessment – or that some children who might need support miss out on an assessment. That in turn could lead to costly legal disputes.

3.52 On the other hand, as with options one and two, some local authorities expressed to us in the lead up to this consultation the view that this threshold is still too low. Their concern is that this threshold will lead to an increase in the number of assessments, in circumstances where there is still a reasonable chance that the child will not be entitled to services.

Option 4: where the child is likely to be eligible for care and support

3.53 The fourth option would be to adopt a higher assessment threshold: that “the child is likely to be eligible for services". This is a variation on option three. It is an option favoured by some local authority stakeholders we have heard from in the lead up to this consultation. Having a higher threshold would meet their concerns that introducing an express duty to assess would result in a significant increase in the number of assessments that have to be carried out, in circumstances where the child is unlikely to be eligible for services. However, a higher threshold could be counterproductive, requiring a time-consuming pre-assessment assessment to establish whether the threshold for an assessment is met. It may also result in costly legal disputes where assessments are refused.

Option 5: where it appears that a child may need care and support in addition to or instead of that provided by the child’s family

3.54 The fifth option would be to adopt the threshold contained in the Welsh legislation. Under section 21(1) of the Social Services and Well-being Act 2014, a local authority’s duty to assess is triggered if it appears to the authority that “a child may need care and support in addition to or instead of that provided by the child’s family”.[67] For this

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[65] Children and Families Act 2014, s 37(1).

[66] See ch 7.

[67] Social Services and Well-being Act 2014 (anaw 4), s 21(1).

purpose, the authority’s view of the child’s likely level of need is irrelevant, as are the financial resources of any person with parental responsibility for the child.[68]

3.55 In deciding whether the threshold for an assessment is met, there is a presumption in section 21(1) of the Social Services and Well-being Act 2014 that “a disabled child is presumed to need care and support in addition to, or instead of, the care and support provided by the child's family”.[69] In the lead up to this consultation, we were told by stakeholders that this statutory presumption in the Welsh legislation is positive as it acknowledges that a disabled child has needs above and beyond what a non-disabled child needs. In England, there is no such presumption.

3.56 It is not clear to us whether the approach set down in the Welsh legislation offers any advantages over the approach modelled on the Care Act 2014 described under option two above. The threshold for providing an assessment under the Welsh legislation is higher than applies under the Care Act 2014, in that the child must appear to need support over and above that provided by their family. But that difference may be negated by the presumption that all disabled children have such a need. We welcome consultees’ views and experiences on this.

Consequential matters

Combining assessment duties

3.57 Expressly setting out the duty to a disabled child in a statute would require consideration to be given to the relationships between that duty to assess and the various other duties we set out in this chapter. There are three main options.

(1) The legislation could make clear that the assessment for a disabled child should be separate and additional to other assessments.

(2) The legislation could remain silent and allow local authorities freedom to choose whether the assessments can or should be combined.

(3) The legislation could encourage or compel the assessments to be combined. This could be done in three different ways.

    (a) By retaining the same power as in the current law.[70] This allows local authorities to assess the needs of a child under the Children Act 1989 at the same time as any other assessment under the Chronically Sick and Disabled Persons Act 1970, the Disabled Persons (Services, Consultation and Representation) Act 1986, the Children and Families Act 2014 or any other enactment.

    (b) By strengthening this power to a duty, with a provision which states that local authorities must carry out assessments together. However, there may be circumstances in which this is not appropriate. Making the duty to

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[68] Social Services and Well-being Act 2014 (anaw 4), s 21(3).

[69] Social Services and Well-being Act 2014 (anaw 4), s 21(1).

[70] Children Act 1989, sch 2, para 3.

combine assessments a statutory one would limit the flexibility that may be needed.

(c) By a rebuttable presumption that assessments should be combined unless there is a good reason not to.

3.58 We also note in this regard the potential to use the concept of "equivalent assessments" to be found in the Mental Capacity Act 2005,[71] which expressly provides for the ability to reuse assessments carried out for another similar purpose. Taking this approach could avoid repetition of unnecessary paperwork and assessments and go some way to mitigating the concerns of local authorities than an express assessment duty opening the bureaucratic floodgates. It would also ensure that children and their parents or carers do not need to repeat their stories. This approach is consistent with any of the three options for combining assessments set out above. We invite consultees' views on the use of equivalent assessments below.

Relationship between the duty to assess and Early Help assessments

3.59 As discussed at paragraphs 3.18 and 3.25, the relationship between Early Help assessments and social care assessments for disabled children is unclear. Having an express duty to assess would not resolve this issue. And the options on combining statutory assessments would not resolve it either because Early Help assessments do not have a clear statutory basis.[72] One option to clarify the interaction between the new duty to assess and assessments for purpose of Early Help (as well as Family Help,[73] to the extent that this embraces Early Help) would be to do so in guidance.

OUR PROVISIONAL PROPOSALS

The duty to assess

3.60 We provisionally propose that there be an express duty to assess the social care needs of disabled children set out clearly in statute. This single express assessment duty would be the gateway to all services for disabled children, including short breaks. We accept that many of the arguments for having an express assessment duty apply equally to children who are not disabled. However, our terms of reference extend only to disabled children and our provisional view is that an express assessment duty is an important step toward ensuring their needs are identified and met.

3.61 At paragraphs 3.42 to 3.56 we set out five options for what the threshold could be for engaging the duty to assess. We seek consultees' views on the most appropriate threshold.

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[71] Mental Capacity Act 2005, sch A1, para 49.

[72] See further paras 3.18 to 3.21.

[73] See further para 3.25.

Consultation Question 3.

3.62 We provisionally propose that that there be a single express duty to assess the social care needs of disabled children.

Do consultees agree?

Consultation Question 4.

3.63 We invite consultees' views on the appropriate threshold for carrying out an assessment. Should an assessment be carried out where:

(1) the child appears to be disabled;

(2) it appears the child may have needs for care and support;

(3) it appears the child may be eligible for care and support;

(4) the child is likely to be eligible for care and support; or

(5) it appears that a child may need care and support in addition to or instead of that provided by their family?

Consequential matters

Combining assessments

3.64 We are provisionally of the view that the law should facilitate assessments being combined. Combining assessments reduces duplication of work for social workers and avoids children and their parents or carers having to retell their stories. We welcome views as to which of the options we have identified at paragraph 3.57 is the most appropriate way to facilitate the combining of assessments.

Consultation Question 5.

3.65 We invite consultees' views on the extent to which, if at all, the law should facilitate the combining of assessments undertaken for other purposes? There are three main options.

(1) The legislation could make clear that the assessment for a disabled child should be separate and additional to other assessments.

(2) The legislation could remain silent and allow local authorities freedom to choose whether the assessments can or should be combined.

(3) The legislation could encourage or compel the assessments to be combined. This could be done in three different ways:

  (a) by giving a power to combine assessments;

  (b) by imposing a duty to combine assessments; or

  (c) by a presumption of combining the assessments which can be rebutted with a good reason.

We invite consultees to indicate, if applicable, which sub-option within option (3) would be preferrable.

3.66 Whichever option to facilitate combining assessments is adopted, we also welcome views on the concept of equivalent assessments (as noted at paragraph 3.58) to allow for the reusing of assessments which are carried out for another similar purpose.

Consultation Question 6.

3.67 We invite consultees to provide their:

(1) experiences of the use of equivalent assessments under the Mental Capacity Act 2005; and

(2) views on whether this approach would be appropriate in the context of disabled children's social care.

3.68 For the avoidance of doubt, we do not think that the provisional proposal in this chapter about assessments or the ways in which we suggest they could be combined can or should undermine the ability of local authorities to investigate genuine safeguarding concerns. In particular, we do not intend this provisional proposal to inhibit the ability of, and duty upon, a local authority to make enquiries under section 47 of the Children Act 1989. As we explain at paragraph 3.26 above, the duty to investigate under section 47 is triggered where there is a reasonable cause to suspect that child is suffering or is likely to suffer significant harm. If, while assessing the social care needs of a disabled child, the local authority was given cause to suspect the child was at risk, the duty to investigate under section 47 would arise. In the absence of any such risk, the focus of the assessment would be limited to considering the child's social care needs.

Chapter 4: Assessing the child's needs – the process and content of the assessment

INTRODUCTION

4.1 Building on Chapter 3, which discusses the circumstances in which a local authority is required to assess the social care needs of a disabled child, this chapter covers the assessment process. It considers the following questions.

(1) How is the assessment carried out?

(2) Who carries out the assessment?

(3) What should be in an assessment?

4.2 At present, as we explain below, the answers to these questions are largely not to be found in legislation. Rather, they are addressed by a combination of legal duties identified by the courts, statutory and non-statutory guidance, and in local protocols for assessment. This means that it is important that we provide some contextual background to explain how this state of affairs has come about, before we turn to the case for reform, the options for reform, and our provisional proposals.

4.3 We make a number of provisional proposals elsewhere in this consultation paper which are relevant to the issues discussed in this chapter. In particular, in Chapter 21 we propose that children with sufficient understanding should have a right to request, and make representations in the course of, an assessment. In Chapter 22 we make provisional proposals on advocacy provision in disabled children's social care. This includes a proposal on the right to independent advocacy during assessments. In addition, in Chapter 20 we propose that local authorities assessing the needs of disabled children should have regard to certain considerations. These include: the importance of the child being provided with the information and support necessary to enable their participation; the views, wishes and feelings of the child; and the characteristics, culture and beliefs of the child. Consultees may wish to refer to these provisional proposals and keep them in mind when considering the issues discussed in this chapter.

THE CURRENT LAW

Background: from a national framework to local protocols for assessment

4.4 Statutory guidance on the process and content of social care assessments has changed significantly over the years. These changes have had a specific impact in practice on how disabled children are assessed under section 17 of the Children Act 1989. In 2000, the Department of Health published a *Framework for the Assessment of Children in Need and their Families* (the Framework) and accompanying practice guidance.[1] This was produced "primarily for the use of professionals and other staff who will be involved in undertaking assessments of children in need and their families under the Children Act 1989".[2] Under the Framework, assessments were split into "initial" and "core" assessments.

4.5 The practice guidance accompanying the Framework had a chapter on assessing disabled children. This was a 30-page chapter that addressed the specific skills required when authorities assessed the needs of disabled children and their families. The Framework was designed to be inclusive of all children in need. The practice guidance explained that:

> Social Services Departments have a duty to ensure that every child is assessed in a way which recognises the child's individuality and particular needs. For many reasons, disabled children are more likely to come to the attention of health, education and social services and are far more likely to be assessed than other children. This guidance is therefore aimed at everyone involved in assessments, not just at those who have a specialist role with disabled children.[3]

4.6 Whilst the Framework is still referred to in the 2023 version of *Working Together*,[4] it no longer has the status of statutory guidance. It was withdrawn when the Department for Education published the 2013 version of *Working Together*, which required instead that local authorities and their partners should develop and publish local protocols for assessment.[5]

4.7 The Framework was withdrawn in response to recommendations made by Professor Eileen Munro in her 2011 review of child protection. She recommended that:

> … guidance on undertaking assessments of children in need should remain on a statutory footing. However, the approach that has been taken in The Framework for Assessment of Children in Need and their Families (2000) needs to be revised and re-issued to present the ten underpinning principles only, but give professionals the responsibility for deciding how they can be implemented in practice.[6]

4.8 The Government at the time then accepted and implemented the recommendation to revise and re-issue the assessment framework. In publishing *Working Together* 2013, the Government said that it was following Professor Munro's recommendation to:

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[1] Department of Health, *Framework for the Assessment of Children in Need and their Families* (2000) and *Assessing Children in Need and their Families: Practice Guidance* (2000).

[2] Department of Health, *Framework for the Assessment of Children in Need and their Families* (2000) p ix.

[3] Department of Health, *Assessing Children in Need and their Families: Practice Guidance* (2000) p 73, para 3.1.

[4] See Glossary at p viii.

[5] Department for Education, *Written statement to Parliament: Working together to safeguard children. Statement from Edward Timpson about the publication of the revised statutory guidance 'Working together to safeguard children*' (March 2013).

[6] E Munro, *The Munro Review of Child Protection: Final Report. A child-centred system* (May 2011) para 3.11.

> … put children's needs back at the heart of assessment by reducing prescription, removing the requirement to have a separate 'initial' and 'core' assessment of children in need and the related 10 working day timescale for completion of the initial assessment. This will make the assessment a continuous process, rather than a stop/start one, and allow professionals the flexibility they need to carry out assessments designed around individual children.[7]

4.9 Professor Munro's focus was not on disabled children, but on child protection generally. Her report did not contain a discussion of the suitability of the Framework document in the context of assessing the social care needs of disabled children.

4.10 The charity Cerebra describes the change brought about in consequence as one where the principles of assessment in the 250 page Framework document were effectively replaced with 5 paragraphs of guidance in *Working Together*. Cerebra notes that this guidance "transferred to local councils responsibility for the process of assessing the care and support needs of disabled children".[8] Withdrawing the Framework also led to the withdrawal of the specific guidance as to the process of assessing disabled children's needs.

How is the assessment carried out?

4.11 The legislation does not prescribe how long it should take to carry out an assessment under section 17 of the Children Act 1989, how it should be carried out or the form it should take. The courts have, however, had cause to consider assessments and have set the following parameters.

(1) They need not necessarily be carried out by a social worker.[9]

(2) Assessments must analyse and assess the child's needs. In *R (TS) v Hackney London Borough Council*,[10] a family successfully challenged a local authority needs assessment. The judge concluded that the assessment documents themselves demonstrated that there had been a failure to analyse and to assess the disabled child's needs, as required by the *Working Together* guidance. This meant, in turn, the local authority had failed to complete a lawful assessment. In similar vein, in *R (AB and SB) v Nottingham City Council*,[11] it was held that a failure by an authority to have in place a "systematic approach" for conducting a core assessment[12] was an "impermissible departure from the guidance". Mr Justice Richards made clear that he considered that it was

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[7] Department for Education, *Written statement to Parliament: Working together to safeguard children. Statement from Edward Timpson about the publication of the revised statutory guidance 'Working together to safeguard children*' (March 2013).

[8] L Clements, A L Aiello, *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children's services departments* (July 2021) p 16, para 2.21, referring to the 2013, 2015 and 2018 iterations of *Working Together*.

[9] *R (L) v Warwickshire County Council* [2015] EWHC 203 (Admin) at [67] by Mostyn J.

[10] *R (TS) v Hackney London Borough Council* [2023] EWHC 3063 (Admin) by Jonathan Glasson KC sitting as a Deputy High Court Judge.

[11] *R (AB and SB) v Nottingham City Council* [2001] EWHC 235 (Admin); (2001) 4 CCLR 295 at [41] by Richards J.

[12] Assessments under the previous framework were split into initial and core assessments.

essential that the result of such an assessment must be that individuals could see “what help and support the child and family need and which agencies might be best placed to give that help”.[13]

(3) Assessments must be conducted fairly. Mrs Justice Cheema-Grubb made clear in *R (AC and SH) v Lambeth London Borough Council* that “where an explanation is required for material matters discovered during an assessment”, the local authority must give “the person concerned a fair and proper opportunity to give that explanation before a provisional assessment is confirmed”.[14] She continued that “this is particularly important where supporting documentation is missing, or a provisional conclusion has been reached that the person is not telling the truth”.[15]

(4) In the same case, Mrs Justice Cheema-Grubb explained that assessments must be more than a purely descriptive summary or statement of strategic objectives. They must contain sufficient detail to demonstrate that the needs of the children have been assessed, and that where needs are identified, action is planned to meet the needs and secure the child’s welfare.[16]

(5) Assessments must also have regard to changes in a child’s circumstances.[17] For example, if a local authority was aware that a child was soon to undergo medical treatment or lose an important carer, this should be considered when assessing the child’s needs.

(6) Whilst assessments must be fit for purpose, they do not need to be perfect.[18]

(7) An assessment is not a care plan.[19] In *R (MM) v London Borough of Hounslow*, Sir Brian Keith, sitting as a Deputy High Court Judge, commenting on how the Guidance should be used, explained that:

> … the assessment of a child’s needs should not be an end in itself … rather, it is a process which should result in a realistic plan of action, identifying the services to be provided, allocating responsibility for such action as needs to be taken, laying down a timetable for that action, and specifying the mechanism by which that action can be reviewed.[20]

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[13] *R (AB and SB) v Nottingham City Council* [2001] EWHC 235 (Admin); (2001) 4 CCLR 295 at [20] by Richards J.

[14] *R (AC and SH) v Lambeth London Borough Council* [2017] EWHC 1796 (Admin); (2018) 21 CCLR 76 at [44(a)] by Cheema-Grubb J.

[15] *R (AC and SH) v Lambeth London Borough Council* [2017] EWHC 1796 (Admin); (2018) 21 CCLR 76 at [44(e)] by Cheema-Grubb J.

[16] *R (AC and SH) v Lambeth London Borough Council* [2017] EWHC 1796 (Admin); (2018) 21 CCLR 76 at [44(b)] by Cheema-Grubb J.

[17] *R (K) v Manchester City Council* [2006] EWHC 3164 (Admin) by Lloyd-Jones J.

[18] *R (MM) v London Borough of Hounslow* [2015] EWHC 3731 (Admin) at [10] by Sir Brian Keith.

[19] As to care plans, see further ch 11.

[20] *R (MM) v London Borough of Hounslow* [2015] EWHC 3731 (Admin) at [8].

4.12 It can be seen from the summary above that the courts have had regard to the extent to which local authorities have followed the guidance set out in the different iterations of *Working Together*. We do not seek to summarise the current version of the guidance, but we note the following key points.

(1) *Working Together* anticipates that local authorities, with their safeguarding partners and any relevant agencies, should develop, agree, and publish local protocols for assessments and support.[21]

(2) *Working Together* anticipates that the assessment process should not take longer than 45 working days from the point of referral. If it does exceed this limit, the lead practitioner (see below) should record the reasons for exceeding the time limit. *Working Together* notes that in some cases "the needs of the child will mean that a quick assessment will be required". If practitioners identify needs during the assessment, *Working Together* makes clear that they do not need to wait until the assessment is over before providing support or commissioning services to support the child and their family.[22]

(3) *Working Together* provides that assessments under section 17 need not necessarily be carried out by a social worker but should draw in "relevant expertise".[23] The guidance provides that they should involve a "lead practitioner" who "should have the skills, knowledge, competence, and experience to work effectively with the child and their family".[24] The 2023 version of *Working Together* provides that a broad range of practitioners can be the lead practitioner for children and families receiving support and services under section 17 of the Children Act 1989.[25] This is a different approach to that in the previous version, in which the lead practitioner role was identified as falling to social workers.[26]

(4) *Working Together* requires assessments of disabled children to be holistic in approach. The assessment must address presenting and underlying issues and each of the child's needs, giving sufficient recognition and priority to the specific needs of disabled children.[27] The guidance also identifies the following.

    (a) Practitioners should consider whether any specialist communication support is required and also consider how advocacy services can support the child to communicate their views.[28]

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[21] HM Government, *Working Together to Safeguard Children 2023* (December 2023) paras 141 to 145.

[22] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 155.

[23] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 162.

[24] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 157.

[25] HM Government, *Working Together to Safeguard Children 2023* (December 2023) paras 121.

[26] HM Government, *Working Together to Safeguard Children* (July 2018) para 70.

[27] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 162.

[28] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 161.

(b) Assessments should recognise the specific pressures on the family and the distinct challenges they may have to negotiate as a result of their child's disability.[29]

(c) The assessment process should focus on the needs of the child and family, be strengths-based,[30] and gather information to inform decisions on the help needed to: ensure the child achieves the best possible outcomes; enable the child's family to continue in their caring role where that is right for the child; safeguard children in cases where there is abuse, neglect, and exploitation; and ensure that appropriate practical support is in place to enable disabled children and their families to thrive.[31]

THE CASE FOR REFORM

Problems with assessments

4.13 Problems with assessments were a common theme raised with us by stakeholders in the lead up to this consultation. We recognise that it was more likely that people would raise problems with us as opposed to situations where things were working and so we also welcome examples of good practice. Some of the problems that were raised with us are set out and explained further below.

(1) That assessments are not always carried out in a timely fashion. For disabled children, especially when they are younger, this can have a real effect on their development and lead to an escalation of their needs.

(2) That assessments are not always carried out by the most appropriate method, and, as we heard from stakeholders, sometimes by unsuitable methods. We were told about an assessment for short breaks that was done over the phone despite the parent asking for it to be in person as her child is non-verbal. We note that this appears to be a long-standing issue. In 2000, the practice guidance accompanying the *Framework for the Assessment of Children in Need and their Families* contained the observation from a mother of an autistic 13-year-old boy with severe learning disabilities:

> I have no problem with you consulting my child. In fact, I would like to know how to do so myself. But sending him this questionnaire is just bizarre. I showed him the form and he tried to eat it.[32]

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[29] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 187.

[30] A strengths-based approach to social care focuses on identifying the strengths, or assets, as well as the needs and difficulties of children, young people and families. See Social Care Institute for Excellence, *Strengths-based social care for children, young people and their families* (September 2018).

[31] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 188.

[32] Department of Health, *Assessing Children in Need and their Families: Practice Guidance* (2000) para 102.

(3) That assessors may lack training, experience and understanding of disability; particularly in conditions such as autism.[33] We have been told that expertise in less common conditions such as Prader-Willi syndrome is particularly rare. Additionally, we have been told by parent carers that it is rare for assessors to have knowledge of alternative communication methods, which can prevent assessors from communicating with a child. Parents themselves end up becoming experts in niche areas of disability to fill the gaps identified above. But when they do so, their expertise and knowledge is not always accepted or considered. We have heard how lack of appropriate expertise can inhibit assessors from correctly identifying the needs of the child they are assessing. For example, we have heard that sometimes, during assessments, challenging behaviour (violence in particular) arising from disability or trauma is not perceived as resulting from unmet needs related to the child's condition or experiences. It is seen, rather, as a result of parental failings. At the same time, however, we have been told that such behaviour is not necessarily seen as the safeguarding issue it is because it is the child themselves who poses the risk to their siblings or parents, as opposed to the child being at risk.

(4) That, where the social care team recognise that they lack the relevant expertise, it can be difficult for them to access necessary expertise from other disciplines such as occupational therapy, speech and language therapy or educational psychology. We have been told that this is not only a problem between organisations, but within the same local authority.

(5) That there can be a lack of communication between departments and teams, inhibiting information gathering, and forcing children and their parents to repeat the same information. We discuss this issue in more detail in Chapter 17.

(6) That the process of assessment does not always properly consider the voices of children, or their parents and carers. We address this issue further in Chapter 21.

(7) That the process of assessments does not always capture the entirety of the child's needs or take a holistic view of those needs.

4.14 A particular issue that was brought to our attention was the focus on safeguarding in assessments, at the expense of consideration of social care needs. This is a well-known problem. In the context of autism, a 2021 report by the (then) Chief Social Worker for Adults and the Chief Social Worker for Children and Families noted:

> Even where the sole reason for contact with children's social care was because of the social care needs of an autistic child, there was a tendency to use the social work assessment as an opportunity to judge parenting capacity through a child protection lens rather than through a lens of social care need. This has long been a complaint of families caring for disabled children. The most common context for support in children's social care is child protection, so even when that is not the necessary focus, it can influence broader practice approaches. Fear of being

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[33] See also L Clements, A L Aiello, *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children's services departments* (July 2021) p 28, para 4.09.

> labelled a bad parent or worries about being blamed as failing as a parent, may limit families' willingness to seek help.
>
> …
>
> We were also particularly troubled by reports we received from families who had been brought into the child protection process because of disagreements with practitioners about how their child's behaviour could best be managed within the home setting … this is a repeated concern that we hear from parents and carers outside of this study in the course of our ongoing communications with families over the years both in our roles as Chief Social Workers and during our many years in practice leadership roles.[34]

4.15 The independent review of children's social care drew attention to this issue as well, noting that:

> … a consistent theme in what the review has heard was that families with disabled children felt 'that they are navigating a system that is set up for child protection, not support' …
>
> … the system appears to be disproportionately spent on assessing and investigating families instead of providing support …[35]

4.16 We have also had regard to the charity Cerebra's report *Institutionalising Parent Carer Blame*.[36] The report's authors used the terminology of "parent carer blame" to describe how parents are:

> … treated in a manner that suggests to them that they are considered to be neglectful and/or abusive parents. Interactions that convey the strong impression that the default position for children's services departments in such cases is to locate the problems families face in parental failings and not in the lack of support that they require in order to overcome the many barriers that confront them as a consequence of their child's impairment.[37]

4.17 Cerebra's research team identified and analysed 143 local authority assessment protocols and found, among other things, that:[38]

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[34] Department of Health and Social Care, Chief Social Workers for Adults and Chief Social Worker for Children and Families, *A spectrum of opportunity: an exploratory study of social work practice with autistic young adults and their families* (February 2021).

[35] J MacAlister*, An independent review of children's social care: The Case for change* (June 2021) pp 29-30.

[36] L Clements, A L Aiello, *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children's services departments* (July 2021).

[37] L Clements, A L Aiello, *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children's services departments* (July 2021) p 6, para 1.04.

[38] L Clements, A L Aiello, *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children's services departments* (July 2021) p 4.

(1) none of the protocols contained a clear explanation that a different approach should be taken when assessing the needs of disabled children where the referral was not accompanied by evidence of neglect or abuse;

(2) 80% of the protocols required the assessor to confirm if the child's bedroom has been seen regardless of whether there was any evidence of neglect or abuse;

(3) 87% of the protocols referred to the need to see or communicate with the child alone regardless of evidence of neglect or abuse; and

(4) none of the protocols required cogent grounds to exist before seeking to see a child's bedroom or seeking to interview a child in the absence of their parents.

4.18 We have heard from some stakeholders how the lack of expertise identified above at paragraph 4.13 can also contribute to a culture of parent blame. For example, we have heard how challenging behaviour (and violence in particular)[39] can be characterised as a result of parental failings rather than disability or trauma. It can, in turn, be met with proposals that parents should undertake parenting courses or that child protection measures (for example, removal of the child from the family home) will be needed if parents cannot remedy the situation.

4.19 In the lead up to this consultation, several stakeholders identified problems with the guidance that plays so substantial a role in practice in determining how assessments are carried out. Some stakeholders have specifically identified that the withdrawal of the *Framework for the Assessment of Children in Need and their Families* has left a gap in the available guidance.

4.20 The Children’s Commissioner for England has also emphasised that:

> The purpose of an assessment and the nature of a plan will be quite different for children who are referred because they are disabled compared to children who are referred for a safeguarding reason. Currently some of the guidance about how assessments should be conducted, and how progress can be monitored – by considering how much improvement parents and carers have made – would not be relevant to all disabled children’s plans.[40]

4.21 A further specific issue that was raised with us was in relation to the expertise of assessors. The charity Cerebra highlights that:

> The almost total lack of statutory guidance concerning the importance of ensuring that disabled children are assessed by assessors with the training, skills, knowledge

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[39] Challenging behaviour is a term that refers to any behaviour which presents a serious risk to the person themselves and/or a challenge to those supporting them. See the Challenging Behaviour Foundation’s “Frequently Asked Questions” in relation to this term, https://www.challengingbehaviour.org.uk/understanding-challenging-behaviour/frequently-asked-questions-the-term-challenging-behaviour/.

[40] Children’s Commissioner, ‘*We all have a voice’ – Disabled children’s vision for change* (October 2023) p 14, para 27.

and competence in undertaking disabled children's assessments is in stark contrast to that relating to the assessment of disabled adults.[41]

4.22 The observations of both the Children's Commissioner and Cerebra pre-date the most recent iteration of *Working Together.* However, this most recent version still contains less about the assessment of disabled children's social care than was contained in the 2000 *Framework* and accompanying practice guidance.

Identifying the law reform issues

4.23 The problems outlined above are multi-faceted, and law reform can only be part of the solution. We have, however, been struck by the contrast in approach between the assessment of disabled children and the assessment of adults who may have needs for care and support. The assessment of adults is governed by a framework of primary legislation, amplified by secondary legislation and statutory guidance, discussed further at paragraphs 4.30 to 4.44 below. Conversely, it can be seen from paragraphs 4.11 to 4.12 above that the process of assessment of disabled children is governed by a minimalistic legislative framework, case law, and guidance that (deliberately) does not descend to specifics regarding the process and content of such assessment.

4.24 In many ways, it is not surprising that this is the case because, as we explained in Chapter 3, section 17 of the Children Act 1989 does not contain an express duty to assess the needs of any individual child. Provisionally proposing an express duty to assess (as we do at paragraphs 3.60 to 3.62) means that we must consider what (if anything) the legislation which contains the duty will say about the process and content of the assessment.

4.25 Furthermore, the issues set out at paragraphs 4.13 to 4.22 appear to show that the lack of a clear and specific framework for the process of assessing disabled children causes problems for both professionals and families. We reiterate though, that we want to hear from consultees about their current experiences of the assessment process to ensure that we have a fully-rounded picture.

Consultation Question 7.

4.26 We invite consultees to tell us about their experiences, both positive and negative, of the current process of assessing the social care needs of disabled children.

OPTIONS FOR REFORM

4.27 As set out above, we need to consider what any legislation containing an express duty to assess the social care needs of disabled children should say about the process and content of the assessment.[42] The two main options are:

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[41] L Clements, A L Aiello, *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children's services departments* (July 2021) p 42, para 5.25.

[42] For a discussion of the difference between legislation and guidance see ch 23.

(1) for the legislation to be silent, and for process and content to be covered by guidance; or

(2) for legislation to set out some or all of the requirements for the process and content of the assessment.

4.28 Option (1) gives rise to two further options.

(a) Expanding the current statutory guidance to include more detail on assessing the social care needs of disabled children. In this regard, we note that *Working Together* is currently 168 pages long. Adding the level of detail that would be required to address the new legislative framework would undoubtedly add significantly to this page length.

(b) Providing additional, specific, guidance on the assessment process. It could be modelled on the practice guidance that accompanied the *Framework for the Assessment of Children in Need and their Families* and go through each stage of the process and content. That would represent a departure from the current approach where the development of the assessment process is made at a local and not a national level.

4.29 Option (2) requires consideration of the extent to which legislation should prescribe process and content. There is a spectrum here.

(a) At one end we can look at the framework for authorising deprivation of liberty contained in the Mental Capacity Act 2005. This is very prescriptive, with the majority of requirements being set out in primary legislation.[43]

(b) At the other end is section 17 of the Children Act 1989, which is entirely silent about the process and content of an assessment. We consider that not having any requirements as to the process and content of assessments set out in legislation would go against the aim of our terms of reference of promoting clarity and consistency in the law.

(c) In the middle is the Care Act 2014. Section 9 of the Care Act 2014 sets out three requirements that an assessment of need must include, as well as who should be involved in the assessment.[44] This is, in turn, amplified by regulations which provide general requirements for an assessment, including the level of expertise required of assessors, and some requirements as to the form of the assessment.[45] Statutory guidance provides a final layer, explaining how the framework operates in practice.

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[43] Mental Capacity Act 2005, sch A1.

[44] Care Act 2014, s 9(4) to (5).

[45] Care and Support (Assessment) Regulations 2014, SI No 2827, regs 2 to 6.

OUR PROVISIONAL PROPOSALS

The overall approach to process and content

4.30 Our provisional view is that option (2)(c) is the best approach. This model was developed after careful consideration and consultation as part of our work on adult social care.[46] It avoids the problems of "government by guidance" that we analyse in Chapter 23 and provides a clear statutory framework. Conversely, it does not fall into the trap of being so prescriptive as to fetter the ability of assessors to adapt to different situations and carry out proportionate assessments. We make specific provisional proposals below which reflect an overall aim of having legislative requirements as to the process and content of assessments which are clear without being too prescriptive. We consider that this approach will bring assessments of disabled children's social care needs further in line with the assessment of adults for their social care needs. Our proposals should also be read in conjunction with those we discuss in Chapters 20 to 22 concerning statutory principles, participation and advocacy respectively.

Proportionate assessments

4.31 A number of local authorities we have heard from in the lead up to this consultation have expressed the concern that introducing an express assessment duty could lead to more assessments taking place and could in turn lead to a drain on local authority resources.[47] One answer to that concern is that assessments do not have to be onerous and resource intensive. As noted in the statutory guidance accompanying the Care Act 2014, an assessment "may come in different formats and can be carried out in various ways".[48]

4.32 For example, assessments could be carried out face-to-face, online or over the phone with the relevant professional. They could also be in the form of a self-assessment or a supported self-assessment, where the parent or carer fills in a form about their child's social care needs and the local authority's role is limited to verifying that the information is accurate. We have been told by some local authority stakeholders that self-assessments of this type can be an effective use of time and resources, particularly in straightforward cases. For example, where all that is being sought is a simple, one-off short break in the form of a supported swimming lesson. Whereas a more involved face-to-face assessment, which draws in multiple expert views and extensive documentation is more likely to be needed for a disabled child with complex needs who is being considered for a residential placement.

4.33 With this in mind, and in order to ensure that assessments are not more complex or time consuming than they need to be, we provisionally propose a legislative requirement that assessments should be proportionate and appropriate. We draw on the approach in adult social care, which provides for this approach in legislation and guidance.[49] A recent guide has been prepared for proportionate assessment under

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[46] Adult Social Care (2011) Law Com No 326, assessments being addressed in chapter 5.

[47] See paras 3.39 to 3.40.

[48] Department of Health and Social Care, *Care and Support Statutory guidance* (March 2024) para 6.3.

[49] The Care and Support (Assessment) Regulations 2014, SI No 2827, reg 3. Department of Health and Social Care, *Care and Support Statutory guidance* (March 2024) para 6.3.

the Care Act 2014 by the (former) Chief Social Worker for Adults, principal social workers and principal occupational therapists.[50] It explains that proportionality means "provid[ing] the right level of response to suit the needs of the person, the situation and the level of risk". Parents and carers we have heard from in the lead up to this consultation have told us that they think assessments should be proportionate and appropriate to the circumstances of the child and their family, and local authorities were also open to the idea.

Consultation Question 8.

4.34 We provisionally propose a requirement that assessments are proportionate and appropriate to the circumstances of the child and their family.

Do consultees agree?

Expertise and training of assessors

4.35 As explained above, we have heard from stakeholders that assessors sometimes lack the relevant training, experience and understanding of disability.[51] The legal framework for adult social care specifically addresses the expertise of assessors in legislation. The regulations accompanying the Care Act 2014 provide that the local authority must ensure that the person carrying out the assessment "has the skills, knowledge and competence to carry out the assessment in question … and is appropriately trained".[52] We provisionally propose that the law on assessments of disabled children's social care needs should mirror this approach.

4.36 In addition, the regulations accompanying the Care Act 2014 make provision for specific expertise in the context of deafblind individuals.[53] We are keen to understand whether it would be appropriate to make specific provision for particular conditions.

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[50] *Proportionate assessment approaches: a guide from the Chief Social Worker for Adults, principal social workers and principal occupational therapists* (March 2024).

[51] See also L Clements, A L Aiello, *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children's services departments* (July 2021) p 28, para 4.09.

[52] Care and Support (Assessment) Regulations 2014, SI No 2827, reg 5(a) and (b).

[53] Care and Support (Assessment) Regulations 2014, SI No 2827, reg 6.

Consultation Question 9.

4.37 We provisionally propose that assessors should be required to have appropriate expertise and training.

Do consultees agree?

4.38 We invite consultees' views on whether assessors should be required to have expertise in specific conditions.

Copies of the assessment

4.39 Given the importance of ensuring that children and their families understand what support (if any) they are to be provided with and why, we provisionally propose that legislation should require local authorities to provide disabled children and their families with a copy of their assessment. This is already the law for parent carer assessments[54] and for parents and (older) children under the Children and Families Act 2014.[55] We have not been able to identify a reason for a different approach in relation to disabled children's social care.

Consultation Question 10.

4.40 We provisionally propose that local authorities should be required to provide disabled children and their families with a copy of their assessment.

Do consultees agree?

Consideration of other statutory assessment duties

4.41 We heard from stakeholders in the lead up to this consultation that in any future legal framework for disabled children, there must be consideration of how the new framework interacts with other statutory provisions which affect them. For example, there was a concern amongst social workers that if the law on assessments is focused only on assessing the child's social care needs arising from disability, it could result in the child's wider needs being overlooked. Those wider needs could include needs arising from poverty, needs relating to the child's immigration status or any safeguarding concerns. To ensure that these factors are not overlooked we provisionally propose that guidance on the process and content of disabled children's social care assessments should emphasise that assessors need to consider whether any other relevant statutory assessment duty is engaged during an assessment. These other statutory assessment duties would include:

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[54] Children Act 1989, s 17ZD(13).

[55] Children and Families Act 2014, ss 39 and 40.

(1) assessment under section 17 of the Children Act 1989 if the assessor has reason to believe that the child is "in need" for the purposes of that provision (this is only relevant if disabled children's social care needs are considered under a new framework as discussed in Chapter 23);

(2) assessment under section 47 of the Children Act 1989 in situations where the local authority may have reasonable cause to suspect that the child is suffering or is likely to suffer significant harm (see further paragraph 3.26); and

(3) assessment under the continuing care framework that applies to children with relevant health care needs (see further paragraphs 14.11 to 14.19).

Consultation Question 11.

4.42 We provisionally propose that guidance should emphasise that assessors need to consider whether any other relevant statutory assessment duty is engaged when assessing the social care needs of a disabled child.

Do consultees agree?

Delegating functions

4.43 In line with our approach of seeking to make the assessment process flexible, having the ability to delegate assessments could be useful for increasing the options available to local authorities. For example, it would allow assessments to be carried out by a body (for instance an NHS body, or a specialist charity) with greater expertise in the particular condition. It could, however, mean that local authorities have less control and oversight over this important function. Having said that, it is arguable that the power to delegate already exists in relation to children,[56] but it is not clear.

4.44 An example of a power to delegate an assessment can be found in section 79 of the Care Act 2014, which provides for local authorities to delegate certain of their functions under that Act, including, most relevantly, the process of assessing needs. This delegation is not absolute. The local authority retains ultimate responsibility for ensuring that the function is carried out properly and in accordance with the relevant statutory obligations. The local authority also retains ultimate responsibility for the standard of the assessments undertaken.

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[56] This was the view we took in relation to assessments of adults in our Adult Social Care project. See Adult Social Care (2011) Law Com No 326 para 5.122.

Consultation Question 12.

4.45 We invite consultees' views on whether it is necessary and appropriate to give local authorities the power to delegate the assessment of the social care needs of disabled children to trusted third parties, retaining ultimate responsibility for the standard of the assessment.

Chapter 5: Assessing the needs of parents and carers

INTRODUCTION

5.1 Assessing the needs of parents and carers is an essential part of the disabled children's social care system. If parents' and carers' needs are not accurately identified, then the correct support cannot be provided to enable them to continue effectively to provide care for their disabled children. This chapter considers the framework governing these assessments.

THE CURRENT LAW

Terminology

5.2 Before explaining the law on assessing parent and carer needs, we need to make clear the distinction in the law between a carer who has parental responsibility and a carer without parental responsibility, as the law on assessments treats these two groups differently.

5.3 The Children Act 1989 defines a "parent carer" as an adult "who provides or intends to provide care for a disabled child for whom the person has parental responsibility".[1] Parental responsibility is a legal status governed by section 3(1) of the Children Act 1989.[2] It is distinct from legal parentage. A child's birth mother automatically acquires parental responsibility from birth. This is also the case for birth fathers and female partners if they were married or in a civil partnership with the child's mother at the time of the birth or conception respectively.[3] Unmarried partners do not automatically have parental responsibility, but they can acquire it in several ways, including by being registered on the child's birth certificate or by making a parental responsibility agreement with the child's mother. It is also possible for carers without parental responsibility and local authorities to acquire parental responsibility.[4] Because the definition of a "parent carer" under the Children Act 1989 requires the carer to have parental responsibility, it excludes carers such as grandparents or extended family members who do not have parental responsibility.

5.4 In the rest of this consultation paper, we have referred to all carers for disabled children collectively under the umbrella term "parents and carers". For the purposes of this chapter only, for clarity and accuracy, we will use the legal term "parent carer" as defined in the Children Act 1989 and the term "carers without parental responsibility"

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[1] Children Act 1989, s 17ZD(2).

[2] Children Act 1989, s 3(1) defines parental responsibility as "all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and [their] property".

[3] Children Act 1989, s 2; Human Fertilisation and Embryology Act 2008, ss 42 and 43.

[4] See further House of Commons Library, *Research Briefing: Parental responsibility in England and Wales* (July 2024).

when referring to all other unpaid adult carers of disabled children.[5] This will include some kinship carers. The Office for National Statistics defines a child as being in a kinship care relationship when a child lives full-time or most of the time with a relative or close family friend, usually because their parents are not able to care for them.[6] Kinship carers include siblings, grandparents, or other relatives, such as their aunts, uncles, or cousins. Some kinship carers, such as those in informal kinship care arrangements, do not have parental responsibility, while others, such as kinship carers with a Special Guardianship Order do.[7] The Law Commission will, in due course, be carrying out a separate review of kinship care. That review, like this one, arises from a recommendation made in the Independent Review of Children's Social Care,[8] which we discuss at paragraphs 1.33 to 1.36. The aim of the review will be to reform the law to facilitate kinship care for children. The approach in this chapter is intended to be consistent with that objective.

5.5 Both parent carers and carers without parental responsibility are legally entitled to an assessment of their needs, but the duty to assess is contained in two different legal frameworks. We set out both frameworks below.

Duty to assess parent carers' needs

5.6 Parent carers are entitled to have their own needs for support assessed if:[9]

(1) they have asked the local authority for an assessment; or

(2) it appears to the local authority that the parent may have support needs;

providing that the child and their family are persons for whom services under section 17 of the Children Act 1989 may be provided (which will generally be the case).[10]

5.7 This assessment is called a "parent carer's needs assessment". Parent carers have a right to ask for an assessment of their needs at any time, unless the local authority has previously carried out a "care-related" assessment for them in relation to the same disabled child.[11] However, the local authority must re-assess if it appears to the authority that the needs or circumstances of the parent carer or the disabled child

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[5] The *Working Together* guidance uses the term "non-parent carers" instead of "carers without parental responsibility". The term "non-parent carers" does not appear in any statute.

[6] Office for National Statistics, *Kinship care in England and Wales: Census 2021, Detailed characteristics of children living in households without their parents but with other relatives in 2021* (September 2023).

[7] For the definitions of different types of kinship care, see Department for Education, *Championing Kinship Care*, *The National Kinship Care Strategy* (December 2023) pp 14 and 44.

[8] J MacAlister, *The independent review of children's social care – Final Report* (May 2022).

[9] Children Act 1989, s 17ZD(1) to (4) and (9) to (13) inserted by s 97 of the Children Act 2014. The specific duty to assess the individual needs of the parent carer, under s 17ZH(1), is supplemented by a general duty, under s 17ZD(14), to take reasonable steps to identify the extent of parent carer need in the area.

[10] Children Act 1989, s 17ZD(1) to (4). An example of a parent carer who might not be entitled to services under s 17 of the Children Act 1989 could be a parent who does not have leave to remain in the United Kingdom. They would be excluded from services under s 17 of the Children Act 1989 by Nationality, Immigration and Asylum Act 2002, sch 3, save to the extent necessary to avoid a breach of their rights under the European Convention on Human Rights.

[11] Children Act 1989, s 17ZD(6).

being cared for have changed since the "care-related" assessment. A "care-related" assessment means:[12]

(1) a parent carer's needs assessment;

(2) an assessment under section 1 of the Carers (Recognition and Services) Act 1995, which is the assessment available to carers without parental responsibility;[13] or

(3) an assessment under Part 1 of the Care Act 2014, which is an assessment under the adult social care framework of an adult who provides care for another adult.

5.8 A parent carer's needs assessment can be combined with the assessment of the disabled child's needs and any young carer's assessment.[14] Young carers' needs assessments are discussed in Chapter 6. The parent carer's needs assessment should include an evaluation of whether it is appropriate for the parent carer to provide, or continue to provide, care for the disabled child, in the light of the parent carer's own needs for support, other needs and wishes.[15] In carrying out the assessment, the local authority should have regard to the parent carer's well-being, as defined in section 1 of the Care Act 2014, as well as the need to safeguard and promote the welfare of the disabled child together with any other children for whom the parent carer has parental responsibility.[16] A person's well-being for these purposes includes consideration of:[17]

(1) their personal dignity;

(2) their physical and mental health and emotional well-being;

(3) whether they are protected from abuse and neglect;

(4) their control over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided);

(5) their participation in work, education, training or recreation;

(6) their social and economic well-being;

(7) their domestic, family and personal relationships;

(8) the suitability of their living accommodation; and

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[12] Children Act 1989, s 17ZD(7).

[13] See paras 5.11 to 5.12 below.

[14] Children Act 1989, s 17ZE(3).

[15] Children Act 1989, s 17ZD(9).

[16] Children Act 1989, s 17ZD(10) and (11).

[17] Care Act 2014, s 1(2).

(9) their contribution to society.

5.9 The parent carer should be given a written record of the assessment.[18] This requirement mirrors the duty under the Care Act 2014 to provide such a record following an assessment of needs under that Act.[19]

5.10 Having carried out the parent carer's needs assessment, the local authority is required to decide whether the needs identified in the assessment can be met under section 17 of the Children Act 1989 and, if so, whether to meet those needs.[20] We discuss meeting the needs of parent carers in Chapter 7.

Duty to assess the needs of carers without parental responsibility

5.11 As explained above, other carers who do not have parental responsibility but who provide care to a disabled child are also entitled to an assessment of their needs. This duty is contained in the Carers (Recognition and Services) Act 1995.[21] This duty is triggered where a carer provides, or intends to provide "a substantial amount of care on a regular basis" for the disabled child.[22] If they meet this threshold, then they may request the local authority to carry out an assessment of their ability to provide, and continue to provide, that care, alongside the assessment of the child's needs.[23] Where the carer does not ask for an assessment, but it appears to the local authority that they may be entitled to one, then the local authority should inform them of their right to make such a request.[24]

5.12 An assessment of a carer's needs under the Carers (Recognition and Services) Act 1995 should include consideration of whether the carer is working or undertaking training, education or leisure activities, or wishes to do any of these things.[25] As with the duty owed to parent carers, the local authority is required to take the results of the assessment into account in deciding whether or not to provide services to the carer.[26] In contrast to the duty owed to parent carers, there is no requirement to provide the carer with a copy of the assessment.

Guidance on assessments for carers

5.13 The *Working Together* guidance provides some information for practitioners working with parents and carers. As well as describing the legal requirements set out above, it

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[18] Children Act 1989, s 17ZD(13).

[19] Care and Support (Assessment) Regulations 2014, SI No 2827, reg 3(4) and (5).

[20] Children Act 1989, s 17ZF.

[21] Carers (Recognition and Services) Act 1995, s 1(1).

[22] Carers (Recognition and Services) Act 1995, s 1(1)(b).

[23] Carers (Recognition and Services) Act 1995, s 1(2). The duty does not extend to those who provide care under a contract or on behalf of a voluntary organisation: Carers (Recognition and Services) Act 1995, s 1(3).

[24] Carers (Recognition and Services) Act 1995, s 1(2B).

[25] Carers (Recognition and Services) Act 1995, s 1(2C).

[26] See chs 7 and 8.

reminds local authorities to "ensure they have a process to facilitate these assessments if requested".[27]

5.14 *Working Together* also encourages joint working with adult social care services when both carrying out assessments and providing support to families where there are young carers or parent carers.[28] In relation to both types of assessments, it notes that "adult assessments, for example, parent carer or non-parent carer assessments, should also be carried out in a timely manner".[29]

5.15 Although not focused specifically on parent carers' needs assessments, the section in *Working Together* on encouraging a child-centred approach with a whole family focus is also relevant to assessments of parents' and carers' needs:

> In the context of a child-centred approach, all practitioners should work in partnership with parents and carers as far as possible. Parents and carers need to understand what is happening, what they can expect from the help and support provided, what is expected of them and be supported to say what they think. …Practitioners need to be particularly skilled in engaging and working with parents and carers whom services have found difficult to engage. Some examples may be parents and carers of disabled children, parents, and carers whose children are at risk of, or experiencing, harm from outside the home, fathers, and male carers, and those who are neurodivergent.[30]

5.16 The *Working Together* guidance provides "four principles" for practitioners that "underpin work with parents and carers" which include, among other things, encouraging practitioners to adapt "their responses to meet…the specific challenges being faced, including by parents and carers of disabled children".[31]

THE CASE FOR REFORM

Inaccessibility

5.17 The fact that there is an express legislative duty to assess the needs of parent carers and carers without parental responsibility means that the law is clearer than it is for children, where the assessment duty is implied (see Chapter 3). Nevertheless, the fact that the legal requirements are spread across three different statutes – the Children Act 1989, the Care Act 2014 and the Carers (Recognition and Services) Act 1995 – arguably makes the law inaccessible.

Inconsistency between parent carers and carers without parental responsibility

5.18 There are also a number of inconsistencies between the assessment duties owed to parent carers and carers without parental responsibility.

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[27] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 190.

[28] HM Government, *Working Together to Safeguard Children 2023* (December 2023) paras 253 and 254.

[29] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 152.

[30] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 18.

[31] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 18.

(1) The two groups have to meet different thresholds in order to qualify for an assessment. We think this inconsistency is significant and we discuss it further below.

(2) There are different routes to obtaining assessments for these two groups: local authorities can assess parent carers where it appears that there is a need to do so, but in the same situation are limited to informing carers without parental responsibility of their right to ask for an assessment. The latter is a more convoluted route to an assessment.

(3) Parent carers have a right to a copy of their assessment whereas carers without parental responsibility do not. Having a copy of the assessment allows the recipient to see whether their needs have been identified correctly and to understand the authority's decision as to what services, if any, they should be provided with. We have not been able to identify a reason of principle why carers without parental responsibility should not also be entitled to a copy of their assessment.

(4) A parent carer's needs assessment must cover a wider range of factors than an assessment for a carer without parental responsibility. In particular, the carer's well-being (as defined in section 1 of the Care Act 2014) must be considered when conducting a parent carer's needs assessment. There is no equivalent statutory requirement when assessing a carer without parental responsibility. However, an understanding of the impact that the carer's responsibilities are having on their wellbeing is relevant to the decision which has to be taken as to whether to provide them with support.

5.19 Of these four inconsistencies, we think that the first is particularly important and warrants closer scrutiny. As we have explained above, for parent carers an assessment will be required if "it appears to the authority that the parent carer may have needs for support". On the other hand, for carers without parental responsibility, an assessment will only be required if the carer "provides or intends to provide a substantial amount of care on a regular basis for the relevant person". We will refer to this as the "substantial and regular test".

5.20 The duty to assess the needs of parent carers was inserted into the Children Act 1989 by the Children and Families Act 2014. Prior to that, there was a single duty to assess the needs of all carers – for children and adults alike, and irrespective of whether they had parental responsibility – under the Carers (Recognition and Services) Act 1995. This meant that *all* carers had to satisfy the "substantial and regular test". The Care Act 2014 took carers of adults out of the scope of the Carers (Recognition and Services) Act 1995, providing instead that they should have their needs assessed under section 10 of the Care Act 2014. Simultaneously, the Children and Families Act 2014 took parent carers out of the scope of the Carers (Recognition and Services) Act 1995, providing instead that they should have their needs assessed under section 17ZD of the Children Act 1989.[32]

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[32] Children and Families Act 2014, s 97; Care Act 2014 and Children and Families Act 2014 (Consequential Amendments) Order 2015, SI No 914, sch 1, para 56(4).

5.21 These changes meant that parent carers and carers of adults were entitled to assessments where it appeared to the local authority that they may have needs for support. But carers without parental responsibility remained subject to the "substantial and regular test". The introduction of this difference does not appear to have been a conscious policy choice. The parent carer's needs assessment duty in section 17ZD was not contained in the original version of the Children and Families Bill. It was introduced by an amendment in the House of Lords.[33] There was no discussion of carers of disabled children without parental responsibility when this amendment was introduced and agreed in the House of Lords. The authors of the leading textbook on disabled children's law suggest that it was "due to a drafting oversight" that the Children and Families Act 2014 "failed to secure the rights of adults who provided unpaid care for disabled children but for whom they lacked parental responsibility".[34]

5.22 There are a number of criticisms which can be made of the retention of the "substantial and regular" test for carers without parental responsibility. Some of these were raised in our review of adult social care law, in which we concluded that it should be abandoned for carers of adults. All of the criticisms go to the central point that it has the potential to prevent some carers without parental responsibility from accessing support, by making it more difficult for them to have their needs assessed.

(1) The first criticism is that the test lacks clarity and is overly complex, resulting in the potential for it to be applied inconsistently by local authorities.[35]

(2) The second criticism is that it can cause inefficiency by requiring local authorities to "undertake pre-assessments to decide whether a carer satisfies the substantial and regular requirement".[36]

(3) The third criticism is that it is directed at the wrong issue. The focus of the "substantial and regular" requirement is on the amount and frequency of the care which the carer provides. Conversely, the focus of the tests that apply to parent carers and to carers of adults is on whether they need (or might need) support in order to provide that care. The point of assessing a carer's needs is so that a local authority can work out whether to provide them with support so that they can continue to provide effective care. Bearing this in mind, it arguably makes more sense to have an assessment threshold which concentrates on the support the carer *needs*, as opposed to concentrating on the care they *provide*.

Assessments not being offered or undertaken

5.23 We have heard from stakeholders that carers' assessments are not always offered or undertaken when they should be. In 2021, the charity Cerebra reviewed 149 local

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[33] *Hansard* (HL), 5 February 2014, vol 752, cols 241-246.

[34] S Broach and L Clements, *Disabled Children: A Legal Handbook* (3rd ed 2020) p 371, para 8.15. See further L Clements, *The 'grandparent' problem* (January 2016), http://complexneeds.org.uk/modules/Module-1.2-The-legislative-context-edition-2/All/downloads/m02p010c/carers-assessments-grandparents-clement-2015.pdf.

[35] Adult Social Care (2011) Law Com No 326 para 7.10.

[36] Adult Social Care (2011) Law Com No 326 para 7.15.

authority protocols for assessment[37] and found that only 3% of them included a reference to a parent carer's needs assessment.[38] In some instances we have heard that assessments are not undertaken even when they have been requested. This may be due to a perception that there would be no point carrying out the assessment as there may not be services available to meet the carer's needs.

Content of assessments

5.24 In the lead up to this consultation, we have heard that where carers' assessments are undertaken there will often be a focus on whether the child's needs are being met. This focus can come at the cost of considering other relevant matters. For example, we have heard that factors such as sleep deprivation and the emotional toll of looking after a profoundly disabled child are not always taken into consideration. In addition, some parents and carers we have heard from feel reluctant to admit to any vulnerability during the assessments – in particular mentioning depression, anxiety or difficulty with coping – for fear that this will be interpreted as meaning that they are not able to care properly for their child. This inhibits candour. However, there is evidence to suggest that such mental health conditions are prevalent amongst carers, with a recent study finding that 42% of parent carers had experienced suicidal thoughts and behaviours while caring.[39] It is not clear to us whether the experiences we have heard reflect a general trend or whether they are isolated occurrences. To help us evaluate this we invite consultees to tell us about their experiences – both positive and negative – of carers' assessments.

Consultation Question 13.

5.25 We invite consultees to tell us about their experiences, both positive and negative, of parent carers' needs assessments, or assessments for carers without parental responsibility.

OPTIONS FOR REFORM

Option 1: Combine the assessment duties

5.26 One option to deal with the complexity and inaccessibility of the law is to combine the duties to assess the needs of parent carers and carers without parental responsibility into one single duty.

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[37] See further HM Government, *Working Together to Safeguard Children 2023* (December 2023) paras 141 to 145. See also paras 4.4 to 4.10 of this consultation paper.

[38] L Clements, A L Aiello, *Institutionalising parent carer blame: The experiences of families with disabled children in their interactions with English local authority children's services departments* (July 2021) p 39, para 5.15.

[39] S O'Dwyer and others, *Suicidal Thoughts and Behaviors in Parents Caring for Children with Disabilities and Long-Term Illnesses* (July 2024) p 8.

5.27 To combine the duties to assess, it would be necessary to resolve the inconsistencies between the two which we explain at paragraphs 5.19 to 5.22. This generates a series of further questions which we set out below.

(1) What is the appropriate threshold for obtaining an assessment? Should an assessment be available if "it appears to the authority that the parent carer may have needs for support"? That is the threshold that currently applies to parent carers. Or should the right to an assessment be restricted to cases where the carer "provides or intends to provide a substantial amount of care on a regular basis for the relevant person": the "substantial and regular test"? That is the threshold that currently applies to carers without parental responsibility.

(2) What is the appropriate route to obtaining an assessment? In addition to carrying out an assessment on request, should a local authority be required to carry out an assessment where it appears that the threshold for providing an assessment is met? That route is currently available to parent carers. Or, in that scenario, should the local authority be limited to informing the parent carer that they have a right to an assessment? That is the process that must currently be used for carers without parental responsibility.

(3) Should there be a right to a copy of the assessment? Parent carers currently have such a right but carers without parental responsibility do not.

(4) Should the assessment be required to consider the well-being of the carer as defined in section 1 of the Care Act 2014?[40] This requirement applies to parent carers but not to carers without parental responsibility.

5.28 We refer consultees to paragraphs 4.43 to 4.45 where we discuss the potential for delegating assessments of children. That is also an option for assessments of carers and the same considerations apply.

Option 2: Retain separate duties

5.29 An alternative option would be to retain separate assessment duties for carers with parental responsibility and carers without. The law could be simplified by placing the two duties in the same legal framework, rather than in two separate statutes. Consistency could be promoted by providing the same routes to an assessment, the same right to have a copy of the assessment and requiring the same factors to be taken into account during the assessment process. However, keeping the duties separate would allow for the different assessment thresholds to be maintained. As we explain above, we do not think that the existence of different assessment thresholds was the result of a deliberate policy choice. Nevertheless, having a higher threshold for carers without parental responsibility might still be justified on the basis that it precludes (for example) carers outside of the family who only provide occasional, minimal care from obtaining an assessment.

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[40] See para 5.8 above.

OUR PROVISIONAL PROPOSALS

5.30 The options that we have set out above are not equally weighted and for the most part we think the appropriate way forward is clear. Our provisional proposals on assessing parents' and carers' needs are set out at (1) to (3) below. These should be read together with the provisional proposals we make in Chapters 20 to 22.[41]

(1) The routes to an assessment should be as simple as possible. We therefore provisionally propose that the more convoluted route to obtaining an assessment for a carer without parental responsibility, described at paragraph 5.18(2) should be abandoned.

(2) We provisionally propose that all carers should have a right to a copy of their assessment. Without this they cannot reasonably be expected to understand what (if any) services they are to be provided with and why. We suspect that, in practice, copies of the assessment are provided to most carers in any event and that making this mandatory in all cases would not substantially change what is happening on the ground.

(3) We also think that the well-being of the carer should be considered in all cases: this is just as relevant to the needs of carers without parental responsibility as it is to parent carers. We therefore provisionally propose that this is made a statutory requirement.

5.31 The more difficult issue is whether the "substantial and regular" test should be retained for carers without parental responsibility. Our provisional proposal is that it should not. As we observe above at paragraph 5.22, it lacks clarity, gives rise to inefficiency and is not focused on the issue which really matters, which is whether the carer may need support to fulfil their caring responsibilities. The fact that the retention of this test appears to have been the result of legislative oversight, rather than deliberate policy choice, makes these defects hard to justify.

5.32 We recognise that, in theory, removing the "substantial and regular" test might lead to an increase in the number of assessments which need to be undertaken for carers without parental responsibility. We cannot, however, see any reason of principle why carers without parental responsibility should not be entitled to an assessment in circumstances where a parent carer would be. Under the current legal framework for disabled children's social care there is no statutory distinction between parent carers and carers without parental responsibility when it comes to eligibility for services. Services can be made available to both groups on equal terms under section 2(4) of the Chronically Sick and Disabled Persons Act 1970 and section 17(1) of the Children Act 1989.[42] Consistently with this, in our provisional proposals in Chapters 7 and 8, we do not propose introducing any distinction between parent carers and carers without parental responsibility when it comes to eligibility for services. If carers without parental responsibility are eligible for services on an equal footing to parent carers, we

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[41] Concerning statutory principles, participation and advocacy respectively.

[42] See in particular, Children Act 1989, s 17(3) and (10) which adopt a deliberately broad definition of family that includes "any person who has parental responsibility for the child *and any other person with whom he has been living*" (emphasis added).

do not think there is any real justification for "gatekeeping" access to those services by making it more difficult for carers without parental responsibility to have their needs assessed. At paragraph 5.29 above we acknowledge the possibility that the "substantial and regular" test might filter out carers outside of the family who only provide occasional, minimal care. But realistically, we think it is unlikely that carers who provide only minimal amounts of care would want an assessment. In any event, it is unlikely that they will need (or appear to need) support, so the lower assessment threshold should be an adequate filter.

5.33 Drawing these threads together, we provisionally propose that there should be one single duty, set out in primary legislation, to assess the needs of carers of disabled children in the local authority's area, irrespective of whether the carer has parental responsibility for the child. The duty should arise either where the carer requests an assessment or where it appears to the local authority that they may have needs for support.

Consultation Question 14.

5.34 We provisionally propose that there should be a single duty to assess the needs of a carer for a disabled child, which should arise upon (a) request by the carer or (b) it appearing to the local authority that the carer may have needs for support.

Do consultees agree?

5.35 In carrying out the assessment, we provisionally propose that the local authority should be required to have regard to the well-being of the carer as defined in section 1 of the Care Act 2014. In addition, we provisionally propose that all carers, regardless of whether they have parental responsibility or not, should have a right to a copy of their assessment.

Consultation Question 15.

5.36 We provisionally propose that, in assessing the needs of a carer for a disabled child, the local authority should be required to have regard to the well-being of the carer.

Do consultees agree?

Consultation Question 16.

5.37 We provisionally propose that all carers should have a right to a copy of their assessment.

Do consultees agree?

5.38 As we set out for children at paragraphs 4.31 to 4.34, we also provisionally propose a requirement that assessments should be proportionate and appropriate. This reflects the idea that a carer’s assessment need not necessarily be a resource intensive or time-consuming task. Rather, the breadth and depth of the assessment should reflect the extent of the carer’s needs.

Consultation Question 17.

5.39 We provisionally propose a requirement that carers’ assessments are proportionate and appropriate to the circumstances of the carer.

Do consultees agree?

Chapter 6: Assessing siblings' needs

INTRODUCTION

6.1 We are tasked with considering the needs of "disabled children and their families". This, by definition, includes the siblings of disabled children.[1] The charity Sibs estimate that there are over half a million siblings of disabled children and young people in the UK, and that 5.1% of children under 16 are siblings of disabled children.[2]

6.2 There are three situations in which the needs of a non-disabled sibling of a disabled child might need to be assessed:

(1) where meeting the sibling's needs may be necessary to meet the needs of the disabled child;

(2) where the sibling is a "child in need" in their own right; and

(3) where the sibling is a "young carer" to the disabled child.

This chapter considers each of these three situations.

THE CURRENT LAW

Sibling requires needs to be met in order to meet needs of a disabled child

6.3 A local authority may be required to meet the needs of a sibling where that is necessary to meet the needs of a disabled child.[3] Alternatively, a local authority has a power to provide services to the sibling of a disabled child "with a view to safeguarding or promoting the [disabled] child's welfare".[4] In either case, the needs of the sibling are, in effect, seen as part and parcel of the needs of the disabled child. This means, in turn, that the sibling's needs will need to be considered in assessing the needs of the disabled child. The rules governing the assessment of disabled children are set out in Chapters 3 and 4.

Sibling a "child in need"

6.4 Siblings may also be classed as children in need if:[5]

(1) they are unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the

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[1] See ch 1. Our terms of reference state that the review will "consider whether existing duties…and accompanying statutory guidance sufficiently meet the specific needs of disabled children and their families".

[2] Sibs (no date), https://www.sibs.org.uk/about-sibs/media/.

[3] Chronically Sick and Disabled Persons Act 1970, s 2(4); Children Act 1989, s 17(3).

[4] Children Act 1989, s 17(3). See also ch 7.

[5] Children Act 1989, s 17(10)(a) and (b).

provision of services by a local authority under Part 3 of the Children Act 1989; or

(2) their health or development is likely to be significantly impaired, or further impaired, without the provision for them of such services.

6.5 In the lead up to this consultation, we have heard examples from stakeholders of situations where living with a disabled brother or sister has consequences for the sibling. We list some examples below.

(1) The sibling faces sleep deprivation. A recent survey conducted by the charity Sibs found that 30% of the siblings of disabled children surveyed were tired at school because they had not managed to have enough sleep.[6]

(2) The sibling faces violence from their disabled brother or sister.

(3) The sibling loses out on time with their parents.

(4) The sibling cannot go on holiday because their disabled brother or sister cannot do so.

(5) The sibling is called upon by their school to help manage their disabled brother or sister, putting significant pressure on the sibling and jeopardising their educational prospects. The charity Sibs estimates that this happens in around 5% of cases.[7]

6.6 If these, or any other factors, give rise to the possibility that they may be a "child in need" then, like any other child, they are entitled to an assessment under section 17 of the Children Act 1989.[8]

Sibling a "young carer"

6.7 In 2013, the Children's Society charity estimated that half of young carers in the UK were siblings of disabled children.[9] We have no reason to consider that the statistics are materially different now. These siblings are more likely than the national average to be "not in education, employment or training" between the ages of 16 and 19.[10]

6.8 A "young carer" is a "person under 18 who provides or intends to provide care for another person and is not doing so under a contract or as voluntary work".[11] Young carers are entitled to a needs assessment from their local authority if:[12]

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[6] Sibs, *If Only You Knew. A report into the school experiences of siblings of disabled children* (April 2024) p 5.

[7] Sibs, *If Only You Knew. A report into the school experiences of siblings of disabled children* (April 2024) p 5.

[8] *R (G) v Barnet London Borough Council* [2003] UKHL 57, [2004] 2 AC 208. See also ch 3.

[9] The Children's Society, *Hidden from view: The experiences of young carers in England* (May 2013) p 9.

[10] The Children's Society, *Hidden from view: The experiences of young carers in England* (May 2013) p 12.

[11] Children Act 1989, ss 17ZA(3) and 17ZB(3).

[12] Children Act 1989, s 17ZA(1)(a) and (b).

(1) it appears to the authority that the young carer may have needs for support; or

(2) the local authority receives a request from the young carer or a parent of the young carer to assess the young carer's needs for support.

6.9 If either criterion is met and the young carer is within the local authority's area then the local authority is under a duty to assess whether they have needs for support and, if so, what those needs are.[13] This is known as a "young carer's needs assessment".[14] A young carer's needs assessment may be combined with an assessment of the person cared for, but only if the young carer and the person cared for agree.[15]

6.10 The young carer's needs assessment recognises the very significant role that the siblings of disabled children can play in their lives. As the charity Sibs explain:

> Neither child nor adult siblings have a duty to care for their disabled brothers or sisters. Many siblings undertake practical tasks with their brother or sister such as feeding, administering medication, lifting and handling, sitting, and helping in the night. They may also support parents, for example listening to their worries, doing housework, going shopping or cooking meals. In addition siblings may offer emotional support such as helping their brother or sister to socialise and teaching them skills such as reading.[16]

6.11 A young carer's needs assessment is not available to a young carer if the local authority has previously carried out a care-related assessment of them in relation to the same person cared for.[17] An assessment must, however, be carried out if it appears to the local authority that the needs or circumstances of the young carer or the person cared for have changed since the last care-related assessment.[18]

6.12 The young carer's needs assessment must include an assessment of whether it is appropriate for the young carer to provide, or continue to provide, care for the person in question, in the light of the young carer's needs for support, other needs and wishes.[19] Providing care means providing practical or emotional support.[20] The factors to which the local authority must have regard when determining this are:[21]

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[13] Children Act 1989, s 17ZA(1).

[14] Children Act 1989, s 17ZA(2).

[15] Children Act 1989, s 17ZB(7).

[16] Sibs, *Assessing the needs of young siblings.* See https://www.sibs.org.uk/supporting-young-siblings/professionals/assessing-the-needs-of-young-siblings/.

[17] Children Act 1989, s 17ZA(4).

[18] Children Act 1989, s 17ZA(5). A care-related assessment for these purposes is a young carer's needs assessment, an assessment under Part 1 of the Care Act 2014 or section 1 of the Carers (Recognition and Services) Act 1995.

[19] Children Act 1989, s 17ZA(7).

[20] Children Act 1989, s 17ZB(5).

[21] Children Act 1989, s 17ZA(8).

(1) the extent to which the young carer is participating in or wishes to participate in education, training or recreation; and

(2) the extent to which the young carer works or wishes to work.

6.13 The young carer's needs assessment must involve the young carer, their parents and anyone else the young carer or their parents want to involve.[22] Following the assessment, the local authority must provide a written record of assessment to all of these individuals.[23]

6.14 The assessment must be conducted in accordance with the Young Carers (Needs Assessments) Regulations 2015.[24] The form of the assessment is not prescribed in the regulations. Rather, the regulations require that it should be carried out appropriately and proportionately "to the needs and circumstances of the young carer".[25]

THE CASE FOR REFORM

6.15 As explained above, there are three situations in which the needs of a non-disabled sibling of a disabled child might need to be assessed:

(1) where meeting the sibling's needs may be necessary to meet the needs of the disabled child;

(2) where the sibling is a "child in need" in their own right; and

(3) where the sibling is a "young carer" to the disabled child.

6.16 The case for reform in relation to the first and second situation can be dealt with together. In the lead up to this consultation, we have heard from a number of parents and carers that the needs of siblings are overlooked, irrespective of whether:

(1) meeting those needs would benefit the disabled child; or

(2) the impact of the needs of the disabled child is such that the sibling themselves might be a child in need.

6.17 We invite consultees' views and experiences on the extent to which siblings are, or are not, considered during the assessment of a disabled child's social care needs. Our initial impression is that such needs are not always being identified and that change may be required to remedy this.

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[22] Children Act 1989, s 17ZA(9).

[23] Children Act 1989, s 17ZA(10).

[24] SI 2015 No 527.

[25] SI 2015 No 527, reg 2(1).

Consultation Question 18.

6.18 We invite consultees to provide their experiences of the extent to which siblings' needs are considered during the assessment of a disabled child.

6.19 Turning to the third situation, we have heard no specific concerns about the conduct or content of young carers' needs assessments. However, the fact that there are separate legal frameworks for assessing the needs of young carers and other carers might be thought to add an unnecessary layer of complexity to the law. Again, we welcome consultees' views on this.

Consultation Question 19.

6.20 We invite consultees to provide their experiences of the conduct of young carers' needs assessments.

OPTIONS FOR REFORM

Sibling requires needs to be met in order to meet needs of disabled child

6.21 In this first situation, the needs of the sibling should be considered as part of the assessment of the needs of the disabled child. There are two options to achieve this.

(1) The first is to make it a legislative requirement. This would have the benefit of clarity and would ensure it is not overlooked. However, it may not be necessary in all cases. Having a rigid requirement may create unnecessary work and intrusion into family life and undermine our provisional proposal in Chapter 4 that assessments should be proportionate.[26]

(2) The second option is to highlight the potential need to consider the sibling's needs in guidance. This is a more flexible option and would be consistent with our provisional proposals in Chapter 4.

Sibling a "child in need"

6.22 The second situation was identified as a problem during our engagement with parents and carers of disabled children in the lead up to this consultation. Some siblings may be children in need but, it appears, this is not always being identified. However, solving this problem lies outside of our terms of reference.[27]

Sibling a "young carer"

6.23 In Chapter 5 we discuss the duties to assess adult carers of disabled children both with and without parental responsibility. In that chapter we provisionally propose that the duties to assess adult carers should be combined, and that assessments should

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[26] See paras 4.31 to 4.34.

[27] See para 1.17.

be available either on request by the carer or it appearing to the local authority that the carer may have needs for support.[28] This is the same threshold as applies to young carers and gives rise to the possibility that the assessment of all carers of disabled children – irrespective of age – could be combined under one assessment duty. This would certainly simplify the law. But the needs of young carers will often be very different to the needs of adult carers and having one assessment duty for both could result in this distinction being glossed over, and the specific needs of young carers being overlooked.

OUR PROVISIONAL PROPOSALS

Sibling requires needs to be met in order to meet needs of disabled child

6.24 The question of whether meeting a sibling's needs is necessary to meet the needs of a disabled child should be considered during the assessment of needs of the disabled child. We do not think, though, that an express and absolute legislative requirement to assess siblings' needs in all cases is the right way to achieve this. In some cases it will not be needed. Whether there is a benefit to doing so is a matter of judgement best left to social workers, and such evaluative judgements are ill-suited to a blanket legislative requirement. However, we think that statutory guidance should highlight that this is an issue which should be considered during an assessment.

Consultation Question 20.

6.25 We provisionally propose that statutory guidance should direct local authorities to consider whether the needs of any siblings need to be taken into account as part of the assessment of the needs of a disabled child.

Do consultees agree?

Sibling a "young carer"

6.26 We provisionally propose that there should be a single duty to assess the needs of all carers of disabled children, whether the carer is under or over the age of 18. The threshold we propose for over-18s[29] is identical to the threshold that currently applies to under-18s: namely, whether it appears the carer may have a need for support or where they request an assessment. We acknowledge that the needs of young carers are different to the needs of adult carers and that different factors will need to be considered when assessing these two groups. But this level of operational detail, in our view, is better dealt with in guidance, as needs vary from case to case and social workers will always need a degree of flexibility in deciding what is relevant to the assessment. Accordingly we do not think that the differences between young and adult carers should necessarily stand in the way of the assessment duties being combined, and that combining the duties will simplify the law.

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[28] See paras 5.26 to 5.34.

[29] See para 5.34.

Consultation Question 21.

6.27 We provisionally propose that there should be a single duty to assess the needs of all carers, whatever their age.

Do consultees agree?

PART 2 – ELIGIBILITY

Chapter 7: Eligibility for services other than short breaks

INTRODUCTION

7.1 In this chapter we consider the legal framework which determines whether or not a disabled child, or their parent or carer, is eligible for services. This involves looking at two interrelated topics:

(1) the powers and duties to provide services; and

(2) the criteria which need to be satisfied for the powers to be available or the duties to apply.

7.2 This chapter is focused exclusively on services other than short breaks. We deal with eligibility for short breaks separately in Chapter 8, for the sake of clarity, because there are some significant differences in the legal framework.

ELIGIBILITY FOR SERVICES – CHILDREN

The current law

Social services' powers and duties

7.3 The two key provisions at the heart of disabled children's social care law are section 17 of the Children Act 1989 and section 2 of the Chronically Sick and Disabled Persons Act 1970. Services for disabled children are generally provided pursuant to these provisions.

7.4 There are other powers and duties which may also be available. For example, accommodation can be provided to children in need (which includes disabled children) under section 20 of the Children Act 1989. To complement this, there are a number of other duties under the Children Act 1989 which, in broad terms, are to provide services to children who are, or have previously been, accommodated by their local authority. These duties reflect the fact that the authority has, to an extent, stepped into the shoes of the child's parent.[1] For example, section 22(3)(b) of the Children Act 1989 requires a local authority looking after a child to "make such use of services available for children cared for by their own parents as appears to the authority reasonable in his case". In addition, local authorities provide services to disabled (and other) children by means of "Early Help". This is described in guidance as "a system of support which aims to support children and families as soon as problems emerge". As we discuss in paragraphs 3.18 to 3.22, the legal basis for Early Help is not clear. But for present purposes the point is simply that Early Help is used to provide services to disabled children. However, services for disabled children are, in general, provided

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[1] Children Act 1989, ss 22 to 22B, 23A and 23B. See paras 8.13 to 8.26 for a discussion of these various duties.

under section 17 of the Children Act 1989 and section 2 of the Chronically Sick and Disabled Persons Act 1970.

7.5 Section 17 of the Children Act 1989 places local authorities under a "general duty" to "safeguard and promote the welfare of children within their area who are in need" by providing a range of services appropriate to those needs.[2] A disabled child is deemed to be a child in need.[3] The duty applies to any child in need within the "area" of the authority. This requires only physical presence in the area of the authority which may mean that the duty is owed by two authorities at once if, for example, a child lives in one area and goes to school in another.[4] As we noted in paragraph 3.9, the focus on physical presence, as opposed to any more technical, legal concept of residence (such as habitual or ordinary residence), has been described by Baroness Hale in a related context as being "an important innovation in the forerunner provision in the Children Act 1948" meaning "there should be no more passing the child from pillar to post while the authorities argue about where he comes from".[5]

7.6 As noted above, section 17 of the Children Act 1989 is a "general duty". In *R (G) v Barnet London Borough Council,*[6] the House of Lords interpreted this to mean that section 17(1) is a "target" duty to help children in need in the area in general, as opposed to a specific duty to meet the assessed needs of a particular child in need within the area. Or, to put it another way, services under section 17 "are discretionary and not as of right to those who qualify".[7]

7.7 In relation to disabled children, this discretion under section 17 is limited and directed by section 2(4) of the Chronically Sick and Disabled Persons Act 1970. This requires a local authority that has functions under Part 3 of the Children Act 1989 in relation to a disabled child who is ordinarily resident in their area, to exercise those functions to "make any arrangements within subsection (6) that they are satisfied it is necessary for them to make in order to meet the needs of the child". Subsection (6) then sets out an exhaustive list of "arrangements", such as "the provision of practical assistance for the child in the child's' home" and the provision of "wireless, television, library or similar recreational facilities". These services are discussed in Chapter 9 below. The requirement that the child should be ordinarily resident in the area of the local authority in order for the duty under section 2(4) to arise differs from the physical presence requirement in section 17 of the Children Act 1989. In the social care context more broadly, the courts have held that a person is ordinarily resident in an area if they are living there voluntarily and for settled purposes, and cannot be

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[2] Children Act 1989, s 17(1).

[3] Children Act 1989, s 17(10) and (11).

[4] *R (Stewart) v Wandsworth London Borough Council, Hammersmith and Fulham London Borough Council and Lambeth London Borough Council* [2001] EWHC Admin 709, [2002] 1 FLR 469 at [23] by Jack Beatson QC sitting as a Deputy High Court Judge. Note that the same phrase has been interpreted differently in the special educational needs and disability context as meaning "ordinarily resident". See *Hampshire County Council v GC* [2024] UKUT 128 (AAC) at [199] to [228] by Upper Tribunal Judge West.

[5] *R (G) v Southwark London Borough Council* [2009] UKHL 26, [2009] 1 WLR 1299 at [28].

[6] *R (G) v Barnet London Borough Council* [2003] UKHL 57, [2004] 2 AC 208.

[7] *R (HC) v Secretary of State for Work and Pensions* [2017] UKSC 73, [2017] 3 WLR 1486 at [43] by Baroness Hale.

ordinarily resident in more than one place at the same time.[8] However, we are not aware of any cases in which the courts have considered the question of what ordinarily resident means for purposes of section 2(4) of the Chronically Sick and Disabled Persons Act 1970. This means that there has not to date been judicial consideration of the relevance of the age and decision-making ability[9] of the child or the weight to be placed upon the purpose and intention of the child's parents or carers.[10]

7.8 It will be noted that section 2(4) of the Chronically Sick and Disabled Persons Act 1970 is not a freestanding duty to provide services. Rather, it is a duty to exercise functions under Part 3 of the Children Act 1989, most typically under section 17. In effect, when the requirements of section 2 are satisfied, the power under section 17 is converted into a duty. One of the consequences of the two provisions being interlocked in this way is that local authorities may charge the parents of a disabled child an amount they consider reasonable for services which section 2(4) of the Chronically Sick and Disabled Persons Act 1970 requires the authority to provide.[11] This means that a local authority can take into account the parents' means and can refuse to provide the services the child needs, if it is of the view that it is reasonable to expect the parents to pay for them. Charging is discussed further in Chapter 12.

7.9 The courts have interpreted section 2 of the Chronically Sick and Disabled Persons Act 1970 as permitting local authorities to take into account their own means in deciding whether it is necessary to meet a disabled child's needs. This is said to reflect the ideas that "needs for services cannot sensibly be assessed without having some regard to the cost of providing them" and that "if my resources are limited I have to need the thing very much before I am satisfied that it is necessary to purchase it".[12] It means that local authorities can devise their own eligibility criteria, setting out more or less stringent conditions for what is an eligible need, depending on the resources they have available. However, once it has been established that a disabled child has eligible needs, those needs must be met (subject to the resources of the parents) and the authority cannot rely on lack of resources to cap arbitrarily the services it provides.[13]

7.10 The relationship between section 17(1) of the Children Act 1989 and section 2(4) of the Chronically Sick and Disabled Persons Act 1970 can be understood as two concentric circles. The larger circle encompasses all children who are in need,

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[8] *R (Cornwall Council) v Secretary of State for Health* [2015] UKSC 46, [2016] AC 137 at [36] and [41] by Lord Carnwath; *R (Worcestershire County Council) v Secretary of State for Health and Social Care* [2023] UKSC 31, [2023] 1 WLR 2790 at [30] and [56] by Lord Hamblen and Lord Leggatt.

[9] As to decision-making ability, see ch 21.

[10] See, in contrast, *R (Cornwall Council) v Secretary of State for Health* [2015] UKSC 46, [2016] AC 137 where the court had to consider such considerations in deciding how the ordinary residence test should be applied to an adult who lacked capacity to voluntarily adopt an ordinary residence of his own. See further *Re A (Children)* [2013] UKSC 60, [2014] AC 1 on the question of where a child is habitually resident, where similar considerations may arise.

[11] Children Act 1989, s 29; *R (Spink) v Wandsworth London Borough Council* [2005] EWCA Civ 302, [2005] 1 WLR 2884.

[12] *R v Gloucestershire County Council ex p Barry* [1997] AC 584, 604 by Lord Nicholls and 611 by Lord Clyde.

[13] *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515.

whether by virtue of being disabled or otherwise. All of these children fall within the scope of the general duty under section 17(1) of the Children Act 1989 and their local authority has a discretion to provide a wide range of services to them and their families to safeguard or promote the child's welfare. The smaller circle encompasses those children in need who are disabled who are also owed the duty under section 2(4) of the Chronically Sick and Disabled Persons Act 1970. Section 2(4) will require certain specific services to be provided to these children or their families under section 17 (or other provisions of Part 3 of the Children Act 1989) where the authority is satisfied that it is necessary to meet the needs of the child. But in deciding whether the power under section 17 should be exercised or the duty under section 2 is owed, the local authority may take resources into account.

7.11 The upshot of all of this is that the "duties" under section 17(1) of the Children Act 1989 and section 2(4) of the Chronically Sick and Disabled Persons Act 1970 – the two key provisions at the heart of social care for disabled children – are not absolute. In deciding whether those provisions require services to be provided to a disabled child, local authorities have a significant degree of discretion and judgement. This enables them to take into account both their own and the parents' finances and apply local eligibility criteria which vary from area to area. Eligibility criteria may limit the provision of services to the most serious case involving, for example, only the most complex disabilities.

Local housing authorities' duties

7.12 Both section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 17 of the Children Act 1989 can be used by social services to fund, make or secure adaptations to the home of a disabled child.[14] However, the making of adaptations also forms the subject of a distinct statutory regime by which local *housing* authorities can provide grants toward the cost of works required for the provision of facilities for disabled persons.[15] These are known as disabled facilities grants.

7.13 To be eligible for a disabled facilities grant a person must be disabled. A child will be regarded as disabled in this context if they satisfy the definition contained in section 17(11) of the Children Act 1989.[16]

7.14 The purposes for which a disabled facilities grant may be made include facilitating access to and from the disabled person's home and making the home safe for the disabled person and anyone else living with them.[17] The overriding purpose of the grant is to "make the dwelling or building suitable for the accommodation, welfare or employment of the disabled occupant".[18]

7.15 A local authority should approve an application for a grant made for one of these statutory purposes as long as it is satisfied that the relevant works are necessary and appropriate to meet the needs of the disabled occupant, and that it is reasonable and

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[14] See further paras 9.2 to 9.3 and 9.7.

[15] Housing Grants, Construction and Regeneration Act 1996, s 1.

[16] Housing Grants, Construction and Regeneration Act 1996, s 100.

[17] Housing Grants, Construction and Regeneration Act 1996, s 23.

[18] *R v Birmingham City Council ex p Mohammed* [1999] 1 WLR 33, 38F by Dyson J.

practicable to carry out the relevant works having regard to the age and condition of the dwelling or building.[19]

7.16 In contrast to section 17 of the Children Act 1989, a local housing authority may not rely on a lack of resources to justify refusing an award[20] and grants for disabled children are not means tested.[21] However, grants cannot be for made for an unlimited amount of money. The maximum amount which a local housing authority may pay is currently capped at £30,000.[22] But if this is not sufficient to cover the costs of the works, social services may choose, or be required, to top-up the grant under section 17 of the Children Act 1989 or section 2 of the Chronically Sick and Disabled Persons Act 1970.

7.17 An application for a disabled facilities grant must be made by the owner, tenant or occupier of the dwelling. It will need to certify that the applicant has the authority to carry out or authorise the adaptations which are sought. It must also certify that the disabled occupant will live in the dwelling as their only or main residence throughout the grant condition period or for such shorter period as their health and other relevant circumstances permit.[23]

The case for reform

The complexity of the law

7.18 Our pre-consultation work suggests that aspects of the legal framework set out above are not well known or understood. In particular:

(1) the complex relationship between section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 17 of the Children Act 1989;

(2) the availability of disabled facilities grants from local housing authorities and the fact that social services can, or may be required to, top them up;

(3) the role of eligibility criteria;

(4) the relevance of resources; and

(5) the legal basis for Early Help;

are matters which are not clear from the legislation or guidance, and frequently lead to confusion. This is an area that is in need of simplification.

7.19 In addition, the relationship between the various powers and duties under which services can be provided to disabled children is, for the most part, undefined and unclear. For example, if a disabled child qualifies for services under section 2 of the Chronically Sick and Disabled Persons Act 1970 (the duty to meet the needs of

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[19] Housing Grants, Construction and Regeneration Act 1996, s 24.

[20] *R v Birmingham City Council ex p Mohammed* [1999] 1 WLR 33, 38G by Dyson J.

[21] See ch 12 on means testing and charging.

[22] Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008, SI No 1189.

[23] Housing Grants, Construction and Regeneration Act 1996, ss 19 and 21-22A.

disabled children) and section 22(3)(b) of the Children Act 1989 (the duty to provide services to looked after children, of a type that would normally be provided by their parents), then under which provision should the services be provided? This is not a question to which the legislation, case law or guidance provides an obvious answer. The answer is likely to be that services should be provided under section 2. This would be on the basis of a principle of statutory interpretation that *specific* statutory provisions usually prevail over *general* ones. But this is open to debate. Moreover, it requires specialist legal knowledge that no parent, carer or social worker can reasonably be expected to have.

7.20 The same points could be made about the relationship between section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 17 of the Children Act 1989, and Early Help. Our view is that the duties owed to disabled children under the former statutory provisions (whether in the form of the duty to assess under section 17[24] or the duty to provide services under section 2) should always prevail over the broad and ill-defined discretion to provide Early Help. But to most people this is unclear.

The “postcode lottery”

7.21 Homing in on eligibility criteria and resources specifically, the fact that local authorities are entitled to adopt their own criteria based on their resources results in a “postcode lottery” of service provision. None of the local authority eligibility criteria we have been able to identify and consider in the lead up to this consultation have been the same. Research published in 2020 by the charities Cerebra and the Disability Law Service considered the eligibility criteria of 149 English local authorities and found as follows.[25]

(1) 23 authorities did not have identifiable, publicly available eligibility criteria at all.

(2) 33 authorities were applying criteria which were potentially unfit for the purpose of determining eligibility. Examples included criteria that used the wrong definition of disability, that referred to legislation that has been repealed or that were logically circular, for instance restricting assessments of the need for specialist social care services to only those children who have been determined to have a need for specialist care services.

(3) 41 authorities used what Cerebra refers to as “autism plus” criteria. This refers to criteria which require autistic children to have an additional condition, characteristic or diagnosis in order to qualify for services. The criteria considered by Cerebra divide into three types: (i) criteria which require that a child should have autism and a significant learning disability (22 local authorities); (ii) criteria which require that a child should have autism and a challenging behaviour (5 authorities); and (iii) criteria which require that a child should have a formal diagnosis of autism (21 authorities). The case of Sammy Alban Stanley involved an example of the first type of criterion. Sammy was autistic and had Prader-Willi syndrome. He died “during an episode of high-risk behaviour, related to his Prader-Willi syndrome, on a background of inadequate

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[24] See ch 3 on the duty to assess.

[25] P Bahri, L Clements, A L Aiello and T Hutchinson, *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (July 2020) ch 3.

support from the Local Authority and Mental Health Services".[26] At the time of his death, his local authority had in place eligibility criteria (since amended) which excluded children with autism from accessing specialist support unless they also had a severe learning disability.[27] The inquest into his death concluded that "it is predictable that a similar incident may arise in other areas if children with complex neurodevelopmental needs are excluded from accessing the care and treatment they require to keep them safe".[28] Cerebra express the concern that criteria of this nature may give rise to unlawful disability discrimination.

(4) 52 authorities had published criteria which did not include an "autism plus" requirement and were not identified as potentially unfit for the purpose.

This is a significant degree of variation.

7.22 To the same end, in research published in 2024 on provision for children in need around the country, the Children's Commissioner observed that:

> Nationally, according to the published data, just under 1% of all children were on a child in need plan on 31 March 2023 (90 per 10,000 children, 0.9%). This ranged from a low of 30 per 10,000 in Newcastle upon Tyne to 316 per 10,000 in Reading.

This, the Children's Commissioner concluded, suggests local areas have substantially different thresholds for providing support.[29]

7.23 This level of variation was not intended under section 2 of the Chronically Sick and Disabled Persons Act 1970. As noted at paragraph 1.50, the Act was meant to affect a shift away from the discretionary system under section 29 of the National Assistance Act 1948 which left local authorities free to decide who qualified for services.[30] Section 2 was meant to bring about this change by introducing a national duty to meet the needs of certain disabled people. The legislative intention underpinning what became section 2 was explained at the second reading of the Chronically Sick and Disabled Persons Bill, in 1969.

> Under Clause 3, subsections (1), (2) and (3), provisions for the disabled which are now permissive would be mandatory upon local authorities. The whole Clause is intended to standardise local provision on the basis of the best existing practice.[31]

7.24 The purpose of this provision is not achieved if local authorities have discretion to decide when the duty should arise, based on their finances. This was explained by

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[26] Sammy Alban Stanley Prevention of Future Deaths Report (March 2022) para 3.

[27] Doughty Street Chambers, *Sammy, aged 13, died against a background of "inadequate support" from his local authority and NHS Trust* (November 2021) https://www.doughtystreet.co.uk/news/sammy-aged-13-died-against-background-inadequate-support-his-local-authority-and-nhs-trust.

[28] Sammy Alban Stanley Prevention of Future Deaths Report (March 2022) para 5(5).

[29] Children's Commissioner, *Children on child in need plans* (March 2024) para 3.1.

[30] A Morris, *Needs before means – an exposition of the underlying purposes of the Chronically Sick and Disabled Persons Act 1970* (1971) pp 4 and 10.

[31] *Hansard* (HC), 5 December 1969, vol 792, col 1856.

one of the dissenting judges in the case of *R v Gloucestershire County Council ex p Barry* which we discuss further below:

> The point can be illustrated by a simple example. Suppose there are two people with identical disabilities, living in identical circumstances, but in different parts of the country. Local authority A provides for his needs by arranging for meals on wheels four days a week. Local authority B might also be expected to provide meals on wheels four days a week, or its equivalent. It cannot, however, have been Parliament's intention that local authority B should be able to say “because we do not have enough resources, we are going to reduce your needs.” His needs remain exactly the same. They cannot be affected by the local authority's inability to meet those needs. Every child needs a new pair of shoes from time to time. The need is not the less because his parents cannot afford them.[32]

Inconsistency with other related areas of law

7.25 As we have explained, the fact that local authorities can take into account their resources in deciding whether a duty is owed to a disabled child, and set local eligibility criteria according to those resources, results in inconsistency around the country. But it also results in inconsistency between disabled children’s social care law and other related areas of law dealing with local authority support. In particular, it is inconsistent with adult social care law, education law and the law on disabled facilities grants. Looking beyond England, it is also inconsistent with disabled children’s social care law in Wales although it is consistent with disabled children’s social care law in Scotland, where section 2 of the Chronically Sick and Disabled Persons Act 1970 applies (in modified form).[33]

Inconsistency with adult social care law

7.26 The legal framework for providing adult social care is contained in the Care Act 2014. Prior to the introduction of this Act, adult social care law – like disabled children’s social care law – was complex. The key provisions were section 29 of the National Assistance Act 1948 and section 2 of the Chronically Sick and Disabled Persons Act 1970. Under this regime (as is the case for disabled children’s social care) local authorities were entitled to take into account their resources in deciding whether the duty under section 2 had arisen.[34] But the consequences of this were not as significant as for disabled children’s social care. This was because national guidance – the *Fair Access to Care Services* (FACS) guidance[35] – limited the extent of the postcode lottery.

7.27 The FACS guidance was first issued to local authorities in 2002 to seek to address inconsistencies across England about who got support, and to put in place a fairer

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[32] *R v Gloucestershire County Council ex p Barry* [1997] AC 584, 599 by Lord Lloyd.

[33] Chronically Sick and Disabled Persons Act 1970, s 29(2). Section 2 of the Act does not apply in Wales following the coming into force of the Social Services and Well-Being (Wales) Act 2014.

[34] *R v Gloucestershire County Council ex p Barry* [1997] AC 584.

[35] Department of Health, *Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care* (2002).

more consistent system for the allocation of care services.[36] The local authority circular which accompanied the guidance noted that:

> The need for guidance on eligibility criteria for adult social care was identified in the 1998 White Paper "Modernising Social Services" as different councils use different eligibility criteria, and reviews of ongoing eligibility are patchy. This leads to considerable variation in access to adult social care, which in turn leads to unfairness. The practice of many councils to apply eligibility criteria for both assessment and particular services is confusing and unnecessary. Further unfairness is caused when councils apply stricter or different eligibility criteria to certain groups of adults seeking help than others.[37]

7.28 The FACS guidance provided a framework for setting eligibility criteria for adult social care services. It contained four bands of need: critical, substantial, moderate and low. Each contained a series of descriptors or factors such as, in the critical band, "there is, or will be, an inability to carry out vital personal care or domestic routines". Local authorities then used this framework as the basis to set their own eligibility criteria. Each authority had the discretion to decide which of the four bands they would provide services to meet, depending on the resources they had available. Hence there was still local variation in eligibility criteria. But it was significantly less than for disabled children's social care, because every local authority based their criteria on the national framework set out in the FACS guidance. Nevertheless, the level of local variation remained significant enough to be singled out for comment in the 2009 green paper *Shaping the Future of Care Together*, which observed that "people with the same needs receive different levels of care depending on where they live".[38] National eligibility criteria were put forward within that paper as a policy option to deal with this.

7.29 The Law Commission consulted further on this option the following year as part of its review of adult social care law.[39] Our final report, published the following year, recommended that the Secretary of State should be required by statute to make regulations prescribing an eligibility framework for the provision of adult social care services. Such regulations, the report noted, could be used to introduce national eligibility criteria[40] which, in due course, is exactly what happened. The recommendations in this report went on to form the basis of the Care Act 2014. Eligibility for care and support under the Care Act 2014 is now based on national eligibility criteria, which look at things like whether the adult can use their home safely, and manage nutrition and toilet needs.[41] If an adult's needs meet the eligibility criteria, the local authority is required to meet those needs.[42] The duty is an absolute one: the fact that a local authority lacks resources and thinks they would be better deployed

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[36] Department of Health, *Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care* (2002) para 1.

[37] Department of Health, *Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care – Local Authority Circular* LAC (2002) p 2.

[38] Shaping the Future of Care Together (2009) Cm 7673 p 42.

[39] Adult Social Care Law (2010) Law Commission Consultation Paper No 192.

[40] Adult Social Care Law (2011) Law Com No 326.

[41] Care and Support (Eligibility Criteria) Regulations 2015, SI No 313.

[42] Care Act 2014, s 18(1).

elsewhere does not permit it to refuse to provide services. This means that an adult who is eligible for care and support in one area should be eligible for support in another.

7.30 We take the following points from this account of the development of adult social care law.

(1) The postcode lottery of local eligibility criteria in disabled children's social care law is out of step with adult social care law where there is no such inconsistency. In this regard, the law relating to children is less favourable than the law relating to adults. This is not to say that adults receive more or better services than children. But it does mean that they receive consistent treatment across the country whereas children do not.

(2) The postcode lottery is long-standing and the potential for such a system to cause unfairness in the context of adult social care has been recognised since at least 1998.

(3) While the adult social care system has repeatedly been changed to try and fix this, initially through the FACS criteria and latterly through the Care Act 2014, disabled children's social care law has not.

(4) Perhaps most significantly, no justification appears to have been put forward for reforming adult social care but not doing the same for disabled children's social care. We have not been able to identify a deliberate policy choice to change the law system for adults but not for children. It may simply be a function of the fact that we were invited to consider adult social care in 2008 but were not invited to consider disabled children's social care until 2023. However, prior to the reform of adult social care law, substantially the same legal framework applied to adults as to children (namely, section 2 of the Chronically Sick and Disabled Persons Act 1970) and it seems to us at this stage that the arguments for reforming the framework in so far as it applied to adults apply equally to children.

Inconsistency with Welsh law

7.31 Building on the approach taken in adult social care in England, Wales has national eligibility criteria for both adults *and* children.[43] The Welsh Government expressly drew upon our recommendations in relation to adult social care and set out to ensure that "service users and their carers with similar needs are treated on the same basis wherever they live in Wales".[44]

Inconsistency with education law

7.32 The principle that social services can take into account their resources in deciding whether there is a duty to provide social care to a disabled child stems from the decision of the House of Lords in the case of *R v Gloucestershire County Council ex p*

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[43] Social Services and Well-being (Wales) Act 2014 (anaw 4), s 32; Care and Support (Eligibility) (Wales) Regulations 2015, SI No 1578 (W 187), reg 4.

[44] Welsh Assembly Government, *Sustainable Social Services for Wales: A Framework for Action* (2011) para 3.47.

Barry.[45] In the case of *R v East Sussex County Council ex p Tandy*,[46] however, the House of Lords decided that this principle did not apply to the duty to provide "suitable" education other than at school, to children unable to attend school because of illness.[47] That case involved a local authority that, faced with budgetary constraints, had adopted a policy of providing only three hours of home tuition per week to children who were out of school. They applied this policy to a child with Myalgic Encephalomyelitis or ME (now also known as Chronic Fatigue Syndrome), who could not attend school full time because of her condition. She had previously been provided with five-hours of tuition per week. In accordance with the policy, this was reduced to three. The House of Lords decided that suitable education connoted a standard to be determined purely by educational considerations and that the availability of financial resources was irrelevant. As a result, the policy the local authority had adopted based on its resource limitations was unlawful and the authority was in breach of its duty to provide suitable education. In reaching this decision, Lord Browne-Wilkinson made the following general observations about allowing resource limitations to be relied on to preclude a statutory duty arising:

> My Lords, I believe your Lordships should resist this approach to statutory duties ... To permit a local authority to avoid performing a statutory duty on the grounds that it prefers to spend the money in other ways is to downgrade a statutory duty to a discretionary power ... Parliament has chosen to impose a statutory duty, as opposed to a power, requiring the local authority to do certain things. In my judgment the courts should be slow to downgrade such duties into what are, in effect, mere discretions over which the court would have very little real control. If Parliament wishes to reduce public expenditure on meeting the needs of sick children then it is up to Parliament so to provide. It is not for the courts to adjust the order of priorities as between statutory duties and statutory discretions.[48]

Inconsistency with disabled facilities grants

7.33 As explained above at paragraphs 7.12 to 7.17, the Housing Grants, Construction and Regeneration Act 1996 contains a scheme for the provision of disabled facilities grants to finance adaptations to the homes of disabled persons. The legal test for provision of a grant involves asking, among other things, whether "the relevant works are necessary and appropriate to meet the needs of the disabled occupant".[49] This is very similar to the language of section 2(4) of the Chronically Sick and Disabled Persons Act 1970 which asks whether services are "necessary … in order to meet the needs" of a disabled child. Notwithstanding the similarity in the wording of the legal tests, the courts have taken the view that the approach in *R v Gloucestershire County Council ex p Barry* to the Chronically Sick and Disabled Persons Act 1970 should not apply to disabled facilities grants. Rather, the courts have held that the approach in *R v East Sussex County Council ex p Tandy* is the right one. Resources are not relevant

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[45] *R v Gloucestershire County Council ex p Barry* [1997] AC 584. That case related to adult social care. It was applied to disabled children's social care in *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515.

[46] *R v East Sussex County Council ex p Tandy* [1998] AC 714.

[47] Education Act 1993, s 298. Now contained in Education Act 1996, s 19.

[48] *R v East Sussex County Council ex p Tandy* [1998] AC 714, 749A to E.

[49] Housing Grants, Construction and Regeneration Act 1996, s 24(3)(a).

to the question of whether the duty to provide a grant has arisen and the eligibility criteria based on resource constraints are not permissible. In the words of Mr Justice Dyson:

> Parliament has chosen to impose a statutory duty in relation to [disabled facilities grants] within section 23(1) purposes. The court should be slow to downgrade such a duty into a mere discretion over which the court would have very little control. If Parliament wishes to redirect public expenditure on meeting the needs of disabled occupants of buildings, then it is for Parliament so to provide.[50]

Options for reform

7.34 We have identified three principal options to deal with the problems we outline above.

7.35 The first is not to deal with them at all, on the basis that local authorities should have the flexibility to decide how best to deploy their limited resources to meet need in their local area. Although this may not have been the original intention of the Chronically Sick and Disabled Persons Act 1970, it reflects widespread practice established over several decades. This option, self-evidently, would not require any change to the law.

7.36 The second option is to seek to deal with them by way of guidance. That could either take the form of national eligibility criteria, or guidance (like FACS) which local authorities could use to design their own eligibility criteria, based on a standardised framework. Such guidance could be issued under section 7 of the Local Authority Social Services Act 1970, meaning that this option would allow a move toward greater consistency without the need for legislative change.

7.37 The third option would be to follow the model of adult social care and introduce a statutory duty to meet the needs of disabled children (in primary legislation), subject to the child meeting national eligibility criteria (to be co-produced by central Government in consultation with local Government and set out in secondary legislation). This would mean that local resources would no longer play a role in deciding whether the duty arises. We envision this would be a single duty, combining the power to provide services to disabled children under section 17 of the Children Act 1989 with the duty to exercise that power under section 2 of the Chronically Sick and Disabled Persons Act 1970.

7.38 This third option would give rise to a series of further questions.

(1) What should the hierarchy be between the new duty and the other powers and duties to help disabled children? For the sake of clarity, a decision would need to be taken as to which power or duty applies, if the criteria for both would otherwise be satisfied.

(2) What residence requirements should apply? Specifically, should the duty be owed to children "in the area" of the local authority (as in physically present) or "ordinarily resident"? The former is the criterion that applies under section 17(1) of the Children Act 1989. The latter applies under section 2(4) of the Chronically Sick and Disabled Persons Act 1970. The former means that help can be

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[50] *R v Birmingham City Council ex p Mohammed* [1999] 1 WLR 33, 42.

provided quickly to a child in the area and saves children being passed from "pillar to post while the authorities argue about where he comes from".[51] The latter means that local authority resources are focused on those with the closest connection to the area.

(3) Should the new duty encompass and replace the duty to provide disabled facilities grants under section 1 of the Housing Grants, Construction and Regeneration Act 1996? Superficially, this is an attractive option. Transferring responsibility for these grants from local housing authorities to social services, by bringing them with the scope of a new single duty to meet the eligible needs of disabled children, would simplify the law. It would mean that the families of disabled children no longer have to approach two different local authorities (in areas where there is no unitary authority), applying two different statutory regimes, if they want to apply for funding to carry out an adaptation to the home costing in excess of £30,000. But the fact that the regimes are:

(a) administered by different authorities, one of which (the local housing authority) will have particular expertise in relation to housing matters;

(b) subject to very different charging schemes;[52]

(c) subject to very different eligibility criteria (eligibility for a disabled facilities grant, for obvious reasons, depends on things like the age and condition of the dwelling or building);[53]

(d) funded separately by central Government;[54] and

(e) overseen by different Government departments (the Department for Education and the Ministry of Housing, Communities and Local Government);

may mean there are considerable practical and legal barriers to this option.

(4) How (if at all) should the needs of disabled children which do not meet the eligibility criteria be met?

(5) How (if at all) should the needs of disabled children be met while their eligibility for services is being assessed?

Our provisional proposals

A single duty to provide services to meet eligible needs

7.39 Our provisional proposal is to pursue the third option set out at paragraph 7.37 above. For the reasons set out below, we provisionally propose that there should be a single statutory duty to provide services to meet the needs of disabled children, subject only

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[51] *R (G) v Southwark London Borough Council* [2009] UKHL 26, [2009] 1 WLR 1299 at [28] by Baroness Hale.

[52] See ch 12.

[53] Housing Grants, Construction and Regeneration Act 1996, s 24.

[54] Housing Grants, Construction and Regeneration Act 1996, s 92.

to the child satisfying national eligibility criteria which should be set out in legislation. We discuss the eligibility criteria below at paragraphs 7.45 to 7.50. The duty would combine the power to provide services to disabled children under section 17 of the Children Act 1989 with the duty to provide services under section 2 of the Chronically Sick and Disabled Persons Act 1970. The services provided under the new single duty (as is currently the case) could be provided to the child's family, and not solely to the child, where necessary in order to meet the child's needs.

7.40 Having a single duty, combining the powers to provide services to disabled children under section 17 of the Children Act 1989 with the duty to provide services under section 2 of the Chronically Sick and Disabled Persons Act 1970, would simplify the law considerably. We are aware, as we explain at paragraph 7.10 above, that the scope of each provision is slightly different: for example, some services can currently be provided under section 17 which cannot be provided under section 2. But we think that the question of what services could be provided under a single duty is distinct from the question of whether there should be a single duty. We discuss the former question below in Chapter 9.

7.41 In reaching this provisional view we take section 2 of the Chronically Sick and Disabled Persons Act 1970 as our starting point. This provision embodies a policy choice made by Parliament that local authorities should have a duty to meet certain needs of disabled children on a standardised basis. See paragraph 7.23. We recognise that this policy choice was made many years ago and does not reflect what is currently happening in practice. But it is a policy choice which was made by the legislature and so – keeping in mind the boundaries of law reform and politics that we discuss at paragraphs 1.29 to 1.31 – is something we need to give considerable weight to. We are not proposing a new or fundamentally different policy choice. Rather, our proposal reflects the fact that the Parliamentary policy choice is not being achieved as a result of the way that section 2 was interpreted in the case of *R v Gloucestershire County Council ex p Barry*.[55]

(1) First, section 2 of the Chronically Sick and Disabled Persons Act 1970 is not operating as a duty. In the words of Lord Browne-Wilkinson in the *Tandy* case, "to permit a local authority to avoid performing a statutory duty on the grounds that it prefers to spend the money in other ways is to downgrade a statutory duty to a discretionary power".[56]

(2) Second, and consequently, needs are not being met on a consistent basis. It is the fact that local authorities can take into account their budgetary constraints in deciding whether services are required under section 2 of the Chronically Sick and Disabled Persons Act 1970 which permits local authorities to adopt local eligibility criteria. They are free to change these criteria as their resources and priorities change. This results in the postcode lottery where certain needs may be met in one area but not another, or may be met by one authority in one year but not in the next. However, and obviously, the underlying needs of a disabled child do not change if they move from an area with more resources to an area with fewer, or vice versa. Nor do they change depending on how much or how

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[55] *R v Gloucestershire County Council ex p Barry* [1997] AC 584.

[56] *R v East Sussex County Council ex p Tandy* [1998] AC 714, 749A to E.

little money their local authority has to meet those needs. As Lord Lloyd put it in the *Barry* case, "[e]very child needs a new pair of shoes from time to time. The need is not the less because his parents cannot afford them".[57]

7.42 For these reasons, our initial assessment is that the policy objectives underpinning section 2 of the Chronically Sick and Disabled Persons Act 1970 are not being achieved. It is our provisional view that a duty to meet a child's needs cannot properly be fulfilled if resources can be relied on to stop the duty arising and authorities are free to adopt different eligibility criteria dependent on their level of resources.

7.43 We think that the introduction of a statutory duty to meet the eligible needs of disabled children is the appropriate way to change this. A single duty would not mean that resources should simply be ignored in the context of disabled children's social care or that local authorities should be asked to do the impossible irrespective of their financial constraints. Rather, it means that resources should be taken into account in the consistent and specific manner which we set out at paragraph 7.50 below.

Consultation Question 22.

7.44 We provisionally propose that there should be a single statutory duty to meet the social care needs of disabled children.

Do consultees agree?

National eligibility criteria

7.45 Our provisional view is that whether the proposed single duty arises should depend solely on the severity of the child's needs, and not the resources of the local authority tasked with meeting them. We think this should be assessed with reference to national and not local eligibility criteria, set out in due course in secondary legislation and co-produced by central and local Government.

7.46 We do not think eligibility criteria can be effectively introduced through guidance alone. Guidance, in the form of the FACS criteria, failed to achieve consistency in adult social care. Moreover, guidance issued under section 7 of the Local Authority Social Services Act 1970 can be departed from where a local authority judges on admissible grounds that there is good reason to do so.[58] If a lack of resources were judged to be an admissible ground, then that would take matters back to square one. In addition, guidance (depending on the statutory basis for it) can generally be changed without Parliamentary oversight, which could allow the postcode lottery to be re-introduced in future.

7.47 Our provisional proposal would achieve consistency as between adult social care law and disabled children's social care law, as well as the other legal frameworks we

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[57] *R v Gloucestershire County Council ex p Barry* [1997] AC 584, 599 by Lord Lloyd.

[58] *R (Rixon) v Islington London Borough Council* (1997–98) 1 CCLR 119, 128D by Sedley J. See further para 23.5.

discuss above. Consistency between adult social care law and disabled children's social care law is not an absolute goal, although it is something we are required to consider under our terms of reference.[59] However, any inconsistency should be justified. In this context, justification boils down to the simple question of whether there is any good reason for disabled children to be treated differently to, or less favourably than, disabled adults? Our provisional view is that there is not. Disabled children are qualitatively different to disabled adults because children, save in exceptional cases, will have a parent or carer to look after them. Disabled adults may do, but often do not. This means that there may be less need for the state to assume responsibility for caring for children. But the fact that children have needs which are different to adults means only that they will require different eligibility criteria. It does not mean that eligibility criteria are unnecessary or undesirable. If disabled adults should be entitled to consistent levels of support across the country, we cannot at this stage see why children should not also be entitled to consistency. Putting it another way, children may be more likely than adults to have someone looking after them. But this is true across the country. It does not justify children in one area receiving services when children in another do not.

7.48 The principal argument against the introduction of national eligibility criteria is that local authorities are best placed to judge how to deploy their limited resources to meet the needs in their local area. This is an important argument, particularly in circumstances where many local authorities are facing real financial difficulties.[60] However, our initial view is that it is an argument which applies equally to disabled adults and does not necessarily justify the differential treatment between children and adults, with the former having local criteria and the latter national.

7.49 Moreover, in effect, this is an argument in favour of local authorities having a discretion to meet needs rather than a duty. It seems to us that that argument was, or should have been, settled in 1970 by the introduction of the duty under section 2 of the Chronically Sick and Disabled Persons Act 1970 which was intended to "make mandatory what was then permissive" under the National Assistance Act 1948.[61] Our terms of reference specifically require us to consider whether existing duties sufficiently meet the specific needs of disabled children.[62] To accept this argument would require us consciously to seek to water down the existing legal protections made available to disabled children. This conflicts with our terms of reference and would undermine what this review seeks to achieve.

7.50 This does not mean that we do not recognise the very difficult financial circumstances in which local authorities operate or think that they are irrelevant to the obligations which should be placed on local authorities to help disabled children. Our provisional proposal would still allow or require resources to be taken into account in the following situations.

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[59] See para 1.17

[60] See paras 1.45 to 1.46 for a discussion of the financial context.

[61] A Morris, *Needs before means – an exposition of the underlying purposes of the Chronically Sick and Disabled Persons Act 1970* (1971) pp 4 and 10.

[62] See paras 1.45 to 1.46 for a discussion of the financial context.

(1) As part of a political discussion between central and local Government in co-producing the national eligibility criteria. Setting the criteria will require political, value judgements about the nature and severity of needs which must be met, which will have to be based, in part, on the money that is made available by central Government to provide services to meet those needs. We accept the argument that some local authorities have made to us in the lead up to this consultation that national eligibility criteria will not be workable if the resources are not made available to meet needs that are eligible under those criteria. But in our view, this does not mean that national eligibility criteria are wrong in principle. Rather it underscores the need for resource allocation to be carefully considered, and for local Government to be a central figure in negotiating the criteria.

(2) In deciding how to meet needs. The decision *whether* to meet needs should be made in accordance with national criteria. But once that decision has been made, we think the decision *how* to meet those needs is best left to the expert judgement of social workers. And resources can properly be taken into account at that stage. If there are two ways in which the eligible needs of a disabled child can appropriately be met, local authorities should properly be able to choose the less costly option.

(3) In deciding whether and how much a family should be charged for any services which they receive. This reflects the current position, which we discuss in detail in Chapter 12.

Consultation Question 23.

7.51 We provisionally propose that the single statutory duty to meet the social care needs of disabled children should be subject to national eligibility criteria.

Do consultees agree?

Consultation Question 24.

7.52 We invite consultees' views on what the essential features of any national eligibility criteria should be.

Consultation Question 25.

7.53 We invite local authority consultees to provide us with copies of any eligibility criteria they apply to disabled children's social care.

The new duty should take precedence over existing duties and powers

7.54 An overarching objective of this review is to simplify disabled children's social care law. In keeping with this objective, we provisionally propose that the new duty should take precedence over any other existing duties or powers in other legislation which might also be available to help a disabled child or their family. For example, if a disabled child who is accommodated by their local authority meets the eligibility criteria under the new duty, we think that they should be provided with services under that duty and not under section 22(3) of the Children Act 1989 or by means of Early Help or any other provision. The purpose of this provisional proposal is to ensure there is no confusion over which power or duty should be used.

Consultation Question 26.

7.55 We provisionally propose that the single statutory duty to meet the social care needs of disabled children should take precedence over any other powers and duties which could be used to provide the services.

Do consultees agree?

Residence requirements

7.56 Any new duty would need, as is currently the case, to be subject to some kind of residence or presence requirement. We seek views on what the most appropriate requirement would be.

(1) Should it be "ordinary residence"? This is the test which currently applies to the duty to provide services in section 2 of the Chronically Sick and Disabled Persons Act 1970.

(2) Or should the requirement be physical presence in the area of the local authority, as required by section 17 of the Children Act 1989? Retaining the ordinary residence test is closest to the status quo. But it lacks the simplicity of the physical presence test and may result in disputes. Such disputes are a recurrent feature of adult social care law.[63]

Consultation Question 27.

7.57 We invite consultees' views on the residence requirements that should apply to the single statutory duty to meet the social care needs of disabled children.

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[63] See for example *R (Worcestershire Council Council) v Secretary of State for Health and Social Care* [2023] UKSC 31, [2023] 1 WLR 2790.

Should disabled facilities grants be provided under the new duty?

7.58 We seek consultees' views on whether the duty to fund home adaptations by means of the provision of disabled facilities grants should be brought within the scope of our proposed new duty. This would undoubtedly be much simpler for families seeking home adaptations than in the current system, whereby disabled facilities grants of up to £30,000 can be sought from local housing authorities but anything in excess of this must be sought from social services by way of a top-up. Transferring complete responsibility for funding home adaptations to social services under the new duty (subject to the child satisfying the eligibility criteria) would streamline this process. However, this would be a significant institutional change that would give rise to a series of practical issues that we set out at paragraph 7.38(3) above.

Consultation Question 28.

7.59 We invite consultees' views on whether disabled facilities grants should be provided under the single statutory duty to meet the social care needs of disabled children.

Powers to meet needs not covered by the duty

7.60 The adoption of national eligibility criteria will, by definition, mean that not every need of every disabled child is met: some needs will not meet the eligibility criteria. A number of social workers we have heard from in the lead up to this consultation have expressed concern that this would limit their ability to meet more moderate needs which might then escalate. This is a valid concern. But it should be acknowledged that this is already a feature of the current system under which local authorities can adopt local eligibility criteria. As is presently the case for children and adults, our provisional view is that local authorities should retain a power to meet such needs.[64]

7.61 Relatedly, it will be necessary for there to be a power to meet needs while the local authority assesses whether the eligibility criteria are met. The availability of such a power may be particularly important where children are waiting for a diagnosis. Again, local authorities already have a power to meet needs pending assessment under section 17 of the Children Act 1989, and our proposal is that an equivalent power should be retained to complement the new duty that we propose. If an ordinary residence test were to apply to the new duty (see paragraph 7.56 above) this power could be available to meet needs pending determination of where the child is ordinarily resident, or in cases where the child is not ordinarily resident.

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[64] Children Act 1989, s 17(1) for children; Care Act 2014, s 19(1) for adults.

Consultation Question 29.

7.62 We provisionally propose that there should be powers to meet needs:

(1) that do not satisfy the national eligibility criteria; and

(2) pending an assessment of needs.

Do consultees agree?

ELIGIBILITY FOR SERVICES – PARENTS AND CARERS

The current law

7.63 Under the current law, there are duties to assess the needs of parents and carers.[65] In general, however, there is no duty then to meet needs identified during the assessment. There is only a discretion under section 17 of the Children Act 1989 to meet the parents' or carers' needs, which (if it is exercised) must be exercised to safeguard or promote the child's' welfare.[66]

7.64 There are two exceptions to this, however. First, there is a duty to provide short breaks in some cases, for example the provision of accommodation under section 20(1) of the Children Act 1989 to a child whose caring arrangements are on the cusp of breakdown.[67] Although framed as a service provided for the child this is, in practical terms, a service for the benefit of the child and the parent or carer. Second, there will be cases where it is strictly necessary to provide services to the parent or carer in order to meet the needs of the child. In that case the duty under section 2 of the Chronically Sick and Disabled Persons Act 1970 will arise. Both of these exceptions to the general rule are covered by the discussions and proposals above at paragraphs 7.1 to 7.62, on children's eligibility for services, and Chapter 8, on eligibility for short breaks. So, we do not deal with them further here.

7.65 Putting aside these two exceptions, what remains is a discretion to meet the needs of parents and carers.

Our provisional proposals

7.66 We do not propose any substantive change to this discretion for the simple reason that we do not think that we can. To do so would be to stray beyond law reform and into making political policy. This is a distinction which we discuss in paragraphs 1.29 to 1.31 above. Our initial view is that the power to provide services to parents and carers reflects a political judgement that the allocation of resources in this area should be properly left to the discretion of local authorities. As such, eligibility for these services is qualitatively different from children's eligibility for services, and eligibility for

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[65] Children Act 1989, s 17ZD(1); Carers (Recognition and Services) Act 1995, s 1(2). See ch 5.

[66] Children Act 1989, s 17(3).

[67] See paras 8.13 to 8.16 below.

short breaks, where a different political judgement has been made that local authorities should be subject to duties.

7.67 For these reasons we make no proposal to change the nature of the power to provide services to parents and carers, beyond those dealt with elsewhere in this paper. Our provisional proposal is that this power must be retained in any future legislative scheme.

7.68 For completeness, we note that short breaks are the main service sought by the parents and carers we have heard from in the lead up to this consultation. We discuss short breaks in detail in Chapter 8 and make the provisional proposal that there should be a short breaks duty. Our provisional view is that this would go a significant way toward meeting the needs of parents and carers.

Consultation Question 30.

7.69 We provisionally propose that there should continue to be a power to meet the needs of parents and carers.

Do consultees agree?

Chapter 8: Eligibility for short breaks

INTRODUCTION

8.1 In this section we consider the legal framework which determines whether a disabled child and their parent or carer are eligible for a short break. The rules governing eligibility for other kinds of service are discussed in Chapter 7. As with the discussion in that chapter, our discussion of eligibility for a short break involves consideration of two closely related issues:

(1) the powers and duties to provide short breaks; and

(2) the criteria which need to be satisfied for the power to be available or the duty to arise.

8.2 A short break is a service designed "to assist individuals who provide care for [disabled] children to continue to do so, or to do so more effectively, by giving them breaks from caring".[1] Examples of short break services include:[2]

(1) day-time or overnight care in the homes of disabled children or elsewhere;

(2) educational or leisure activities for disabled children outside their homes; and

(3) services to assist parents and carers in the evenings, at weekends and during the school holidays.

8.3 Historically, the term "respite care" was used rather than short breaks, and it tended to be used to refer to breaks for the child in a residential setting. For example, the review of child care law that preceded the Children Act 1989 noted that "respite care" – at that time provided under "the broad service-providing powers in Schedule 8 of the NHS Act 1977 and section 21 of the National Assistance Act 1948" – was "most commonly found in relation to [disabled] children who are looked after for short periods away from home to give both them and their families a brief break".[3] But "respite care" had negative connotations, suggesting parents and carers needed respite from their children. It also gave the impression that the options for providing a break were limited to stays away from home. "Short breaks" has now become the preferred term, encompassing a wider range of services than just residential care that provide a break for both the parent or carer and the child.[4]

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[1] Children Act 1989, sch 2, para 6(1)(c).

[2] Breaks for Carers of Disabled Children Regulations 2011, SI No 707, reg 4(2).

[3] Department of Health and Social Security*, Review of Child Care Law, Report to Ministers of an Interdepartmental Working Party* (September 1985) para 6.1.

[4] J Robertson, "The Impacts of Short Break Provision on Disabled Children and Families: An International Literature Review" (2011) 19(4) *Health Soc Care Community* 337; Every Disabled Child Matters, *Short breaks in 2015: An uncertain future* (2015).

8.4 Viewed in this way, short breaks can be seen as a service that is provided simultaneously to, and for the benefit of, both disabled children *and* their parents or carers. This is reflected in the legislation. As noted at paragraph 8.2, the objective of short breaks provision is to give breaks to parents and carers in order for them to care for their children more effectively.[5] Inherent in this goal is the idea that the needs of the child and their parent or carer are inextricably linked. This can also be seen from the fact that short breaks can be provided under legal provisions targeted at children[6] or their parents and carers.[7] In similar vein, the Department for Education's guidance acknowledges that short breaks can mean that:

> Children benefit from new interests, relationships and activities, while parents and carers can catch up with 'everyday activities' (sleep, cleaning, shopping), attend to their physical and psychological wellbeing, and maintain and develop social networks.[8]

8.5 The fact that short breaks are simultaneously a service for children and their parents and carers sets them apart from other services for disabled children. Short breaks are also, in our view, uniquely important in terms of the impact they can have on families. They can provide a lifeline for parents and carers, enabling them to continue caring for their children and averting a family breakdown, preventing the need for a more costly intervention. Eligibility for short breaks is also governed by slightly different rules than the other services provided to disabled children or their parents and carers. For all of these reasons, we discuss eligibility for short breaks here as a distinct topic from eligibility for other services for children and their families, which is discussed in Chapter 7. We reiterate, however, that our provisional proposals for reform, set out at paragraphs 8.39 to 8.51, envision a unified approach.

THE CURRENT LAW

8.6 Under the Children Act 1989, there is a general duty on local authorities to provide services "to assist individuals who provide care for such children to continue to do so, or to do so more effectively, by giving them breaks from caring".[9] This general duty was introduced by the Children and Young Persons Act 2008[10] and formed a part of the *Aiming High for Disabled Children* programme.[11] The introduction of this general short breaks duty followed the Every Disabled Child Matters campaign.[12] The charities that led this campaign supported a series of Parliamentary hearings that took place in 2006. In those hearings a cross-party panel of MPs heard that short breaks provision

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[5] Breaks for Carers of Disabled Children Regulations 2011, SI No 707, reg 3.

[6] For example, Children Act 1989, s 20(4).

[7] For example, Children Act 1989, s 17(1) and (3).

[8] Department for Education, *Short breaks for carers of disabled children - Departmental advice for local authorities* (March 2011) para 1.1.

[9] Children Act 1989, sch 2, para 6(1)(c).

[10] Children and Young Persons Act 2008, s 25.

[11] Department of Health, Department for Children, Schools and Families and NHS, *Aiming High for Disabled Children Transforming services for disabled children and their families* (2008).

[12] House of Commons Library, *Research Paper on the Disabled Children (Family Support) Bill* (February 2007) pp 14 to 15.

for disabled children at that time was “grossly inadequate” and noted that “lack of short breaks was the single biggest cause of unhappiness with service provision” in the submissions they received.[13]

8.7 The short breaks duty, contained in paragraph 6 of schedule 2 to the Children Act 1989, is not a specific duty to provide a short break to an individual child or their parent or carer. Rather, it is a general duty requiring local authorities to make short breaks available. The explanatory notes which accompanied the introduction of the duty explained that:

> Section 25 amends paragraph 6 of Schedule 2 to the 1989 Act (provision for disabled children) to impose a duty on local authorities to provide, as part of the range of services they provide for families, breaks from caring to assist parents and others who provide care for disabled children to continue to do so, or to do so more effectively. The intention is that breaks should not only be provided to those struggling to care for disabled children but also to those for whom a break from their caring responsibilities will improve the quality of the care they provide. Local authorities must provide such services in accordance with regulations made by the appropriate national authority.[14]

8.8 As these notes envisage, the performance of this general duty is now supplemented by regulation 4 of the Breaks for Carers of Disabled Children Regulations 2011[15] which sets out the range of short breaks which should form part of the service that local authorities provide. This range of short breaks options is set out above at paragraph 8.2. In the words of Mr Justice Stadlen in the case of *R (RP) v Brent London Borough Council*, the combined effect of these provisions is to create “a general obligation on the part of a local authority to provide a range of services” as opposed to “a duty owed to a particular child or carer”.[16]

8.9 This means that whether there is a duty owed to a particular child or carer – or indeed whether there is a power available to assist them – depends on whether one or other of the powers or duties in the Chronically Sick and Disabled Persons Act 1970 or the Children Act 1989 is available. When the Children Act 1989 was devised, the intention was that section 17 would be the relevant power. The *Review of Child Care Law* recommended that “respite care…should be provided under the power described in the previous chapter to promote the care and upbringing of children within their families”.[17] In its response, the Government proposed to give local authorities:

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[13] Ad hoc Parliamentary Committee, *Parliamentary hearings on services for disabled children* (October 2006) pp 45 to 46.

[14] Explanatory notes to the Children and Young Persons Act 2008, para 109.

[15] SI 2011 No 707.

[16] *R (RP) v Brent London Borough Council* [2011] EWHC 3251 (Admin) at [262].

[17] Department of Health and Social Security*, Review of Child Care Law, Report to Ministers of an Interdepartmental Working Party* (September 1985) para 6.3.

> a broad “umbrella” power to provide services to promote the care and upbringing of children, and to help prevent the breakdown of family relationships which might eventually lead to a court order committing the child to the local authority's care”.[18]

Respite care was intended to be one such service.

8.10 In practice, the situation has proved more complicated. Short breaks can be provided under section 17. But, as we explain below, they can also be provided under the powers and duties contained in section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 20 of the Children Act 1989. And the requirements of each provision, and the way in which they operate, are markedly different.

Section 17 of the Children Act 1989

8.11 Starting with section 17 of the Children Act 1989, the broad powers contained in that provision encompass services for disabled children as well as their families, and include the provision of accommodation, “assistance in kind” (non-cash goods and services) and cash.[19] These powers allow local authorities to provide all of the various types of short break set out at paragraph 8.2. Because they are powers and not duties, they can be made subject to local eligibility criteria.[20] In setting those criteria a local authority can take into account its budgetary constraints. And even where a disabled child meets the eligibility criteria, budgetary constraints may mean that (save where the duty under section 2 of the Chronically Sick and Disabled Persons Act 1970 applies) the child’s needs are not met in full. The various safeguards and entitlements, described below at paragraphs 8.17 to 8.21, which apply to accommodation provided under section 20 of the Children Act 1989, do not apply to accommodation provided under section 17.

Section 2 of the Chronically Sick and Disabled Persons Act 1970

8.12 Section 2 of the Chronically Sick and Disabled Persons Act 1970 requires local authorities to provide certain services under Part 3 of the Children Act 1989 to meet the needs of disabled children.[21] Those services include providing practical assistance in the home and recreational facilities outside the home, and facilitating the taking of holidays.[22] This encompasses most of the different types of short breaks set out at paragraph 8.2 but, significantly, the services do not generally include overnight stays at residential placements. In deciding whether a short break is necessary to meet a disabled child’s needs, local authorities may apply their own local eligibility criteria, reflecting their budgetary constraints. But once a decision has been taken that it is

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[18] The Law on Child Care and Family Services (1987) Cm 62 paras 15 to 18.

[19] Children Act 1989, s 17(1), (3), (6), (10) and (11). See further ch 9 on the range of services that can be provided.

[20] *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515, para 101 by Black J. See further ch 7 on eligibility criteria.

[21] See paras 7.3 to 7.11 for a discussion of the relationship between Chronically Sick and Disabled Persons Act 1970, s 2 and Children Act 1989, s 17.

[22] Chronically Sick and Disabled Persons Act 1970, s 2(4) and (6)(a), (c) and (f).

necessary to meet the child's needs, they must be met in full and budgetary constraints cannot be relied on to provide a reduced service.[23]

Section 20(1) of the Children Act 1989

8.13 Under section 20(1)(c) of the Children Act 1989, local authorities are required to provide accommodation for any child in need who appears to require accommodation as a result of:

> the person who has been caring for him being prevented (whether or not permanently, and for whatever reason) from providing him with suitable accommodation or care.

8.14 This duty encompasses disabled children, which is one category of child in need. The courts have interpreted this duty as one that is intended to deal with actual crises and not with possible or prospective ones. This means that it cannot be used to provide a short break in the form of residential accommodation in circumstances where "without assistance… a parent may (or possibly, even, will) be prevented from providing the child with suitable accommodation or care".[24] But the duty will be owed where a parent or carer is at "breaking point" and cannot continue to provide suitable accommodation or care.[25]

8.15 The duty is an absolute one: local authorities cannot take into account their budgetary constraints in deciding whether the duty is owed, and the use of eligibility criteria is not permissible.[26]

8.16 If the duty is owed, the courts have emphasised that accommodation must be provided and a local authority cannot side-step the duty by claiming to have acted under some other power, such as section 17 of the Children Act 1989.[27] This is important as there are various further duties which may be owed to a child who is accommodated under section 20 of the Children Act 1989. In broad terms, these duties are intended to make up for the fact that children accommodated under section 20 do not have a parent or carer who is in a position to accommodate them. Not all of these duties apply to children who are provided with accommodation under section 20 by way of a short break. But we set them out in full here as they provide important context to the provisional proposals we make below.

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[23] *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515 at [98] to [99] and [103] by Black J.

[24] *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515 at [96] by Black J.

[25] *R (TS) v Hackney London Borough Council* [2023] EWHC 3063 (Admin), (2024) 27 CCLR 117.

[26] *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515 at [70] to [71] and [100] by Black J.

[27] *R (M) v Hammersmith and Fulham London Borough Council* [2008] UKHL 14, [2008] 1 WLR 535 at [42] by Baroness Hale; *R (G) v Southwark London Borough Council* [2009] UKHL 26, [2009] 1 WLR 1299 at [9] by Baroness Hale.

Further duties owed to children accommodated under section 20[28]

Duties owed to looked after children

8.17 A child who is accommodated by a local authority under section 20 of the Children Act 1989 for a continuous period of 24 hours or more is classed as a "looked after child".[29] Children in the care of their local authority are also classed as looked after children. Children accommodated under section 17 are not. A local authority looking after a child is under a duty to:[30]

(1) safeguard and promote their welfare;

(2) make use of the services that are provided to children cared for by their own parents, to the extent that appears reasonable; and

(3) maintain the child in other respects apart from the provision of accommodation.

8.18 These duties could, in our view, require the local authority to meet needs arising from a looked after child's disability. This would be the case where those needs were not already being met by the provision of the short break itself, or under section 2 of the Chronically Sick and Disabled Persons Act 1970 or section 17 of the Children Act 1989. However, the hierarchy between these various provisions is not clear.

8.19 A local authority looking after a child must prepare a care plan for them. This should be based on an assessment of the services that the child needs in order to achieve or maintain a reasonable standard of health or development.[31]

8.20 A local authority must also appoint an independent reviewing officer in respect of every child they are looking after.[32] The independent reviewing officer must be a registered social worker with sufficient experience to carry out their role independently and with regard to the child's best interests.[33] The independent reviewing officer's job is to monitor the performance of the local authority's functions, ensure that the child's wishes and feelings are taken into account and participate in regular reviews of the child's case.[34]

8.21 The Care Planning, Placement and Case Review (England) Regulations 2010 contain various procedural requirements and safeguards that generally apply to looked after children. These cover matters such as visits to the child, record keeping, the content of the care plan and the conduct of the reviews.[35] But these general requirements

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[28] See further S Luh and C Johnston, *Migrant Support Handbook* (1st ed 2023) paras 9.71 to 9.138.

[29] Children Act 1989, s 22(1) and (2)

[30] Children Act 1989, ss 22(3) and 22B.

[31] Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, regs 2(1) and 4(1).

[32] Children Act 1989, s 25A.

[33] Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, reg 46(1) and(2).

[34] Children Act 1989, s 25B; Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, regs 36 and 45.

[35] Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, regs 5, 7, 9, 13, 28, 33 and 49.

apply differently to disabled children accommodated under section 20 as a short break. The various safeguards and requirements are adapted or dispensed with if the child has been placed in a series of short break placements with the same person or in the same accommodation and:[36]

(1) no single placement is intended to last for longer than 17 days;

(2) at the end of each such placement, the child returns to the care of their parent or carer; and

(3) the short breaks do not exceed 75 days in total in any period of 12 months.

For example, reviews take place less frequently and the care plan does not need to set out a long-term plan for the child's upbringing but should instead address their health and emotional development needs associated with their disability. These dispensations and adaptations to the rules that apply to other looked after children reflect the fact that a disabled child who meets the criteria set out above will have more parental involvement in their life than other children accommodated under section 20.

Duties owed to care leavers

8.22 Children who have been looked after by their local authority for a period of time are generally referred to as "care leavers". This term is not defined in the legislation. Rather it is an umbrella term which refers to several different legal categories of child and young adult. Children falling into any of these categories have entitlements to additional support – often referred to as "leaving care rights" – from their local authority, reflecting the fact that the local authority has, in effect, stepped into the shoes of the child's parents. The two categories of care leaver of principal relevance to this section of the consultation paper are "eligible" and "relevant" children.

8.23 A 16–17-year-old who has been looked after by a local authority for a total period of 13 weeks or more, beginning on or after their 14th birthday and ending on or after their 16th birthday will be classed as an "eligible child".[37] A local authority that is looking after an eligible child will owe them the same duties as would be owed to any other looked after child.[38] In addition, an eligible child is entitled to an assessment of their needs, a "pathway plan" setting out how their needs will be met and a personal adviser to advocate for them.[39]

8.24 The general rule is that the 13-week period does not need to have been continuous. It can consist of a series of shorter placements, providing the total amounts to 13 weeks or more.[40] But, again, short breaks provide an exception to the general rule. If the

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[36] Children Act 1989, sch 2, para 19B(3)(b) and Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, reg 48.

[37] Children Act 1989, sch 2, para 19B(2); Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, reg 40(1).

[38] See paras 8.17 to 8.21 above.

[39] Children Act 1989, sch 2, paras 19B to 19C.

[40] Children Act 1989, sch 2, para 19B(2)(b).

child has been placed in a series of short break placements as set out at paragraph 8.21 above, then they will not be an eligible child.[41]

8.25 A child is only classed as an eligible child while they continue to be looked after by their local authority. If the local authority stops accommodating them then they are known as a “relevant child” until they reach the age of 18.[42] A local authority which is responsible for a relevant child is required, among other things, to maintain them and safeguard and promote their welfare.[43] As with the additional duties owed to looked after children, these additional duties owed to relevant children could, in our view, require the local authority to meet needs arising from the child’s disability, to the extent those needs were not already being met. However, the hierarchy between the various duties and powers which could be used to meet the child’s needs is not clear.

Section 20(4) of the Children Act 1989

8.26 Local authorities have a power under section 20(4) of the Children Act 1989 to provide accommodation to any child within their area if they consider that to do so would safeguard or promote the child's’ welfare. This power can be used to provide short breaks. Because it is only a power and not a duty – as is the case for section 17 – it can be made subject to local eligibility criteria and in setting those criteria a local authority can take into account its budgetary constraints.[44] Even where a disabled child meets the eligibility criteria, budgetary constraints may mean that the child’s needs are not met in full. Children accommodated under section 20(4) will be entitled to the same additional duties as children accommodated under section 20(1), described at paragraphs 8.17 to 8.25 above. Statutory guidance provides that local authorities are free to choose between providing short breaks under section 17 and section 20(4). In reaching this decision, factors such as the child’s vulnerability, the parenting capacity of their parents or carers and the need for an independent reviewing officer should be taken into account.[45]

THE CASE FOR REFORM

8.27 We think the legal framework that we have set out above is too complex and fragmented. Short breaks are one of the most important services that a local authority can provide for the benefit of a disabled child. The law governing access to these services should be accessible and easy to understand. Unfortunately, as is evident from the analysis above, this is not currently the case.

8.28 Short breaks can be provided under four different statutory provisions, with different eligibility rules depending on which provision is used. Only two of these legal routes to

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[41] Children Act 1989, sch 2, para 19B(3)(b); Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, regs 40(2) and 48.

[42] Children Act 1989, s 23A(2) and(3); Care Leavers (England) Regulations 2010, SI No 2571, reg 3(1) and(2).

[43] Children Act 1989, ss 23A(1) and 23B(8).

[44] *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515 at [101] by Black J.

[45] Department for Children, Schools and Families, *Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks* (April 2010) paras 2.7 to 2.8.

short breaks are recognised in the current statutory guidance, published in 2010.[46] Those are the powers under sections 17 and 20(4) of the Children Act 1989.[47] The duties under section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 20(1) of the Children Act 1989 are not covered. These duties are recognised in non-statutory, departmental advice that was provided to local authorities in 2011 following the case of *R (JL) v Islington London Borough Council*,[48] to provide context to a consultation on short breaks.[49] But the statutory guidance – which carries significantly more legal force and is directed at families of disabled children as well as local authorities – does not refer to these crucial provisions. This may create the impression that short breaks provision is entirely discretionary, which it is not. We do not highlight this lacuna in the guidance as a criticism. But the fact that these duties were initially overlooked and that it took a court judgment to bring them to light is an indication that the law is too complicated and fragmented.

8.29 In addition, our pre-consultation engagement has led us to the provisional view that the law on short breaks may not be achieving its objectives. The explanatory notes that accompanied the introduction of the general short breaks duty into schedule 2 to the Children Act 1989 state that:

> The intention is that breaks should not only be provided to those struggling to care for disabled children but also to those for whom a break from their caring responsibilities will improve the quality of the care they provide.[50]

8.30 The impression that we have gained from many of the parents, carers, children and young people from whom we have heard in the lead up to this consultation is that this is not happening. Research on short breaks conducted by the charity Mencap in 2006 found that half of families surveyed had not had a carer's assessment and half of those that had still did not receive any services.[51] Our initial impression is that this situation may not have improved. Many of those we have heard from have not had assessments, and many that have had assessments have not been offered services. Of those who have been offered services, they have often been unable to take them up. This is either because the services cannot be fitted around the responsibilities of caring for a disabled child, or because the services on offer are not particularly helpful. Examples of the former of which we heard in the lead up this consultation include Tai Chi classes and gym memberships. Examples of the latter include head massages.

8.31 We would like to hear consultees' views on whether our initial impression is representative of the situation nationally, or whether the examples we cite here are outliers and short breaks are in fact being provided more widely and effectively than

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[46] This is the guidance published by the (then) Department for Children, Schools and Families: *Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks* (April 2010).

[47] Department for Children, Schools and Families, *Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks* (April 2010) paras 2.3 to 2.6.

[48] *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515.

[49] Department for Education, *Short breaks for carers of disabled children - Departmental advice for local authorities* (March 2011) ch 4.

[50] Children and Young Persons Act 2008, Explanatory Notes, para 109.

[51] Mencap*, Breaking Point – families still need a break* (September 2006) p 16.

we have understood them to be. Assuming that our initial impression is correct and that there is a general lack of sufficient, appropriate short breaks provision, the reason for this is not clear to us. Again, we welcome views on this. It does not appear to be simply a consequence of budgetary constraints: nationally, planned local authority expenditure on short breaks has increased each year from around £193 million in 2015-16 to £248 million in 2024-25.[52] But the potential for adverse impacts if there is insufficient, appropriate short break provision is clear. Many of the parents and carers from whom we have heard in the lead up to this consultation have explained that, without access to short breaks, they struggle to provide the best care they can for their disabled children and find themselves anxious, tired and – in the worst-case scenario – close to breaking point. This is significant because the consequence of care arrangements breaking down can be that local authorities have to step in and provide longer term care or residential accommodation for the child. Supporting families to stay together is generally better for the child, in keeping with the ethos of Part 3 of the Children Act 1989, the United Nations Convention on the Rights of the Child, and the United Nations Convention on the Convention on the Rights of Persons with Disabilities.[53] It also costs less. For this reason, it is particularly important for us to hear consultees' experiences of short break provision so that we can gain a more comprehensive understanding of the reality on the ground.

Consultation Question 31.

8.32 We invite parent and carer consultees to provide their experiences of accessing short breaks.

Consultation Question 32.

8.33 We invite local authority consultees to tell us about the short break services available in their area and any criteria which must be met to access those services.

8.34 In any event, there are further features of the current system which suggest that reform is needed. In particular, it is difficult to identify a good reason for the existence of local eligibility criteria reflecting budgetary constraints which are applied to some types of short breaks provision but not to others. This is a recipe for confusion. It also has the potential to result in significant local variation in service provision which can mean that the needs of a disabled child would be met in one part of the country but not another. This is a problem which applies to the provision of disabled children's social care more broadly, and which we consider in detail in Chapter 7. A number of local authorities to whom we have spoken in the lead up to this consultation have indicated that it applies to short breaks provision too.

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[52] Department for Education, *Planned expenditure on the children's and young people's services budget* (September 2024).

[53] See paras 20.21 to 20.25.

8.35 Focusing on the duty under section 2 of the Chronically Sick and Disabled Persons Act 1970, there is no particular justification that we can see for having certain kinds of short breaks provision falling within the scope of the duty and not others. This strikes us as unnecessarily complicated.

8.36 Finally, the fact that local authorities can, in some cases, choose whether residential short breaks are provided under section 17 or section 20(4) of the Children Act 1989 means that there can be an inconsistency in the safeguards and benefits made available. Specifically, if a child is accommodated under section 17, they will not be classified as "looked after". This means that the local authority will not owe them the same duties to provide them with the "services that are provided to children cared for by their own parents" or "maintain [them] in respects apart from the provision of accommodation".[54] Those duties would be owed, however, if the local authority had chosen to accommodate them under section 20(4) of the Children Act 1989. Children accommodated under section 17 of the Children Act 1989 are also not entitled to the oversight of an independent reviewing officer and miss out on the various procedural safeguards relating to care planning, record keeping, reviews and visits which we set out above.[55] Moreover, they are not entitled to leaving care rights.[56] There are some valid reasons why a disabled child accommodated by their local authority as a short break may not need all of these benefits and protections. Children accommodated for a short time, who will imminently return to the care of a family which can meet all their needs, may not require the same level of monitoring and support as children accommodated in the longer term, who lack the same family support. But this is already built into the Care Planning, Placement and Case Review (England) Regulations,[57] which relaxes or dispenses with many of the additional benefits and safeguards associated with section 20 status for children who are accommodated in a series of short breaks.[58] As such, the fact that local authorities are free to choose between section 17 and section 20(4) is, arguably, arbitrary and anomalous as two children with identical needs in neighbouring areas might be accommodated under different provisions and receive differing levels of support and protection.

OPTIONS FOR REFORM

8.37 The first option is to do nothing. This would reflect the view that save in the most serious cases where a family is at risk of imminent breakdown – in which case accommodation must be provided under section 20(1) of the Children Act 1989 – it is appropriate that local authorities should have discretion as to how best to deploy their limited resources. However, this would not address the complexity of the law. Nor would it address what appears to be a situation in which some families who need short breaks are not getting them, such that the law is not achieving its policy objective. It would also not deal with the mismatch in benefits and safeguards that

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[54] See para 8.17 above.

[55] See paras 8.19 to 8.20 above. Note, however, that, as explained at para 8.21, some of these safeguards are modified or dispensed with for those accommodated in a series of short-term placements.

[56] See paras 8.22 to 8.25 above. The same exceptions for those accommodated in a series of short-term placements apply to leaving care rights.

[57] SI 2010 No 959.

[58] See para 8.21 above.

apply depending on whether a local authority chooses to provide accommodation under section 17 or section 20(4). For these reasons, our preliminary view is that it is not an appropriate option.

8.38 The second option is to seek to simplify the various routes to providing short breaks into a single legal provision. If that option is pursued, further questions arise for consideration.

(1) Should there be a power to provide short breaks (as there is under section 17 and section 20(4) of the Children Act 1989) or should it be a duty (as it is under section 2 of the Chronically Sick and Disabled Persons Act 1970 or section 20(1) of the Children Act 1989)?

(2) If a duty is thought to be the best way forward, what should the threshold be for triggering the duty? Related to that, should there be local eligibility criteria set by local authorities, or national eligibility criteria set by central Government in consultation with local authorities? And on what principles should those criteria be based?

(3) When (if at all) should the various additional benefits and safeguards available to children looked after under section 20 of the Children Act 1989[59] be available?

(4) Should the provision of short breaks be treated as a service for the child, the parent or carer, or both?

OUR PROVISIONAL PROPOSALS

The definition of a short break

8.39 Below, we make a series of detailed provisional proposals relating to eligibility for short breaks. For these proposals to be effective, there must be clarity about what a short break is. In this respect, our intention is not to change the current law but to clarify it. With that in mind, consistent with the various definitions, objectives and examples of provision set out in the current legislation, we provisionally propose that short breaks should be defined as follows.

Services to:

(a) provide breaks for the benefit of disabled children; and/or

(b) assist individuals who provide care for disabled children to continue to do so, or to do so more effectively, by giving them breaks from caring.

Including:

(a) accommodation;

(b) the provision of care at home or elsewhere;

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[59] See paras 8.17 to 8.25 above.

(c) educational or leisure activities; and

(d) services to assist parents and carers in the evenings, at weekends and during the school holidays.

Consultation Question 33.

8.40 We provisionally propose to define short breaks as:

Services to:

(a) provide breaks for the benefit of disabled children; and/or

(b) assist individuals who provide care for disabled children to continue to do so, or to do so more effectively, by giving them breaks from caring.

Including:

(a) accommodation;

(b) the provision of care at home or elsewhere;

(c) educational or leisure activities; and

(d) services to assist parents and carers in the evenings, at weekends and during the school holidays.

Do consultees agree?

A single duty to provide short breaks

8.41 Our provisional proposal is that there should be one single statutory provision under which short breaks are made available for disabled children and their families. It seems to us that the law, as it stands, is too complex. We have not identified any convincing justifications for having different provisions, under which different types of short breaks can be made available according to different eligibility criteria.

8.42 We provisionally propose that the single statutory provision should be an individually enforceable duty, not subject to resource constraints. Section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 20(1) of the Children Act 1989 already contain duties to provide virtually the entire range of short breaks provision. So having a single duty encompassing all type of short breaks would not constitute a significant departure from the policy that underpins the current regime. As is the case under the current regime, local authorities would be permitted to charge for short breaks provision where necessary and appropriate to do so. We discuss charging separately in Chapter 12. But for present purposes we simply highlight that we are not proposing any substantive legal change to the current law on charging.

8.43 In keeping with our aim of simplifying the law, we provisionally propose that the duty to provide short breaks should fall within the wider duty we propose in Chapter 7, to meet the eligible needs of disabled children. That is, there should be one single duty to meet the eligible needs of disabled children. Provision of a short break would simply be one way of performing that duty.[60]

8.44 It is implicit within this element of the provisional proposal that short breaks should be treated by the law as a service for the child rather than the parent or carer. In reality, short breaks tend to be for benefit of both, as we explain at paragraphs 8.4 to 8.5 above. With that in mind, the duty would need to be phrased in such a way as to make it clear that, although the duty is owed to the child, it can be performed by the provision of services to the parent or carer. We discuss the provision of services other than short breaks to parents and carers in Chapter 7.

8.45 If this provisional proposal were implemented, sections 17 and 20 of the Children Act 1989 would remain on the statute book. These provisions perform much wider functions for children in need generally, and not just disabled children. But they would no longer be used to provide short breaks for disabled children. Mainstream housing and homelessness legislation should not be used for this purpose either. Generally speaking homeless 16 and 17 year olds are the responsibility of social services under section 20 of the Children Act 1989 and not local housing authorities.[61] The exception to this general rule is where the child has refused, on a fully informed basis, the help of social services.[62] This division of responsibilities should also apply to the new, single duty to provide services to disabled children that we propose.

Consultation Question 34.

8.46 We provisionally propose that short breaks should be made available under a single statutory duty to meet the social care needs of disabled children.

Do consultees agree?

National eligibility criteria

8.47 As with services for disabled children more generally (see Chapter 7), we think that this duty should be subject to national eligibility criteria contained in secondary legislation, co-produced by central Government in consultation with local authorities. We develop this provisional proposal at paragraphs 7.39 to 7.50.

8.48 However, the eligibility criteria for short breaks would, we think, need to be different to the eligibility criteria for other types of service. That would require the statutory duty to include a power to make regulations setting out different eligibility criteria for different purposes. We think that bespoke eligibility criteria would be needed for short breaks

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[60] See further ch 9 on the range of services we propose should be available under this duty.

[61] Homelessness (Priority Need for Accommodation) (England) Order 2002, SI No 2051, art 3; *R (G) v Southwark London Borough Council* [2009] UKHL 26, [2009] 1 WLR 1299.

[62] Department for Education and Ministry of Housing, Communities & Local Government, *Provision of accommodation for 16 and 17 year olds who may be homeless and/or require accommodation* (April 2018) para 3.13.

because there are a number of features of the current legislation which apply to short breaks, and not to other kinds of service. For example, the Breaks for Carers of Disabled Children Regulations 2011 require local authorities, in deciding whether to provide a short break, to have regard to the needs of those carers who would be unable to continue to provide care unless breaks from caring were given to them.[63] This requirement does not apply to other services that local authorities provide to the families of disabled children. If requirements such as these are to be retained that will necessitate separate eligibility criteria.

Consultation Question 35.

8.49 We provisionally propose that eligibility for a short break should be subject to national eligibility criteria.

Do consultees agree?

The additional benefits and safeguards accompanying short break accommodation

8.50 In proposing that short breaks should no longer be provided under section 20 of the Children Act 1989, we do not propose that there should be any reduction in the rights and entitlements of children currently provided with short breaks under section 20. We propose that the benefits (looked after status and leaving care rights) and safeguards (such as the independent reviewing officer) associated with section 20 of the Children Act 1989 would also apply under our proposed new duty subject to the existing exceptions. We recognise that currently not all children provided with accommodation as a form of short break are entitled to these benefits and safeguards. Children accommodated under section 17 of the Children Act 1989 are not. This means that this element of our proposal would represent a departure from the current regime. But it would, in our view, represent a minor and justifiable departure.

(1) As to the additional benefits, children who would currently be accommodated under section 17 of the Children Act 1989 because they only need a short stay away from home and have full parental support will not require much if any additional support, over and above the short break itself, to maintain them. Nor would they need, or become entitled to, leaving care rights.

(2) As to the safeguards (such as having an independent reviewing officer) we think that all children accommodated away from their parents would benefit equally from these protections and we cannot presently see a good reason for inconsistency in the level of protection provided to children away from home.

We welcome consultees' views on these matters.

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[63] SI 2011 No 707, reg 3(a).

Consultation Question 36.

8.51 We provisionally propose that children who are provided with a short break in the form of accommodation away from the family home should have the same benefits and safeguards as currently apply to children provided with a short break under section 20 of the Children Act 1989.

Do consultees agree?

PART 3 – SERVICE PROVISION

Chapter 9: The range of services that should be available

INTRODUCTION

9.1 In Chapters 7 and 8, we discussed eligibility for disabled children's social care. Having decided that a child or their parent or carer is eligible for services, the next issue which a local authority needs to consider is what services the child, parent or carer requires. The range of services that should be available for these purposes is the subject of this chapter.

THE CURRENT LAW

Section 17 of the Children Act 1989

9.2 Section 17(1) of the Children Act 1989 permits local authorities to provide a broad selection of services with a view to safeguarding and promoting the welfare of disabled children, as well as other children in need. The range of services is not exhaustively defined but includes accommodation, assistance in kind (which means goods and services other than money) and cash.[1] This non-exhaustive list covers the principal services generally needed by disabled children and their families.

(1) The provision of accommodation allows local authorities to provide residential short breaks.[2]

(2) Assistance in kind can encompass personal care in the home, such as assistance with washing or using the toilet. It may extend to nursing care, so long as the care is not primarily medical in nature, in which case it would cross the line between social care and health care.[3] It can also include things like adaptations to the home.[4]

(3) The power to provide cash allows local authorities to make direct payments which enable disabled children and their families to purchase a broad range of services for themselves.[5]

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[1] Children Act 1989, s 17(6).

[2] Children Act 1989, sch 2, para 6(1)(c); *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515.

[3] *R (T, D and B) v Haringey London Borough Council* [2005] EWHC 2235 (Admin), (2006) 9 CCLR 58. See further ch 14 on the distinction between health and social care.

[4] *R (Spink) v Wandsworth London Borough Council* [2005] EWCA Civ 302, [2005] 1 WLR 2884.

[5] Children Act 1989, s 17A(1); Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, reg 4 and sch 1. See further paras 10.8 to 10.13 on direct payments.

Section 2 of the Chronically Sick and Disabled Persons Act 1970

9.3 Section 2 of the Chronically Sick and Disabled Persons Act 1970 is focused exclusively on disabled children. The services that can be provided as a result of section 2 are more limited and consist of:[6]

(1) providing practical assistance for the child in their home;

(2) providing "wireless, television, library or similar recreational facilities" for the child, or assisting them to obtain them;

(3) providing lectures, games, outings or other recreational facilities outside the home;

(4) assisting the child to take advantage of educational facilities;

(5) putting in place and/or helping with travel arrangements, so that the child can participate in the services that have been arranged for them;

(6) providing assistance in arranging adaptations to the home;

(7) providing facilities to secure greater safety, comfort or convenience for the child;

(8) facilitating the taking of holidays by the child;

(9) providing meals for the child; and

(10) providing a telephone for the child, or special equipment necessary for the child to use one.

9.4 Technically, these services are not provided under section 2 itself. The services are provided under Part 3 of the Children Act 1989, and most typically section 17.[7] But the effect of section 2 of the Chronically Sick and Disabled Persons Act 1970 is to *require* local authorities to provide these specific services – which would otherwise be discretionary – in circumstances where the local authority judges it to be necessary in order to meet the needs of a disabled child.

Section 20(1) and (4) of the Children Act 1989

9.5 Section 20 of the Children Act 1989, like section 17, is targeted at all children in need. This includes, but is not limited to, disabled children. Under section 20(1) and (4) of the Children Act 1989 local authorities have, respectively, a duty and a power to provide accommodation to children in need. This allows, or in some circumstances requires, local authorities to provide accommodation to disabled children. This might be because the nature of the disabled child's needs is such that those needs can only

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[6] Chronically Sick and Disabled Persons Act 1970, s 2(6).

[7] Chronically Sick and Disabled Persons Act 1970, s 2(4); *R (Spink) v Wandsworth London Borough Council* [2005] EWCA Civ 302, [2005] 1 WLR 2884. See further paras 7.3 to 7.11.

be met in residential accommodation, or because accommodation is required in order to provide the child and their parent or carer with a short break.[8]

Other provisions of the Children Act 1989

9.6 There are a number of other duties under the Children Act 1989 which, in broad terms, are designed to provide services to children who are, or have previously been, accommodated by their local authority.[9] The idea underpinning these duties is that the local authority has taken on the role of "corporate parent" in accommodating the child and should provide the same support that a reasonable parent would.[10] A proportion of children who are owed these duties will be disabled. Theoretically, local authorities could use any of these provisions to meet the needs arising from the child's disability. However, the relevant statutory provisions do not spell out precisely what services can be provided. Rather, the scope of what can be provided is determined by the purpose of the service. For example, services provided to children being looked after by their local authority must be provided to safeguard and promote their welfare and be of a type which could be made available to children cared for by their parents.[11] Viewed in this way, these additional duties do not add to the broad range of services that can be provided under section 17.

Section 1 of the Housing Grants, Construction and Regeneration Act 1996

9.7 As noted above at paragraphs 9.2 and 9.3, both section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 17 of the Children Act 1989 can be used by local authority children's services departments to fund, make or secure adaptations to the home of a disabled child. However, the making of adaptations to the home also forms the subject of a distinct statutory regime which allows local *housing* authorities to provide grants toward the cost of works required for the provision of facilities for disabled persons.[12] These disabled facilities grants are discussed further at paragraphs 7.12 to 7.17.

Summary

9.8 Taken together, the various powers and duties to assist disabled children allow for the provision of a very broad range of services. Providing the services can properly be regarded as social services and do not cross the line into health care provision,[13] and are used to safeguard and promote the child's welfare there is no real limit to what can be provided. All of the principal forms of support which families generally need[14] are covered, including:

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[8] *R (JL) v Islington London Borough Council* [2009] EWHC 458 (Admin), [2009] 2 FLR 515; *R (TS) v Hackney London Borough Council* [2023] EWHC 3063 (Admin), (2024) 27 CCLR 117.

[9] See further paras 8.17 to 8.26 on the duties owed to looked after children and care leavers.

[10] Children Act 1989, ss 22, 22B, 23A and 23B.

[11] Children Act 1989, s 22(3).

[12] Housing Grants, Construction and Regeneration Act 1996, s 1.

[13] See ch 14 on the distinction between health and social care.

[14] See What Works for Children's Social Care, *Understanding services provision for children in need in England* (May 2022) p 29.

(1) personal care;

(2) short breaks;

(3) adaptations to the home;

(4) accommodation (whether as a short break or something longer term); and

(5) money to purchase services.

THE CASE FOR REFORM

9.9 The list of services contained in section 2 of the Chronically Sick and Disabled Persons Act 1970 is out of date. Most obviously, the provision of a wireless – which is a reference to a wireless radio – is obsolete. Most of the young people we have heard from in the run up to this consultation have not heard of a wireless radio and assume that wireless refers to wireless internet. The phrase “assistance in kind” in section 17 of the Children Act 1989 is also dated and is not universally understood.

9.10 But save for modernising the language used to describe the services that can be provided, we do not think there is any particular case for reform of the range of services that can be made available. In the lead up to this consultation we have not heard any concerns from parents and carers or from local authorities that the range of services that local authorities are permitted to provide is too limited.

9.11 Nevertheless, elsewhere in this paper, we make a number of provisional proposals which will affect the various legal provisions we discuss above. In particular, we provisionally propose that there should be a new, single duty to meet the eligible needs of disabled children, complemented with powers to meet non-eligible needs and the needs of parents and carers.[15] This requires us to think about the range of services that should be made available under these duties and powers. We also need to think about how that range of services should be expressed in the legislation.

OPTIONS FOR REFORM

9.12 There are three main options available. The first is to leave the range of services undefined and to give local authorities flexibility to provide the services that they think are appropriate to meet the child’s needs. That is the model that applies to the duty to meet the needs of looked after children under section 22 of the Children Act 1989. The range of services is not completely unlimited. They must be services which safeguard and promote the child’s welfare, and the kind of services that are available to children cared for by their own parents. But as long as the local authority stays within these parameters, there is no limit on what can be provided.

9.13 The second option is to provide a non-exhaustive list of services which local authorities can provide subject to certain parameters. This is the model of section 17 of the Children Act 1989, which permits the provision of a range of services, including accommodation, assistance in kind and cash, in order to safeguard and promote the

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[15] See ch 7.

welfare of children in need. It is also the model used in the adult social care legislation. Section 8(1) of the Care Act 2014 provides that:

> The following are examples of what may be provided to meet needs under sections 18 to 20—
>
> (a) accommodation in a care home or in premises of some other type;
>
> (b) care and support at home or in the community;
>
> (c) counselling and other types of social work;
>
> (d) goods and facilities;
>
> (e) information, advice and advocacy.

9.14 The third option is to provide an exhaustive list of services. That is the model used by section 2 of the Chronically Sick and Disabled Persons Act 1970.

OUR PROVISIONAL PROPOSALS

9.15 We provisionally propose the second option: a non-exhaustive list of services to be provided which is subject to certain parameters. The parameters would be defined by the power or duty under which the services are provided. As explained above, we are provisionally proposing that there should be a duty to meet the eligible needs of disabled children. Hence, by definition, the service provided must be of a type which meets those needs. But we do not think that there should be a limit on what can be provided to achieve that objective, save that the service cannot cross the line into health care provision. That would be ruled out by the express statutory exclusion which we discuss at paragraphs 14.50 to 14.51.

9.16 We do not think that limiting the range of services that can be made available any further than this would be helpful. First, because we do not want to limit the flexibility of social services to adapt to the particular needs of the child. Each disabled child is unique. What helps one child may not help another. Second, because an exhaustive list will – as technology and society develops – rapidly go out of date. The list of services in section 2 of the Chronically Sick and Disabled Persons Act 1970 illustrates this point.

9.17 However, we do think there is merit in providing a non-exhaustive list of the services that can be made available. The purpose of this would be to promote clarity and avoid disputes. The importance of this cannot be overstated. Every major piece of children's social care legislation since 1963 has given rise to a legal dispute that has had to be resolved by the Court of Appeal as to whether social services can use their powers to provide accommodation to homeless children, young people or their families.[16] Such

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[16] *Attorney General ex rel Tilley v Wandsworth London Borough Council* [1981] 1 WLR 854, [1981] 1 All ER 1162 (whether accommodation could be provided under Children and Young Persons Act 1963, s 1); *R v Tower Hamlets London Borough Council ex p Monaf* (1988) 20 HLR 529 (whether accommodation could be provided under Child Care Act 1980, s 1); *R (W) v Lambeth London Borough Council* [2002] EWCA Civ 613, [2002] 2 All ER 901 (whether accommodation could be provided under Children Act 1989, s 17); *R (O) v*

disputes cost a huge amount of money. Clarity in the legislation, in the form of a detailed list of the services, can help avoid them and leave local authorities, parents and carers clear as to what services can be made available. But making the list non-exhaustive preserves a degree of flexibility allowing local authorities to adapt to meet the needs of disabled children in an ever-changing society.

9.18 For these reasons, we provisionally propose that any new legislation should include a non-exhaustive list of services that can be provided to meet the needs of disabled children and their parents or carers.

9.19 We seek consultees' views on examples of services that it would be helpful to include in that list. The example list of services provided under section 17 is a helpful starting point, except that we think the term "assistance in kind" should not be used as many people are unfamiliar with it. This list of services could potentially be combined with the clearer, more modern list of services which can be made available under the Care Act 2014. The list could be adapted to refer specifically to some of the important services we refer to above, including short breaks and home adaptations. The list should include accommodation. But it should make it clear that accommodation is to be provided for the purposes of meeting the social care needs of disabled children. Accommodation for other purposes – for example because a child is homeless, or their home environment is not safe – should continue to be provided under the existing provisions of Part 3 of the Children Act 1989.[17]

9.20 Drawing these threads together, we provisionally propose that the list should include the following examples of services:

(1) accommodation;

(2) the provision of care at home or elsewhere;

(3) educational or leisure activities;

(4) services to assist parents and carers in the evenings, at weekends and during the school holidays;[18]

(5) adaptations to the home;

(6) counselling and other types of social work;

(7) goods and facilities; and

(8) information, advice and advocacy.

Barking and Dagenham London Borough Council [2010] EWCA Civ 1101, [2011] 1 WLR 1283 (whether accommodation could be provided under Children Act 1989, s 23C).

[17] Children Act 1989, ss 20 to 21 and 22A.

[18] Items (1) to (4) of the list are commonly provided as forms of short break. See ch 8. But they may also be required in other circumstances. For example, care in the home may be provided to supplement the care provided by a parent or carer, rather than to provide them with a break. Equally some disabled children require accommodation in the long-term and not simply as a short break.

9.21 For completeness, we are not suggesting these services must always be provided by the local authority directly. In Chapter 10 we provisionally propose that services could also be provided by another person or organisation arranged by the local authority or purchased by the parent or carer using direct payments. As we are proposing that services could be purchased by parents using direct payments, we do not think it is necessary for "cash" to be included in the example list of services. But we welcome views on this.

Consultation Question 37.

9.22 We invite consultees to tell us what, in their experience, are the main social services that disabled children require.

Consultation Question 38.

9.23 We invite consultees to tell us about the main social services for disabled children that are available in their area.

Consultation Question 39.

9.24 We provisionally propose that legislation should provide a non-exhaustive list of the social services that can be provided to disabled children.

Do consultees agree?

Consultation Question 40.

9.25 We invite consultees' views on the services that should be included in the list referred to in Consultation Question 39.

Chapter 10: How to provide services

INTRODUCTION

10.1 In the previous chapter of the consultation paper, we discussed the range of services that should be available to meet the needs of a disabled child or their parent or carer. Having decided which of these range of services are required, the next question for a local authority to consider is how the services should be provided.

THE CURRENT LAW

The three methods of providing disabled children's social care

10.2 There are three ways in which local authorities can secure the provision of services for a disabled child or their family. The first is by providing those services directly, for example, in the form of support from a local authority social worker.

10.3 The second is by arranging for another person or organisation to provide the service. For example, the local authority might arrange for personal care to be provided to a disabled child in their home by a carer employed by an agency. Accommodation is another example of a service which is frequently provided by third parties. Local authority children's services departments do not generally have their own stock of accommodation. So, they will often arrange for accommodation to be made available to disabled children by a specialist provider of supported accommodation, staffed by carers.

10.4 The third is by providing money to the parent or carer of the disabled child, or the child themselves if they are old enough, so that they can purchase the service for themselves. These are known as "direct payments".

10.5 All three of these methods are available for services provided under section 17 of the Children Act 1989 or section 2 of the Chronically Sick and Disabled Persons Act 1970. Section 17 refers expressly to local authorities providing services, facilitating others to provide services and putting in place arrangements for others to act on their behalf in providing services.[1] Similarly, section 2 of the Chronically Sick and Disabled Persons Act 1970 refers to local authorities "making arrangements" for the provision of various services: a phrase that is broad enough to encompass providing services directly or indirectly through third parties. As to direct payments, section 17A of the Children Act 1989 gives local authorities the power to provide services under section 17 using this method. This also applies to section 2 of the Chronically Sick and Disabled Persons Act 1970, as the services made available pursuant to that duty are generally provided under section 17.[2]

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[1] Children Act 1989, s 17(1) and (5).

[2] Chronically Sick and Disabled Persons Act 1970, s 2(4); *R (Spink) v Wandsworth London Borough Council* [2005] EWCA Civ 302, [2005] 1 WLR 2884. See further paras 7.7 to 7.10 above.

10.6 Only the latter two methods for arranging services are available in relation to disabled facilities grants for home adaptations under the Housing Grants, Construction and Regeneration Act 1996. As the scheme provides for the provision of grants, it is not open to a local authority to carry out the works of adaption themselves. However, grants can be paid directly to the contractor undertaking the works.[3]

10.7 Of these three methods for providing disabled children's social care services, it is the third – direct payments – which are the most complex. In addition, our pre-consultation work has led us to form the impression that this is the method where problems tend to arise. To contextualise these problems, it is necessary to look at the law on direct payments in a little more detail.

Direct payments

10.8 Direct payments are payments made by social services to a person who has parental responsibility for a disabled child, or the disabled child if they have reached the age of 16, to purchase a service for themselves.[4]

10.9 The idea behind this is to give families some autonomy and control over the service they receive. However, direct payments do not give families free rein to purchase *any* service. The payments are intended to cover only the particular service that the local authority has decided the disabled child needs.[5] Hence, if a local authority decides that the child needs personal care at home, the provision of direct payments would allow the family to choose their own carer. But they could not be used to fund an adaptation to the home.

10.10 Direct payments must be made where:[6]

(1) the parent or child (as the case may be) consents;

(2) the parent or child appears to the local authority to be capable of managing a direct payment;

(3) the parent or child does not fall within a list of exclusions, relating to persons with drug or alcohol issues;

(4) the need for the relevant service can be met by securing the provision of it by means of a direct payment; and

(5) the welfare of the child in respect of whom the service is needed will be safeguarded and promoted by securing the provision of it by means of a direct payment.

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[3] Housing Grants, Construction and Regeneration Act 1996, s 39.

[4] Children Act 1989, s 17A(1); Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, reg 4 and sch 1.

[5] Children Act 1989, s 17A(1) and (2); Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, reg 15.

[6] Children Act 1989, s 17A(1)-(2); Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, regs 4 and 7.

10.11 The default position, unless the local authority decides otherwise, is that payments are made at a rate which the authority estimates as the reasonable cost of securing the service. This is subject to a condition that the payee must reimburse the authority an amount (which could be zero) that the authority decides it would be reasonably practicable for them to pay.[7]

10.12 Providing that the local authority is satisfied that the need which calls for the provision of the service will be secured by the payee's arrangements, the authority is relieved of any statutory obligation to provide the service itself.[8] Curiously, however, local authorities are not under a statutory obligation to keep the sufficiency of direct payments made under the Children Act 1989 under review. This contrasts with direct payments made under section 57 of the Health and Social Care Act 2001 to fund aftercare services under section 117 of the Mental Health Act 1983. Such payments must be reviewed at least annually.[9] But this review requirement does not apply to direct payments under section 17A of the Children Act 1989. Previously, statutory guidance accompanying section 17A suggested that recurrent reviews should be carried out "so that the council remains satisfied that the direct payments promote and safeguard the welfare of the child",[10] but this guidance has been withdrawn.

10.13 Where the payment is not used to pay for the service for which it was provided, the local authority may require it to be repaid in full or in part.[11]

Comparison with special educational needs and disability law and adult social care law

10.14 The more modern statutory schemes dealing with special educational needs and disability (SEND) law and adult social care law provide an additional method for meeting the needs of children and adults with additional needs: the personal budget. Both the Children and Families Act 2014 and the Care Act 2014 provide a right to have a personal budget.[12]

10.15 In the SEND context, the personal budget is described as "an amount of money identified by the local authority to deliver provision set out in an [education, health and care plan] where the parent or young person is involved in securing that provision".[13] The parent or young person can be involved in securing provision with this funding

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[7] Children Act 1989, s 17A(3A); Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, reg 9. See further ch 12.

[8] Children Act 1989, s 17A(3A); Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, reg 14.

[9] Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, reg 16.

[10] Department of Health, *Guidance on direct payments: for community care, services for carers and children's services* (England) (2009) para 226. The Framework guidance document referred to is no longer in force.

[11] Children Act 1989, s 17A(3A); Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, reg 15.

[12] Children and Families Act 2014, s 49(1); Care Act 2014, s 25(1)(e).

[13] Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years* (January 2015) para 9.95.

either by means of direct payments, or arrangements where the local authority or a third party holds and manages the funds.[14]

10.16 The budget can be used as a tool to facilitate the use of direct payments. Alternatively, it can be used as a distinct method of providing services which takes the form of a "notional budget", which families "can devise with the local authority and which the local authority can spend on their behalf at their direction by arranging the provision".[15] It can also be used as a combination of both. Authors of the leading textbook on disabled children's law describe the philosophy underpinning the "notional budget" approach in the following terms:

> The idea behind such an arrangement is that a personal budget can provide some of the benefits of a direct payment without the disabled person or the parent having to take on the full responsibilities of managing a direct payment. In theory, the individual is encouraged to decide in what other ways the money could be spent to maximise their child's sense of independence and well-being. In this intermediate phase, instead of a direct payment being made, the monies are retained by the local authority… with the disabled person or their parents (if a child) encouraged to exercise as much control as they wish over directing how the budget is used.[16]

10.17 It can be seen from the account we provide here that the personal budget is not an entirely separate method of providing services to the three methods that are available in relation to disabled children's social care. Rather, it is a combination of the three methods which involves families being provided with the information they need so they can decide how they want the services to be provided.

10.18 Viewed in this way there is nothing that we can see which would stop local authorities from providing personal budgets in relation to disabled children's social care. Indeed, some authorities may well do this already. But, in contrast to SEND and adult social care law, families do not have a right to have services under a personal budget.

10.19 In addition to the lack of a right to a personal budget, disabled children's social care law differs from SEND law in a number of respects in relation to direct payments.

(1) In SEND law the amount paid must be "sufficient to secure the agreed provision".[17] As opposed to an amount which "the authority estimate to be equivalent to the reasonable cost of securing the provision of the service concerned".[18]

(2) In SEND law the use of direct payments must be reviewed at least once within the first three months of a payment being made. In carrying out the review the

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[14] Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years* (January 2015) para 9.101.

[15] Explanatory notes to the Children and Families Act 2014, para 253. See further, in relation to personal budgets in adult social care law, Department of Health and Social Care, *Care and Support Statutory* Guidance (March 2024) para 11.3.

[16] S Broach and L Clements, *Disabled Children: A Legal Handbook* (3rd ed 2020) p 128, para 3.103.

[17] Special Educational Needs (Personal Budgets) Regulations 2014, SI No 1652, reg 10(1).

[18] Children Act 1989, s 17A(3A) and (3B).

authority must consider whether “the amount of direct payments continues to be sufficient to secure the agreed provision”.[19] As we note above at paragraph 10.12, there is no statutory obligation to keep the sufficiency of direct payments made under the Children Act 1989 under review.

THE CASE FOR REFORM

10.20 The main concerns that we have heard in the lead up to this consultation about the methods by which local authorities provide services relate to the use of direct payments. Concerns that we have heard repeatedly from parents who have received direct payments include the following.

(1) That they are not always sufficient. In particular, direct payments made to secure the services of a carer are often calculated on the basis that the carer should be paid the national minimum wage. But caring for disabled children is skilled work and it can be difficult to find carers who will work for minimum wage. This may be particularly so in rural areas, where carers generally need to have a car.

(2) There is a general shortage of carers on whom to spend direct payments, irrespective of how much they cost.

(3) There may be considerable and complex responsibilities associated with spending direct payments on carers. For example, it may involve the parent of the disabled child becoming an employer and having to purchase, pay or administer National Insurance, holiday pay, sick pay, maternity/paternity pay, employers’ liability insurance, public liability insurance and VAT.[20]

(4) Direct payments are sometimes used as a way to deliver services even when they have not been requested and are not wanted.

(5) Local authorities do not always review the provision of direct payments and so the problems above are not always picked up.

(6) Alternatively, when parents raise these problems, it does not always result in the local authority assuming responsibility for providing the service directly or arranging for someone else to provide it.

10.21 Where these problems occur, the needs of the disabled child – needs which have been assessed as eligible for services – may not be met. This means, in turn, that the power or duty that the local authority is seeking to use, is not used effectively. Because of that, some of the parents we have heard from have expressed a sense of grievance that they have had to repay the money they have been unable to spend and have not been allowed to spend it on alternative provision for their children.

10.22 It is easy to see why these problems arise. Insufficient payments are a foreseeable consequence of the fact that the statutory scheme requires payments to be made for

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[19] Special Educational Needs (Personal Budgets) Regulations 2014, SI No 1652, reg 11.

[20] Department of Health, *Guidance on direct payments for community care, services for carers and children’s services England* (October 2010) para 114. This guidance has been withdrawn.

an amount the authority estimate to be equivalent to the reasonable cost of securing the provision, rather than an amount which is actually sufficient to secure the agreed provision.[21] Personal budgets can be a transparent device to allow parents to see how much they will get and form a view on whether it will be enough. The lack of any right to a personal budget makes it harder for parents to decide whether a direct payment will work for them. The lack of a review mechanism makes it more likely that problems with accessing care with direct payments will be overlooked. The fact that making a direct payment effectively relieves a local authority of its statutory obligation to provide the service itself makes it less likely that the authority will step in to provide the service when problems arise.

10.23 Problem (4) is slightly different to the other problems we identify at paragraph 10.20. This cannot be regarded as an inevitable or foreseeable consequence of the statutory scheme. Quite the opposite. This should not be happening at all, because direct payments should not be made without consent. But the fact that we have heard that this happens suggest that the system is not being monitored as closely as may be necessary. However, as a matter of law, the relevant monitoring body (Ofsted) has the power to inspect the performance of this function.[22] This is not therefore strictly a law reform issue.

OPTIONS FOR REFORM

10.24 The main option for reform we have identified is to bring the disabled children's social care system closer in line with the SEND system. Specifically:

(1) direct payments should be an amount that is sufficient to secure the provision needed, as opposed to an amount that is estimated to be reasonable;

(2) direct payments should be kept under review, so that their sufficiency can be monitored and alternative arrangements made if necessary; and

(3) there should be a right to a personal budget to increase the transparency and flexibility of the system.

OUR PROVISIONAL PROPOSALS

10.25 Our provisional view is that this option should be pursued. Elsewhere in this paper, we propose that there should be a single duty to meet the eligible needs of disabled children.[23] We think that local authorities should retain the flexibility to perform this duty – along with the various powers to meet needs that we propose[24] – by means of:

(1) providing services directly;

(2) arranging for services to be provided by a third party; and

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[21] See para 10.11 above.

[22] Education and Inspections Act 2006, ss 135(1)(e) and 136(1).

[23] See paras 7.39 to 7.43.

[24] See paras 7.60 to 7.61 and 7.66 to 7.68.

(3) making direct payments.

However, the duty cannot effectively be discharged if the direct payments system does not function properly. Our provisional view is that a system which is closely modelled on the SEND regime, as set out at paragraph 10.24 would provide a more better functioning model.

10.26 In proposing that a right to a personal budget should be introduced into disabled children's social care law, we are aware that there are criticisms of the use of personal budgets. The amounts provided under personal budgets are often calculated with reference to "resource allocation schemes" which some research has suggested can be opaque and inaccurate.[25] We welcome views on this. But our provisional view is that such operational problems speak to a need for practical improvements in the ways that personal budgets are administered. They do not, we think, justify providing children with a right to personal budgets in the SEND context but not in the context of disabled children's social care. In this particular situation, when we are purely focused on the way that local authorities can provide services for disabled children, we cannot identify any difference of principle between the two legal contexts.

Consultation Question 41.

10.27 We provisionally propose that local authorities should be able to provide services:

(1) directly;

(2) indirectly through third parties; and

(3) by means of direct payments.

Do consultees agree?

Consultation Question 42.

10.28 We provisionally propose that parents, carers and children aged 16 and over should have a right to a personal budget.

Do consultees agree?

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[25] L Series and L Clements, "Putting the cart before the horse: resource allocation systems and community care" (2013) 35(2) *Journal of Social Welfare and Family Law* 207.

Consultation Question 43.

10.29 We provisionally propose that the regime for direct payments should be adapted so that:

(1) the amount of the payment is the amount sufficient to secure the provision needed, as opposed to an amount that is estimated to be reasonable; and

(2) payments should be kept under review, so that their sufficiency can be monitored and alternative arrangements made if necessary.

Do consultees agree?

Chapter 11: The plan to meet the needs of a disabled child

INTRODUCTION

11.1 In Chapters 9 and 10, we considered the range of services that local authorities can provide to disabled children, and the various methods they have available to deliver them. In simple terms, selecting the services that are to be made available and the method by which they are delivered respectively requires a local authority to decide *what* services a disabled child and their family need and *where*, and *who* is going to provide them. All that remains after this is to decide *when* the services are to be provided. At that juncture, the local authority has the core elements of a plan to meet the needs of a disabled child. Care planning – the process of considering, collating and communicating this information to a disabled child and their family – is the subject of this chapter.

11.2 Within the chapter we refer to a number of different types of plan which must be prepared by social services under the current legal framework: a "child in need plan", a "care plan" and a "pathway plan". They all perform similar functions, albeit in slightly different contexts for different purposes: setting out what services are to be provided, where, when and by whom.

11.3 We also consider education, health and care plans (EHCPs) prepared by the education department within a local authority in this section, as the content of an EHCP can overlap with these other plans. We do not consider care plans produced by health bodies.

THE CURRENT LAW

The "child in need plan"

11.4 Part 3 of the Children Act 1989 contains no general requirement to produce a written plan for every disabled child for whom services will be provided. But the courts have taken the view that children in need – a term which includes but is not limited to disabled children – are entitled to a plan. This is on the basis that it is "the means by which the local authority assembles the relevant information and applies it to the statutory ends, and hence affords good evidence to any inquirer of the due discharge of its statutory duties".[1] Hence guidance provides that the assessment process should culminate in a "plan of action" which "should set out which services are to be delivered, and what actions are to be undertaken, by whom and for what purpose".[2] Or, as one judge has succinctly put it, having identified the child's needs, the plan

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[1] *R v Islington LBC ex p Rixon* (1997–98) 1 CCLR 119, 128D by Sedley J.

[2] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 177.

should set out “what was to be done about them, by whom and by when”.[3] This particular plan is referred to in the guidance as a “child in need plan”.[4]

11.5 The general requirements of a child in need plan set out above are not specific to disabled children. They apply to all children in need who are provided with services. But the nature of the requirements is such that, for a disabled child, the plan will be focused on the services that the child requires to meet the needs arising from their disability.

11.6 There is, however, specific guidance on the content of a child in need plan for disabled children who are going to be provided with a short break or breaks.[5] In that scenario, the plan should set out:[6]

(1) the nature and frequency of the short break services;

(2) the child’s health, emotional and behavioural development including full details about any disabilities and clinical needs the child may have and medications they may require;

(3) the child’s specific communication needs, especially for children who communicate non-verbally.

The “care plan”

11.7 There are further statutory requirements relating to plans for children who are accommodated by their local authority. Some, but not all, of these children will be disabled and, as with the child in need plan, the requirements are not specific to disabled children. But in practice, as with the child in need plan for a disabled child, the meeting of needs arising from the child’s disability will be a significant part of the plan.

11.8 A child who is in the care of a local authority or accommodated under section 20 of the Children Act 1989 for a continuous period of 24 hours or more is classed as a “looked after child”.[7] The duties owed to looked after children are discussed further at paragraphs 8.17 to 8.21. It is a statutory requirement that a local authority looking after a child must prepare a “care plan” for them.[8]

11.9 The care plan should be based on an assessment of the services that the child needs in order to achieve or maintain a reasonable standard of health or development. It should generally include a record of the arrangements made by the local authority to meet the child’s needs in relation to health, education and training, emotional and

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[3] *R (AB) v Nottingham City Council* [2001] EWHC Admin 235, (2001) 4 CCLR 295 at [43] by Richards J.

[4] HM Government, *Working Together to Safeguard Children 2023* (December 2023) p73.

[5] See further ch 8 for short breaks.

[6] Department for children, schools and families, *Short Breaks - Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks* (April 2010) para 3.16.

[7] Children Act 1989, s 22(1) to (2).

[8] Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, regs 2(1) and 4(1).

behavioural development, and family and social relationships, among other things.[9] It should also incorporate a “placement plan”, demonstrating how the accommodation the child has been placed in will contribute to meeting their needs.[10]

11.10 Statutory guidance emphasises that there should be “clarity in the care plan, particularly about the desired outcomes for the child and those expected from services and other actions identified”. Specifically, the care plan should:[11]

(1) describe the identified developmental needs of the child and the services required to meet those needs;

(2) include specific, achievable, child-focused outcomes intended to safeguard and promote the welfare of the child; and

(3) clearly identify and set out the roles and responsibilities of family members, the child’s carers and practitioners.

In addition, regulations require that the care plan should include a contingency plan, in the event that the primary plan is not achievable. The plan should be kept under review.[12]

11.11 As we explain in paragraph 8.21, some of the care planning requirements are relaxed or dispensed with where disabled children are accommodated under a series of short breaks of relatively short duration. This is on the basis that such children will spend most of their time living at home with their parents or carers, so there is less of a need or justification for the local authority to assume full responsibility for planning their care.

The “pathway plan”

11.12 Children who have been looked after by their local authority for a period of time are generally referred to as “care leavers”. This is not a term of art. Rather, it is an umbrella term which refers to several different legal categories of child and young adult who are entitled to additional, longer-term support reflecting the fact that the local authority has, in effect, stepped into the shoes of the child’s parents. See further paragraphs 8.22 to 8.25. Care leavers – like children in need and looked after children – are statutorily entitled to a written plan.

11.13 There are two relevant categories of care leaver in this context: “eligible” and “relevant” children. Again, some of these children falling within these categories will be disabled. Both categories of child are entitled to a “pathway plan”.[13] The purpose of the pathway plan, is to set out the action that must be taken by the local authority

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[9] Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, reg 5(1).

[10] Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, regs 5(1), 9 and sch 2.

[11] Department for Education, *The Children Act 1989 guidance and regulations. Volume 2: care planning, placement and case review* (July 2021) paras 2.2, 2.29 and 2.45.

[12] Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, reg 6 and pt 6.

[13] Children Act 1989, ss23A(1) and 23B(3) and sch 2, para 19B(1) and (4); Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, reg 43(1).

looking after the child to ensure that they are “provided with the services they need to enable them to achieve their aspirations and make a successful transition to adulthood”.[14] As with the other types of plan, these are not disability-specific requirements, but the meeting of needs arising from the child’s disability will need to form part of the plan.

11.14 The pathway plan must:[15]

(1) contain the child’s care plan;

(2) include the nature and level of contact and personal support to be provided to the child, and by whom; and

(3) set out–

    (a) the precise manner in which the local authority proposes to meet the child’s needs;

    (b) the date by which any action required to implement the plan will be carried out; and

    (c) the identity of the person responsible for that action.

The “EHCP”

11.15 As we discuss in detail in Chapter 13, some children with special educational needs are entitled to an EHCP. This is prepared and maintained by the education department of the local authority. It sets out the plan to meet the child’s special educational needs. But the child’s social care needs form a part of this plan. Specifically, there is a requirement that section H of the EHCP includes:[16]

(1) any social care provision which must be made for the child resulting from section 2 of the Chronically Sick and Disabled Persons Act 1970; and

(2) any other social care provision reasonably required by the child’s learning difficulties or disabilities which result in them having special educational needs.

11.16 The social care provision within the plan should be “detailed and specific and should normally be quantified, for example, in terms of the type of support and who will provide it”.[17]

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[14] Department for Education, *Children Act 1989: transition to adulthood for care leavers* (February 2022) para 3.5.

[15] Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, reg 43 and sch 8.

[16] Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years* (January 2015) para 9.62.

[17] Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years* (January 2015) para 9.69.

Summary

11.17 There are various types of plan which must be prepared by local authorities for children in need, looked after children, care leavers and children with special educational needs. These plans are not produced solely for disabled children. Rather, they reflect the requirements of a planning process which applies to children generally whom the local authority is supporting in different ways. But disabled children who are receiving services from their local authority to meet their needs may be entitled to one or more of these plans.

11.18 Each plan serves a slightly different purpose. For example, the care plan focuses on a looked after child's accommodation and the support that will be provided alongside it. By contrast, a pathway plan focuses on the support that a care leaver needs to make the transition to adulthood. Nevertheless, all of the plans – in broad terms – are intended to set out what support the child is to receive and from whom. The way in which services will be delivered to meet the needs arising from their disability will be an important aspect of the plan.

THE CASE FOR REFORM

11.19 A disabled child in receipt of services from their local authority, is entitled to a child in need plan, setting out what services they are to receive, when and from whom. They may or may not also be entitled to one of the other types of plans we set out above. But a child in need plan is the core requirement. However, this requirement is non-statutory. It has been implied into the legislative scheme by the courts and is reflected in guidance. This is in contrast with the other types of plans we refer to above, which are provided under express statutory requirements.

11.20 It has been a consistent theme of our pre-consultation engagement with parents, carers and local authorities that disabled children's social care law is complex and inaccessible. Important legal requirements which are not written down in the legislation are, in our view, one of the causes of this problem.

11.21 The relationship between the various plans set out above is also, in our view, not entirely clear. In particular, it strikes us that there is a risk of duplication and that a child may end up with multiple plans covering the same or very similar material. Or that a parent or carer may be confused as to whether their child needs to have two or more separate plans or whether the plans can be combined.

11.22 These problems, we note, are not unique to disabled children. But it is only disabled children who fall within the remit of this consultation paper and so our provisional proposals below relate to disabled children only.

OPTIONS FOR REFORM

11.23 The principal reform option to deal with the problems we outline above is to put the requirement to prepare a plan for the provision of services to disabled children on a statutory footing. The main argument against is that it would introduce inconsistency into the legal framework, if disabled children have a statutory right to a plan and other children in need do not.

11.24 Putting the plan for a disabled child on a statutory footing would require consideration to be given to the relationships between that plan and the various other plans we set out in this chapter. The options are that the legislation could:

(1) make it clear that the plan for a disabled child should be separate and additional to their care plan, pathway plan or EHCP;

(2) remain silent and allow local authorities freedom to choose whether the plans can or should be combined; or

(3) encourage or compel the plans to be combined.

OUR PROVISIONAL PROPOSALS

11.25 We provisionally propose that there should be a statutory requirement for a plan for the provision of services to disabled children. The right to a written plan is an important one. It provides children and families with clarity as to what they will receive, and where, when and how those services will be provided. It also provides them with a starting point for discussion with their local authority and – if needs be – a basis for complaint or challenge, if they are unhappy with the services that are to be provided, or the method by which they will be delivered. These objectives are of sufficient importance that we cannot at present see any particular reason why the right to a plan should not be set out in statute like the other plans we refer to. Doing so would promote clarity. As such, we provisionally propose that disabled children should have a statutory right to a care plan, setting out these matters.

Consultation Question 44.

11.26 We provisionally propose that disabled children who are eligible to have their needs met by social services should have a statutory entitlement to a plan setting out what services they are to receive, and where, when and how those services will be provided.

Do consultees agree?

11.27 We do not think it is appropriate for us, or for legislation, to be more prescriptive about the content of a care plan over and above requiring that it sets out the existing, core requirements of “what, where, when and how”. In some instances, a short and simple plan may suffice. For example, a child who uses a wheelchair and who is seeking a short break in the form of swimming lessons to aid the development of their motor skills may require nothing more than a letter setting out when, where and with whom the lesson is to take place. Conversely, a child whose needs are so complex that these needs can only be met in long-term residential accommodation with the support of multiple carers may require a far more detailed document, including the identities of the carers, a detailed timetable for the provision of care, and a contingency plan. The different requirements of the plans that would be needed in such cases are, in our view, better left to guidance. The permutations are too many and varied to be set out in legislation.

11.28 It is important, in our view, to allow local authorities to retain a degree of flexibility in the length and content of the plan. In proposing a statutory right to a plan to meet the needs of disabled children, we are not proposing to impose more onerous obligations on local authorities. What we are proposing should, in our view, reflect current practice. The purpose of the proposal is primarily to simplify and clarify the law. To introduce more detailed and onerous planning requirements into the law would go beyond this objective.

Consultation Question 45.

11.29 We provisionally propose that the content of the plan to meet the needs of a disabled child should be dealt with in guidance.

Do consultees agree?

11.30 The content of the plan for meeting the needs of a disabled child may potentially overlap with the content of the various other plans we describe above, such as their EHCP, care plan or pathway plan. To avoid duplication, we provisionally propose a statutory provision clarifying that a plan to meet the needs of a disabled child can be combined with any of these other plans where appropriate and that no additional plan would be required. This option makes it clear that the plans can be combined: if the legislation were silent on this, the point might be open to debate, resulting in unnecessary disputes. But it leaves local authorities with a degree of discretion as to whether combining the plans is appropriate. We cannot at present envisage a situation where separate plans would be desirable, given the significant overlap between the various plans. However, we are open to the possibility that such a situation could arise, in which case the hands of the local authority should not be tied.

Consultation Question 46.

11.31 We provisionally propose that the plan to meet the needs of a disabled child should be combined, where appropriate, with other plans for the child such as their EHCP, care plan or pathway plan.

Do consultees agree?

Chapter 12: Means testing and charging

INTRODUCTION

12.1 In this chapter we discuss the rules which permit local authorities to inquire into the means of the families of disabled children and charge them for the provision of disabled children's social care. The precise rules depend on the legal basis for providing the service, and how it is being provided. But in broad terms local authorities have a wide discretion as to whether to charge or not for services and we have heard that some authorities, in practice, choose not to do so.

12.2 We will say at the outset that we are not proposing any substantive changes to the charging regime. The funding of disabled children's social care is pre-eminently a matter for elected officials rather than law reform: see paragraphs 1.29 to 1.31 on the boundary between politics and law reform. As such we make no proposals to change the principles underpinning the charging regime which dictate who can be charged, how much and when.

12.3 However, we think that there may be scope for simplification of the charging regime without fundamentally changing the principles on which it is based. That will depend to a large extent on the views consultees take on some of the other questions we pose in this consultation paper. In particular, it will depend on their views as to whether we should have a separate legal framework for disabled children's social care and whether disabled facilities grants should fall within that framework.[1] As we discuss in Chapter 23, we do not think that it would be possible to introduce changes to the charging regime otherwise.

12.4 Irrespective of this, the charging regime provides important context to the other proposals in this consultation paper. We invite consultees' views on what existing charging practices are and how our proposals might affect them at the end of this chapter.

THE CURRENT LAW

Charging for services under section 17 of the Children Act 1989

12.5 Section 17 of the Children Act 1989 allows local authorities to provide services either unconditionally or subject to conditions requiring the value of the service to be repaid in full or in part.[2] To facilitate the exercise of that power, local authorities are required to have regard to the means of the child concerned and their parents before providing assistance under section 17 or imposing repayment conditions.[3]

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[1] See ch 23 and paras 7.12 to 7.17, 7.38 and 7.58.

[2] Children Act 1989, s 17(7).

[3] Children Act 1989, s 17(8).

12.6 The power to impose repayment conditions may be applied to anyone: no-one is exempt from the charging regime. But those who are in receipt of the main, means-tested welfare benefits are not liable to make any repayments.[4] The benefits are:

(1) universal credit;

(2) income support;

(3) any element of child tax credit other than the family element;[5]

(4) working tax credit;

(5) income-based jobseeker's' allowance; or

(6) income-related employment and support allowance.

12.7 Charges can be recovered from:[6]

(1) the child's parents, where the service is provided for a child under 16;

(2) the child themselves, if they are 16 or over; or

(3) any other member of the child's' family who is provided with services.

Unpaid charges can be recovered as a civil debt, through the courts.[7]

12.8 The amount which a local authority can charge is limited by section 29 of the Children Act 1989 to that which the authority "consider reasonable". This represents the upper limit. The authority can only recover this amount if, having regard to the person's means, it would be "reasonably practicable" for them to pay this much. Otherwise, the amount is limited to that which the person can "reasonably be expected to pay".[8]

12.9 This regime applies to children in need generally. It is not unique to disabled children.

Direct payments

12.10 As discussed in Chapter 10, one of the ways in which services may be provided under section 17 is by means of direct payments.[9] There is a separate, complementary charging regime, for direct payments.

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[4] Children Act 1989, ss 17(7) and 29(3).

[5] Individuals receiving certain payments toward childcare costs under s 17 are treated as though they are in receipt of an element of child tax credit other than the family element or working tax credit, and so are not liable to make repayments: Children Act 1989, s 17(12) and Children Act 1989, Section 17(12) Regulations 2003, SI No 2077, reg 3.

[6] Children Act 1989, s 29(1) and (4).

[7] Children Act 1989, s 29(5).

[8] Children Act 1989, s 29(1) and (2).

[9] Children Act 1989, s 17A(1) and (2).

12.11 Direct payments can either be “gross” or “net”. The default position is that payments should be gross, unless the local authority decides otherwise. Gross payments are made at the rate the authority estimate to be equivalent to the reasonable cost of securing the provision of the service concerned but can be made subject to repayment conditions. The amount to be repaid is limited to that which the authority determine it is “reasonably practicable” for the person to pay. Net payments are made at the same rate – the reasonable cost of securing the provision – minus a deduction, by way of contribution to the cost of the service. The deduction is (again) limited to the amount which the authority determine it is reasonably practicable for the person to pay. In order to decide how much the repayment or deduction should be, the authority, in all cases, is required to have regard to the person’s means.[10]

12.12 This charging regime only applies to disabled children and their families, as these are the persons for whom direct payments can be made.[11] Although the charging regime for direct payments is a little more complex than the charging regime for other services under section 17 of the Children Act 1989, the fundamental principles are the same. A local authority is required to consider the person’s means before making a payment and having done so, can levy a charge (by way of deduction or repayment condition) limited to that which the authority think it is reasonable to expect them to pay.

Charging for the maintenance of looked after children

12.13 At paragraph 8.17 we discussed the duty to maintain children who are in the care of their local authority or accommodated by them under section 20 of the Children Act 1989.[12] Part 3 of schedule 2 to the Children Act 1989 contains a further, standalone charging regime which applies in relation to the maintenance of these children. Contributions are limited to that which the authority consider to be reasonable, and an individual cannot be charged more than is reasonably practicable for them to pay. In addition, there is no liability to pay while a person is in receipt of the benefits listed at paragraph 12.6 above.[13] In these respects, the regime is similar to the charging regime under section 17. But the process for recovering charges is different and involves the service of a “contribution notice” upon the person, specifying the amount payable. If the person does not agree with the amount payable the local authority can make an application to the court for a “contribution order”.[14]

12.14 This regime applies to all children who are looked after by their local authority. It is not unique to disabled children.

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[10] Children Act 1989, s 17A(3)(b), (3A) and (3B); Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, reg 9(1) and (2).

[11] Children Act 1989, s 17A(2).

[12] Children Act 1989, s 22B.

[13] Children Act 1989, sch 2, paras 21(2), (4) and 22(5).

[14] Children Act 1989, sch 2, paras 22 and 23.

Charging for services under section 2 of the Chronically Sick and Disabled Persons Act 1970

12.15 As we discuss at paragraph 7.8, the duty to provide services to disabled children under section 2(4) of the Chronically Sick and Disabled Persons Act 1970 is not a freestanding duty to provide services. Rather, it is a duty to exercise functions under Part 3 of the Children Act 1989, most typically under section 17. One of the consequences of this is that the section 17 charging regime described above at paragraphs 12.5-12.12 applies.[15]

Charging for disabled facilities grants

12.16 Disabled facilities grants provided by local housing authorities to carry out adaptations to the homes of disabled persons are subject to a distinct and complex charging regime. In contrast to the general discretion to charge a reasonable amount that applies to services under the Children Act 1989, the provision of disabled facilities grants is subject to a much more prescriptive regime. This requires the amount paid to be reduced (or a contribution to be calculated) based on the amount by which the disabled person's income exceeds an "applicable amount", which is deemed to reflect the needs of the household.[16]

12.17 The guidance on disabled facilities grants describes the process, and the purpose behind it, in the following terms:

> B98. The [disabled facilities grant] means test is in place to ensure that [disabled facilities grant] funding reaches those people who are on the lowest incomes and least able to afford to pay for the adaptations themselves. Means testing applies to applications made by owner-occupiers, tenants and occupants of a qualifying houseboat or caravan. Different rules apply where the application is made by a landlord (see para B108).
>
> B99. The assumed weekly needs of the household (the "applicable amount") is calculated taking into account the number of people, their ages and other circumstances. This is then compared to actual income, and where income is greater than the applicable amount, a "loan generation factor" is applied to the "excess income" to arrive at a notional "affordable loan".
>
> B100. This is the amount by which the grant is reduced, or the contribution expected from the applicant. The reduction in grant caused by this test is lower for tenants because it is assumed that loans will be available on less favourable terms than owner occupiers.
>
> Contribution = (actual income – applicable amount) x loan generation factor.

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[15] *R (Spink) v Wandsworth London Borough Council* [2005] EWCA Civ 302, [2005] 1 WLR 2884.

[16] Housing Grants, Construction and Regeneration Act 1996, s 30; Housing Renewal Grants Regulations 1996, SI No 2890, regs 10 to 12, 14, 16, 18 and sch 1.

> B101. It is the income of the disabled person, and where applicable their partner, that is taken into account - rather than the applicant if that is a different person. In the regulations this is the “relevant person”.[17]

12.18 However, where the disabled person is a child, the local authority must assume that their income is not greater than the applicable amount meaning, in effect “that they are exempt from means testing and the amount of their grant is not reduced - i.e. they do not have an assessed contribution”.[18]

THE CASE FOR REFORM

12.19 The legal framework we have set out above is complex and fragmented. It comprises four separate charging regimes which apply to disabled children. But the regimes do not all apply exclusively to disabled children. The charging regimes for services under section 17 of the Children Act 1989 and for the maintenance of looked after children, also apply to other children who are in need or in the care of their local authority. As we discuss below, this means that although there may be a case for simplifying the law, the options for achieving this in this review may be limited.

OPTIONS FOR REFORM

12.20 In identifying options for reform we need to keep two points in mind. The first is our terms of reference which are directed at disabled children’s social care, and not social care more generally. The second is that, as a law reform body, it is not appropriate for us to propose options that would fundamentally change who can be charged for disabled children’s social care, how much or when.

12.21 Looking first at the Children Act 1989, the legal framework for charging could potentially be simplified. It comprises three separate charging regimes – covering services for children in need, the maintenance of looked after children and direct payments for disabled children – which are all based on the same principles that:

(1) charging is discretionary;

(2) a person should not be charged more than is reasonably practicable for them to pay;

(3) that charge should be subject to an upper limit, which does not exceed the amount which the local authority considers reasonable for the provision of the service; and

(4) those in receipt of the main means-tested welfare benefits should not be liable to pay charges.

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[17] Department for Levelling Up, Housing & Communities and Department of Health and Social Care, *Disabled Facilities Grant (DFG) delivery: Guidance for local authorities in England* (March 2022) Appendix B, paras B98 to B101.

[18] Department for Levelling Up, Housing & Communities and Department of Health and Social Care, *Disabled Facilities Grant (DFG) delivery: Guidance for local authorities in England* (March 2022) Appendix B, para B104.

12.22 Hypothetically, these regimes could be unified, and this would certainly simplify the law for disabled children. But it is only the direct payments charging regime which applies exclusively to disabled children. The other two regimes, as we have noted, apply to other children who are in need or in the care of their local authority. This means that so long as disabled children's social care continues to fall within the Children Act 1989, simplifying the charging framework for disabled children would have consequences that exceed our terms of reference. However, simplification could be achieved without these consequences if – as we provisionally propose in Chapter 23 – a separate legal framework was to be adopted for disabled children's social care. That new legal framework could contain a single charging regime based on the existing principles that we summarise at paragraph 12.21. In the circumstances, we make no proposals at this stage to simplify the charging framework under the Children Act 1989. But we invite consultees to take into account the potential for a simpler, unified framework for charging for disabled children's social care when deciding whether a separate legal framework is necessary or desirable: see paragraph 23.17.

12.23 Whether the charging regime for disabled facilities grants could also be brought within any new legal framework raises further questions. First, it depends on consultees' views on whether transferring responsibility for disabled facilities grants from local housing authorities to social services is a viable option. We discuss and invite consultees' views on this issue at paragraphs 7.12 to 7.17, 7.38 and 7.58. Second, it depends on current charging practices. As we explain above at paragraphs 12.16 to 12.18 above the charging regime for disabled facilities grants is, on paper, quite different to the charging regimes of services under the Children Act 1989. Proposing unification of these regimes in so far as they apply to disabled children could in theory constitute a substantive change to charging policy that goes beyond our law reform remit. But whether this would be the case in practice is less clear. We seek further information on local authority charging practices to help us evaluate this.

12.24 Irrespective of whether unification and simplification of the charging framework is achievable within the scope of this review, local authority charging practices provide important context to the review. We seek examples of these practices and views on how our other proposals might affect them. We are particularly interested in whether local authorities think that they would need to resort to charging more, or more often if the other provisional proposals in this consultation paper were implemented.

Consultation Question 47.

12.25 We invite consultees to provide examples of local authority charging practices.

Consultation Question 48.

12.26 We invite consultees’ views on whether local authority charging practices would be likely to change if any of the provisional proposals in this consultation paper were implemented. In particular, is it likely that local authorities would need to charge more, or more often?

PART 4 – SYSTEMIC ISSUES

Chapter 13: The intersection between disabled children's social care and special educational needs and disability

INTRODUCTION

13.1 In this review we focus on the reform of disabled children's social care law, the core elements of which date back to the 1970s and 80s. We do not consider the reform of special educational needs and disability (SEND) law, which was comprehensively updated in 2014 and the subject of a House of Commons inquiry in 2019.[1] Reform of SEND law falls outside of our terms of reference.[2]

13.2 However, the law on SEND is relevant to the review for a number of reasons.

(1) SEND law and disabled children's social care law intersect. In particular, social care provision forms part of the support which children with special educational needs are entitled to receive under an education, health and care plan. See paragraphs 13.6 to 13.16 below.

(2) There is a degree of overlap between children who need support to meet their special educational needs and disabled children who have social care needs.

(3) Our terms of reference require us to consider the scope for alignment between SEND and disabled children's social care law. See paragraph 1.17.

(4) One of the concerns that has been raised by parents and carers in the lead up to this consultation is that families often have to tell their stories repeatedly to different professionals working in SEND and disabled children's social care. This is a problem we need to address in so far as we can.

13.3 With these points in mind, this chapter provides an introduction to SEND law. It allows consultees to understand references to and comparisons with SEND law. It also allows us to consider the scope for aligning or combining the legal framework governing disabled children's social care with the SEND system.

THE CURRENT LAW

Key definitions and concepts

13.4 The legal framework relating to children with SEND is contained in Part 3 of the Children and Families Act 2014. Part 3 contains the following definitions and concepts.

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[1] Special educational needs and disabilities, Report of the House of Commons Education Committee (2019-20) HC 20.

[2] See para 1.17.

(1) “Child” means a person who is not over compulsory school age (under 16).[3] This differs from the Children Act 1989 and the United Nations Convention on the Rights of the Child, where “child” means a “person under the age of eighteen”.[4] For the purposes of this chapter only, for the sake of legal accuracy, we use the word “child” as it is used in the Children and Families Act 2014 to mean a person not over compulsory school age.

(2) “Young person” means a person over compulsory school age but under 25 (16-25).[5] Again, for the purpose of this chapter only, we use the phrase “young person” for the sake of legal accuracy to refer to those aged 16-25. However, consideration of those who are over-18 fall outside of our terms of reference.

(3) A child or young person has “special educational needs” if they have a “learning difficulty or disability” which calls for “special educational provision” to be made for them.[6]

(4) A child or young person of compulsory school age has a “learning difficulty or disability” if either:

  (a) they have significantly greater difficulty in learning than the majority of others of the same age; or

  (b) they have a disability which prevents or hinders them from making use of the kind of facilities generally provided for others that age in mainstream schools or post-16 institutions.[7]

(5) Younger children who are likely to fall into one of these categories when they reach compulsory school age are also classed as having a learning difficulty or a disability.[8]

(6) “Disability” in this context has the same meaning as in the Equality Act 2010.[9]

(7) “Special educational provision”, for those aged two and over, means the provision of education or training over and above that which is generally available in mainstream educational settings and nurseries for others of the same age.[10]

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[3] Children and Families Act 2014, s 83(7); Education Act 1996, ss 8(3) and 579(1).

[4] Children Act 1989, s 105(1); United Nations Convention on the Rights of the Child, art 1.

[5] Children and Families Act 2014, s 83(2) and (7); Education Act 1996, s 8(3).

[6] Children and Families Act 2014, s 20(1).

[7] Children and Families Act 2014, s 20(2).

[8] Children and Families Act 2014, s 20(3).

[9] Children and Families Act 2014, s 83(3). See ch 19 for a discussion of this definition.

[10] Children and Families Act 2014, s 21(1).

(8) “Social care provision” means provision made by a local authority under particular statutory functions including section 2 of the Chronically Sick and Disabled Persons Act 1970 and the Children Act 1989.[11]

(9) “Health care provision” means the provision of health care services by the NHS.[12]

(10) But “health care provision” or “social care provision” which educates or trains a child or young person is to be treated as special educational provision.[13]

(11) An “education, health and care plan” (EHCP) is a plan specifying:[14]

(a) a child's or young person's special educational needs;

(b) the outcomes sought for them;

(c) the special educational provision they require;

(d) any health care provision reasonably required by the learning difficulties and disabilities of the child or young person, which result in them having special educational needs;

(e) any social care provision which must be made by virtue of section 2 of the Chronically Sick and Disabled Persons Act 1970;

(f) any other social care provision reasonably required by the learning difficulties and disabilities of the child or young person, which result in them having special educational needs; and

(g) any other health or social care provision which is reasonably required, and which the local authority wishes to include in the EHCP.

EHCPs were introduced in 2015 and replaced statements of special educational needs.

Specific duties and powers relating to individual children

13.5 There are two ways in which the special educational needs of a child or young person may be met in a school (or other institution).

(1) Their needs could be met by the school itself pursuant to the duty under section 66(2) of the Children and Families Act 2014. This is a duty to use “best endeavours” to ensure that the necessary special educational provision is made. That duty is not absolute, and the school’s resources will impact on the endeavours that it is able to make.

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[11] Children and Families Act 2014, s 21(4); Local Authority Social Services Act 1970, s 1A and sch 1.

[12] Children and Families Act 2014, s 21(3).

[13] Children and Families Act 2014, s 21(5).

[14] Children and Families Act 2014, s 37(2) and (3).

(2) Provision for the child or young person's needs could be made in accordance with an EHCP secured and maintained by the local authority under section 37(1) of the Children and Families Act 2014. This is an absolute duty: "resource constraints are irrelevant once special educational provision has been identified in the EHC plan".[15]

13.6 This chapter is primarily concerned with the second of these two options: provision in accordance with an EHCP. The first step to obtaining an EHCP is an assessment. A local authority is required to assess the education, health and social care needs of a child or young person if it is of the opinion that:[16]

(1) the child or young person has, or may have, special educational needs; and

(2) it may be necessary for special educational provision to be made for the child or young person in accordance with an EHCP.

This assessment is referred to as an education, health and care (EHC) needs assessment and may be requested by the child's parent, the young person (as the case may be) or their school or other educational institution.

13.7 The child and their parent, or the young person, should be involved in the assessment process. In particular, advice and information as to the child or young person's needs, and what provision might be required to meet those needs, should be sought from the child's parent or the young person.[17] In addition, the local authority is required to take into account the wishes and feelings of the child and their parent, or the young person, and ensure they are able to participate in decisions.[18] Where the local authority takes the view that the child's parent or the young person requires information, advice or support to effectively participate in the process, this should be provided.[19]

13.8 Advice and information in relation to social care should also be sought from, or on behalf of, the local authority. This could, for example, be the child or young person's child in need plan.[20]

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[15] *Nottinghamshire County Council v SF and GD* [2020] EWCA Civ 226, (2020) 23 CCLR 241 at [8] to [10] by the Senior President of Tribunals.

[16] Children and Families Act 2014, s 36(1), (2) and (8).

[17] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 6(1)(a).

[18] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 7(a) and (d).

[19] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 9. See further ch 21 on participation.

[20] Special Educational Needs and Disability Regulations 2014, SI No 1530 reg 6(1)(e); Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years* (January 2015) para 9.49. See further ch 11 on care planning.

13.9 The EHC needs assessment should be combined with an assessment of the child's social care needs under section 17 of the Children Act 1989 "where appropriate" and reviews should be "synchronised".[21]

13.10 Following the assessment, the local authority must notify the child's parent or the young person of the outcome and whether it proposes to secure the preparation of an EHCP.[22] This is a question of whether or not it is "necessary for special educational provision to be made" for the child or young person in accordance with an EHCP.[23] This involves consideration of whether the special educational provision the child or young person needs "can reasonably be provided from within the resources normally available to mainstream early years providers, schools and post-16 institutions".[24] If the answer is no, then the local authority must secure that an EHCP is prepared, and then maintain the EHCP.[25] Whether it is "necessary" for special educational provision to be made in accordance with an EHCP has been described as a "evaluative judgement" based on the "nature and extent of the provision required for the child concerned". Exercise of this judgement involves a comparison with that which is available nationally in mainstream education.[26]

13.11 The EHCP comprises 11 separate sections, headed A-J: special educational provision falls within section F; health provision within section G; and social care provision within section H, which is divided into two sub-sections, H1 and H2. Any social care provision which is required by virtue of section 2 of the Chronically Sick and Disabled Persons Act 1970[27] should be set out in sub-section H1. Any other social care provision which is reasonably required should be specified in sub-section H2.[28]

13.12 Having secured the preparation of an EHCP, the local authority then comes under a duty to secure the special educational provision specified in it.[29] Similarly, where the plan specifies health care provision which is "reasonably required", the responsible commissioning body – who will have needed to have agreed to the provision in order for it to be included in the EHCP[30] – must arrange that provision.[31] In contrast, Part 3 of the Children and Families Act 2014 does not impose any additional duties on the

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[21] Children Act 1989, sch 2 para 3; *Special educational needs and disability code of practice: 0 to 25 years* paras 10.18 to 10.20. See further ch 3 on obtaining an assessment.

[22] Children and Families Act 2014, s 36(9).

[23] Children and Families Act 2014, s 37(1).

[24] *Special educational needs and disability code of practice: 0 to 25 years* para 9.55.

[25] Children and Families Act 2014, s 37(1).

[26] *Nottinghamshire County Council v SF and GD* [2020] EWCA Civ 226, (2020) 23 CCLR 241 at [38]-[39] by the Senior President of Tribunals.

[27] See paras 7.3 to 7.11 for a discussion of the Chronically Sick and Disabled Persons Act 1970, s 2.

[28] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 12(1)(h).

[29] Children and Families Act 2014, s 42(2).

[30] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 12(2); *Special educational needs and disability code of practice: 0 to 25 years* para 9.71.

[31] Children and Families Act 2014, s 42(2).

local authority to make the social care provision set out in the plan.[32] Of course, by definition, the local authority must make any provision set out in section H1 which is required by section 2 of the Chronically Sick and Disabled Persons Act 1970. But the local authority is not under a statutory duty to provide the additional social care provision (that which is “reasonably required”) which is set out in section H2.[33] That having been said, the fact that the authority itself has decided that this support is reasonably required would generally suggest that it intends to provide it.

13.13 One of the ways in which the provision set out in the child or young person’s EHCP may be secured is by means of a personal budget. This is “an amount of money identified by the local authority to deliver provision set out in an EHC plan where the parent or young person is involved in securing that provision”.[34] The personal budget can include funding from education, health and social care.[35] The parent or young person can be involved in securing provision with this funding either by means of direct payments,[36] whereby they purchase and manage the services themselves, or arrangements where the local authority or a third party holds and manages the funds.[37] Local authorities are required to prepare a personal budget for a child or young person in respect of their EHCP when asked to do so by the child’s parent or the young person.[38]

13.14 The duties to maintain an EHCP for a child or young person and secure the educational provision therein by definition only apply so long as they remain a child or young person. This means that they cease to apply when the young person reaches the age of 25. They may, however, come to end prior to that in certain circumstances where the local authority is no longer responsible for the child or young person[39] or where the authority determines that it is no longer necessary for the plan to be maintained.[40] Conversely, as a matter of discretion, a local authority may choose to

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[32] The Joint Committee on Human Rights recommended that the legislation should include social care duties, but this recommendation was not implemented. See Legislative Scrutiny: Children and Families Bill; Energy Bill, Report of the Joint Committee on Human Rights (2013–14) HC 452 and HL Paper 29, para 72.

[33] *Special educational needs and disability code of practice: 0 to 25 years* para 9.137.

[34] *Special educational needs and disability code of practice: 0 to 25 years* para 9.95.

[35] *Special educational needs and disability code of practice: 0 to 25 years* para 9.110. See further ch 10 for a discussion of the different ways in which disabled children’s social care can be provided.

[36] Children Act 1989, s 17ZA and Community Care, services for Carers and Children’s Services (Direct Payments) (England) Regulations 2009, SI No 1887; National Health Service Act 2006, s 12A and National Health Service (Direct Payments) Regulations 2013, SI No 1617; Children and Families Act 2014, s 49(3) and Special Educational Needs (Personal Budgets) Regulations 2014, SI No 1652.

[37] *Special educational needs and disability code of practice: 0 to 25 years* para 9.101.

[38] Children and Families Act 2014, s 49(1).

[39] A local authority is responsible for a child or young person if they are in the area and have been identified by the authority, or brought to their attention, as someone who has or may have special educational needs: Children and Families Act 2014, s 24(1).

[40] Children and Families Act 2014, s 45; Special Educational Needs and Disability Regulations 2014, SI No 1530, regs 29 to 31.

maintain an EHCP until the end of the academic year during which a young person reaches the age of 25.[41]

13.15 The powers and duties to make social care provision under section 2(4) of the Chronically Sick and Disabled Persons Act 1970 and section 17(1) of the Children Act 1989 would normally stop prior to this, when the young person reached the age of 18. But the Children Act 1989 provides for support under section 17 to continue after this age while the EHCP is maintained and even, in certain cases where the young person is making the transition to adult social care, after that point.[42] This fills the gap that might otherwise appear in the young person's EHCP if social care provision ceased to be available at 18.

13.16 Under the framework of the Children and Families Act 2014, planning for a child or young person to make this transition to adulthood should start at an early stage. Where the child or young person is in or beyond year nine (aged 13 to 14), the EHCP must include – within the special educational provision, health care provision and social care provision – provision to assist the child or young person in preparation for adulthood and independent living.[43] Every review from year nine onward should include a focus on this.[44]

13.17 A child's parent or a young person who is unhappy with many of the various different decisions that a local authority must make in discharging the functions set out above may have a right to appeal to the First-tier Tribunal. In particular, a right of appeal lies against:[45]

(1) a decision not to secure an EHC needs assessment;

(2) a decision that it is not necessary for special educational provision to be made for the child or young person in accordance with an EHCP;

(3) the special educational needs specified in the EHCP;

(4) the special educational provision specified in the EHCP;

(5) the school or other institution named in the EHCP, or the type of school or institution;

(6) the fact that no school or institution is named in the EHCP;

(7) a decision of a local authority not to secure a re-assessment of the needs of a child or young person following a request to do so;

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[41] Children and Families Act 2014, s 46(1).

[42] Children Act 1989, ss 17ZG to17ZI. See further ch 15 on the transition to adult social care.

[43] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 12(3).

[44] *Special educational needs and disability code of practice: 0 to 25 years* para 8.9. Reviews are carried out prior to transitions between phases of education: Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 18(1).

[45] Children and Families Act 2014, s 51(1)-(2).

(8) a decision not to amend/replace an EHCP following a review or re-assessment; and

(9) a decision to cease to maintain an EHCP.

13.18 Appeals are discussed in more detail in chapter 18. For the purposes of this overview, suffice to say that in deciding an appeal the First-tier Tribunal has the power to make recommendations as to the social care needs set out in the EHCP, and the social care provision to meet those needs.[46] In contrast to the Tribunal's power to make binding orders in relation to special educational needs and special educational provision, requiring the amendment of the EHCP,[47] recommendations in relation to social care are simply that: recommendations. That having been said, a failure or refusal on the part of a local authority to comply with the recommendations should be justified by written reasons within five weeks and a failure to provide such reasons can be challenged in the courts by way of judicial review.[48]

13.19 In exercising all of the various functions set out above local authorities should have regard to the following matters:[49]

(1) the views, wishes and feelings of the child and their parent, or the young person;

(2) the importance of the child and their parent, or the young person, participating as fully as possible in decision-making;

(3) the importance of the child and their parent, or the young person, being provided with the information and support necessary to enable participation in decision-making; and

(4) the need to support the child and their parent, or the young person, in order to facilitate their development and to help them achieve the best possible educational and other outcomes.

General duties and powers relating to children in the area

13.20 As well as the specific duties, outlined above, which are owed to individual children, local authorities – together, in some instances, with NHS England and integrated care boards (ICBs) – are subject to a number of more general duties. These duties are considered in detail in chapters 16 and 17. In broad terms these are meant to ensure that local authorities:

(1) have an understanding of levels of need in the local area;

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[46] Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations 2017, SI No 1306, regs 4-5.

[47] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 43.

[48] Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations 2017, SI No 1306, reg 7.

[49] Children and Families Act 2014, s 19. See further ch 20 on statutory principles.

(2) work together with other relevant bodies to make sure the right services are available to meet that need; and

(3) let people in the area know about those services.

13.21 The first of the general duties requires local authorities to exercise their functions with a view to identifying all of the children and young people in the area who:[50]

(1) have or may have special educational needs; or

(2) have a disability.

13.22 In addition, local authorities have a duty to promote the integration of education, health and social care provision, in order to improve the well-being of children or young people in the area who have special educational needs or a disability, or the quality of special educational needs provision.[51] This duty is complemented by a further duty which requires local authorities, NHS England and ICBs to work together to make joint commissioning arrangements for education, health and care provision.[52] The local authority must keep this provision under review and consider, in consultation with children who have a disability or special educational needs and their parents (among others), whether it is "sufficient to meet the educational needs, training needs and social care needs of the children and young people concerned".[53]

13.23 The education, health and care provision which a local authority expects to be available should be set out in its "SEN and disability local offer".[54] The local offer should be published and kept under review. Regulations specify particular information which needs to be included in the local offer.[55] The required information includes services under section 17 of the Children Act 1989 and any eligibility criteria for social care that the authority applies in deciding whether to provide those services.[56]

13.24 The joint commissioning duty described at paragraph 13.22 is one particular instance of joint working required under the Children and Families Act 2014. But joint working more generally is also facilitated by sections 28 and 31 of that Act which, respectively, require:

(1) local authorities, NHS England and ICBs (among others) to co-operate with each other in the exercise of the authorities' functions under Part 3 of the Children and Families Act 2014; and

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[50] Children and Families Act 2014, s 22. The attaches to the exercise of any of the local authorities functions and not simply those under Children and Families Act 2014, pt 3 or the Act more generally.

[51] Children and Families Act 2014, s 25(1).

[52] Children and Families Act 2014, s 26.

[53] Children and Families Act 2014, s 27.

[54] Children and Families Act 2014, s 30.

[55] Special Educational Needs and Disability Regulations 2014, SI No 1530.

[56] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 53 and sch 2, paras 13 and 18.

(2) other local authorities, NHS England and ICBs (among others) to comply with a request from a local authority for co-operation, unless that would be incompatible with their duties or otherwise have an adverse effect on the exercise of their functions. The time limit for complying with such a request is six weeks.[57]

THE SCOPE FOR ALIGNMENT BETWEEN DISABLED CHILDREN'S SOCIAL CARE AND SEND LAW

13.25 There are a number of similarities between the legal framework for SEND and the framework governing disabled children's social care. There are also a number of points where the two legal frameworks intersect. Nevertheless, our provisional view is that complete alignment of SEND law and disabled children's social care law is not possible without rewriting the Children and Families Act 2014 (which lies outside of the scope of our terms of reference). We take the view that complete alignment is not possible. This is primarily because eligibility for an EHC needs assessment and an EHCP is based on the following factors which are unique to the education context which could not be transposed to the context of disabled children's social care.

(1) To be eligible for an EHCP a child or young person must have a learning difficulty or a disability. Similarly, to be eligible for an EHC needs assessment it is a requirement that the child or young person has, or may have, a learning difficulty or a disability. This refers to a disability which prevents or hinders them from making use of the kind of facilities generally provided for others that age in mainstream schools or post-16 institutions. See paragraph 13.4(4) above.

(2) To be eligible for an EHCP it must be necessary for special educational provision to be made for the child or young person in accordance with an EHCP. Similarly, eligibility for an EHC needs assessment depends on whether it may be necessary for special educational provision to be made for the child or young person in accordance with an EHCP. Whether these thresholds are met will depend on whether the provision that the child or the young person requires, or may require, is typically available nationally in mainstream schools. See paragraphs 13.4(7), 13.6 and 13.10 above.

13.26 In addition, our pre-consultation engagement has led us provisionally to consider that not all children who require support to meet their special educational needs (whether under an EHCP or otherwise) will have a disability (within the meaning of the Equality Act 2010)[58] which requires the provision of social care, and vice versa. The overlap between these two groups of children may be significant. But it is not complete. Examples we were given in the lead up to this consultation included:

(1) a dyslexic child, who may require support to meet their special educational needs at school, but not require any social care input at home; and

(2) a child who uses a wheelchair who may require social care provision at home (for example in the form of a grant to make adaptations to the home) but who

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[57] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 8.

[58] See ch 19 for a discussion of how disability should be defined in the social care context.

does not require any additional support at school because mainstream educational settings are generally wheelchair accessible.

13.27 For these reasons, we do not think that complete alignment between SEND and disabled children's social care law is achievable without fundamentally changing the Children and Families Act 2014. The two systems are targeted at different children, even if there is substantial overlap, and eligibility for help is based on different principles.

13.28 Nevertheless, we think there could be scope for some measure of alignment in the following contexts.

(1) The assessment of need. See Chapters 3 to 6.

(2) The provision of direct payments and personal budgets as a way of meeting needs. See Chapter 10.

(3) The provision of a plan, setting out how needs are to be met. See Chapter 11.

(4) Transition planning. See Chapter 15.

(5) The use of statutory principles. See Chapter 20.

We seek consultees' views on whether further alignment would be possible or desirable.

Consultation Question 49.

13.29 We invite consultees' views on the extent to which disabled children's social care law can and should be aligned with SEND law.

Chapter 14: The intersection between disabled children's social care and health care

INTRODUCTION

14.1 One of the themes that came through in the lead up to this consultation was the difficulties that arose where a disabled child has both social care needs and health care[1] needs. Those could be either physical health care needs or mental health care needs. Our terms of reference do not extend to health care matters, but in this chapter we set out our provisional proposals in relation the intersection between health care and social care.

THE CURRENT LAW

14.2 Parents and carers who care for a disabled child with needs may not be clear whether they are health care or social care needs. Nevertheless, parents and carers (as well as professionals) need to understand the difference between the two, because the legal frameworks for assessing and meeting the two different types of need are fundamentally different.

The provision of health care

14.3 We do not set out here a comprehensive overview of the law governing the provision of health care to disabled children.[2] In broad outline, since the National Health Service (NHS) was established in 1946,[3] there has been a requirement – now imposed by the National Health Service Act 2006[4] – for the Secretary of State to promote a comprehensive health service in England. As a consequence of successive legislative reforms, the NHS, in turn, involves "a complex web of organisations with separate roles to play in the provision of services to patients".[5]

14.4 By contrast to social care where – even in respect of children – it is possible for a local authority to charge,[6] the starting point is that NHS health care is free unless statute

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[1] The relevant legislation and guidance use the terms "health care" and "healthcare" inconsistently. We use "health care" in this chapter, save where quoting from legislation or guidance which uses the term "healthcare".

[2] An overview focused on disabled children can be found in chapter 5 of S Broach and L Clements, *Disabled Children: A Legal Handbook* (3rd ed 2020). See also, more broadly, D Lock, H Gibbs and L Glenister, *NHS Law and Practice* (2nd ed 2024).

[3] By the National Health Service Act 1946.

[4] National Health Service Act 2006, s 1(1).

[5] *Keep Wythenshawe Special Ltd v NHS Central Manchester CCG and others* [2016] EWHC 17 (Admin), (2016) 19 CCLR 19 at [1] by Dove J.

[6] Children Act 1989, s 17(7). See ch 12.

provides to the contrary.[7]

14.5 Since the National Health Service and Community Care Act 1990, there has been a division between those responsible for commissioning services, and those responsible for providing care. The majority of services are commissioned by integrated care boards,[8] either because statute gives the board such responsibility directly, or because NHS England has delegated its responsibility to them. There are 42 such boards across England. Section 3(1) of the National Health Service Act 2006 imposes a duty on each board to arrange for the provision of specified health services "to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility". They are target duties, rather than duties owed to specific individuals.[9] Those services can either be primary care or secondary care. The patient's first point of contact in the community is usually with a primary care provider such as a general practitioner. Secondary care providers deliver specialist or acute care in a setting such as a hospital (for instance a planned surgical procedure), and the patient is usually referred by a primary care provider.

14.6 In addition, NHS England retains direct commissioning responsibility for specialist services including so-called "tertiary" acute services. For present purposes, the most important of these specialist services are what are known as "Tier 4" Child and Adolescent Mental Health Services. These are the services required to meet the most complex mental health needs of children and adolescents which cannot be met by care commissioned locally.

14.7 Local authorities also have responsibility for commissioning services to improve public health in their areas under section 2B of the National Health Service Act 2006. The duty under section 2B is a duty to "take such steps as [the local authority] considers appropriate for improving the health of people in its area". Local authorities therefore retain considerable discretion as to how to discharge that duty.[10] They are, separately, required by regulations to carry out public health functions on behalf of the Secretary of State including, most relevantly for our purposes, securing universal health visitor reviews of pregnant women and infants.[11] These reviews are to be carried out once for each child aged between (a) one day and two weeks; (b) six and eight weeks; (c) nine and fifteen months; and (d) twenty-four and thirty months.[12]

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[7] See National Health Service Act 2006, s 1(4). The main exceptions are in relation to overseas visitors: see National Health Service Act 2006, s 175 and the regulations made thereunder.

[8] Until the coming into force of the Health and Social Care Act 2022, Clinical Commissioning Groups.

[9] *N v ACCG* [2017] UKSC 22, [2017] AC 549 at [37] by Baroness Hale.

[10] Emphasised in *R (Ncube) v Brighton and Hove City Council* [2021] EWHC 578 (Admin), [2021] WLR 4762, concerning whether section 2B extended to providing temporary accommodation for migrants with no recourse to public funds.

[11] Under The Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013, SI No 351, regs 5A and 5B.

[12] The Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013, SI No 351, reg 5A(1).

14.8 Local authorities not only have responsibilities for public health. They also have responsibility for what are often called the social determinants of children's health.[13] Section 17 of the Children Act 1989 provides that a child is to be taken to be in need not only if they are disabled, but also if:

(1) they are unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for them of services by a local authority under Part 3 of the Act; or

(2) their health or development is likely to be significantly impaired, or further impaired, without the provision for them of such services.[14]

14.9 "Health" for these purposes includes both physical and mental health.[15]

14.10 The Health and Care Act 2022 introduced integrated care partnerships as part of a move towards integrated care systems.[16] Integrated care partnerships are intended to be partnerships of organisations that come together to plan and deliver joined-up health and care services, and to improve the lives of people who live and work in their area. The introduction of these partnerships did not change the underlying statutory responsibilities set out above.

14.11 There is therefore considerable scope for overlap between the responsibilities of local authorities and the NHS when it comes to health care needs. In the context of adults, the dividing line is now set out in statute.[17] There is no statutory dividing line in relation to children. In practice, local authorities and health care bodies apply the (non-statutory) *Children and Young People's Continuing Care Framework* guidance (the *Continuing Care Framework*).[18] This makes clear that the starting point is that:

> 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.[19]

14.12 The services referred to here are NHS services, social care services and educational services. A child could be identified as having potential continuing care needs by a range of professionals, from bodies including local authorities.[20] Assessment is,

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[13] M Marmot, "Social determinants of health inequalities" (2005) 365 *The Lancet* 1099.

[14] Children Act 1989, s 17(10)(a) and (b).

[15] Children Act 1989, s 17(11).

[16] Health and Care Act 2022, s 26.

[17] Care Act 2014, s 22, following recommendations in our 2011 Adult Social Care Report (Law Com No 326) paras 11.16 to 11.21.

[18] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016).

[19] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016) p 5.

[20] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016) paras 55 to 57.

however, led by a person nominated by the integrated care board.[21] The *Continuing Care Framework* includes a decision support tool to be used to assist in assessing children's needs across 10 domains (covering areas such as breathing, eating and drinking, and mobility). The decision support tool sub-divides each domain into ascending levels of need, with descriptions given of the matters corresponding to each level of need in each domain. The *Continuing Care Framework* states that 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".[22] However, the *Continuing Care Framework* makes clear that this is not a firm rule, and that assessors, when presenting recommendations to the decision-making forum, should "consider the level of need identified in all care domains in order to gain the overall picture".[23]

14.13 Whilst assessment of whether the child has needs which cannot be met by existing universal or specialist services is led by the integrated care board, the final decision as to whether they have a continuing care need is taken by a multi-agency forum or panel.[24] Similarly, the actual package of care which the child will receive is a matter which is decided jointly.[25] This is because the funding for the package will not be the sole responsibility of the relevant integrated care board. This is different to the situation that applies in relation to adults, where a decision that the adult has continuing health care needs means that funding responsibility will rest solely with the NHS. In the case of children, funding continuing care will be a joint responsibility of the integrated care board[26] and the local authority,[27] with relative levels of contribution depending on the precise needs of the child.

14.14 Whilst funding continuing care is a joint responsibility, the courts have identified that there are limits to what local authorities can do. The leading case is that of *R (T, D and B) v Haringey London Borough Council*.[28] As summarised in the *Continuing Care Framework*, the effect of that judgment is that:

> there are clear limits to what care should be funded by the local authority, which should not be a substitute for additional NHS care for children. In this case, the High

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[21] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016) para 7.

[22] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016) para 148.

[23] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016) para 149.

[24] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016) para 10.

[25] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016) paras 11 and 12.

[26] Under the National Health Service Act 2006,

[27] Most obviously under Children Act 1989, s 17.

[28] *R (T, D and B) v Haringey London Borough Council* [2005] EWHC 2235 (Admin), (2006) 9 CCLR 58.

Court determined that the duty under section 17 of the Children Act 1989 did not extend to meeting essential medical needs.[29]

14.15 The facts of the *Haringey* case illustrate how the dividing line between health and social care works in practice, and how (depending on the circumstances) the same care could be seen as either social care or health care. The case concerned a disabled child with complex health needs. She required a tracheostomy which needed regular suctioning. The child's mother was fully trained in how to clear the tube through suctioning, how to change the tapes that held the tube in place and how to change the tube. The relevant health body had been providing 20 hours of respite care per week for the child's mother, as she had to be awake through the night when she was caring for her daughter. That respite care was provided by qualified nurses, although it could have been provided by non-medically qualified people if they had received the appropriate training. A number of assessments suggested that the mother required more respite care. The local authority accepted that additional provision was required and agreed to provide an extra 10 hours a night of respite care, although it maintained that the service provided was a health service and should therefore be provided by the health body. The health body argued that the local authority had the power to provide the service, either under the Children Act 1989 or the Chronically Sick and Disabled Persons Act 1970.

14.16 The parties in the case, and Mr Justice Ouseley, agreed that there was "a divide which had to be respected between health provision and social care provision".[30] Mr Justice Ouseley found the "scale and type" of the nursing care to be key in deciding which side of the line the care fell.[31] On the facts of the case before him, Mr Justice Ouseley found that the extra care was necessary, but that the care provided was not respite care for the mother, but medical care for the daughter, and that "the intention behind the provision of that medical care is her safety while her mother enjoys respite".[32] He also noted that:

> The gravity of the consequences of a failure in care, the duration of the care need, which required her carer always to be present lest something had to be dealt with rapidly, underscores the medical rather than social service nature of the provision.[33]

14.17 Taken together, the evidence in the *Haringey* case persuaded the court that the care required was medical care and the responsibility of the NHS, not the local authority.[34]

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[29] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016) para 26.

[30] *R (T, D and B) v Haringey LBC* [2005] EWHC 2235 (Admin), (2006) 9 CCLR 58 at [53].

[31] *R (T, D and B) v Haringey LBC* [2005] EWHC 2235 (Admin), (2006) 9 CCLR 58 at [62].

[32] *R (T, D and B) v Haringey LBC* [2005] EWHC 2235 (Admin), (2006) 9 CCLR 58 at [65].

[33] *R (T, D and B) v Haringey LBC* [2005] EWHC 2235 (Admin), (2006) 9 CCLR 58 at [66].

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

14.18 In *R (JP) v NHS Croydon Clinical Commissioning Group*,[35] Mr Justice Mostyn rejected the argument that section 1 of the Localism Act 2011 empowers the local authority to provide medical care which is clearly within the remit of the NHS.

14.19 As we noted above, the process for determining eligibility for a continuing care package is set out in non-statutory guidance. However, if an integrated care board agrees to provide funding for part of the package for a child, the child gets a statutory right to a personal health budget for that part of the package funded by the NHS.[36] A separate application could be made under the Care and Support (Direct Payments) Regulations 2014[37] to the local authority for a direct payment for the social care elements of any jointly funded package.[38]

Care to meet mental health needs

14.20 So far, we have been concerned primarily with meeting the needs arising out of physical health conditions. However, disability can also take the form of conditions requiring mental health services. The most recent statistics show that 1,103,495 children were in contact with NHS-funded secondary mental health, learning disabilities and autism services at some point during the financial year 2022-23.[39] Services to such children are often provided in the community, but in some cases are provided in hospital.

14.21 Where mental health services are provided in hospital, the Mental Health Act 1983 may come into play. This Act is for the most part concerned with the regulation of admission for assessment and treatment of mental disorder, including under circumstances of compulsion. The Mental Health Act 1983 can apply to a person of any age, and in 2023-2024, 274 children aged 15 or under and 689 children aged 16 or 17 were admitted compulsorily under the Act for either short term assessment or (generally) long-term treatment.[40] Other children will be there informally. In 2020, the Children's Commissioner identified that there were 944 children in a bed in a Tier 4 children's mental health unit. Of those, 545 were formally detained, 235 were there informally, and the status of 105 was not recorded.[41] We do not know whether the overall numbers have gone up or down since then.

14.22 The Mental Health Act 1983 is not primarily concerned with the arranging of services to meet needs arising from mental disorder. Those services will be commissioned under the arrangements set out above. The Mental Health Act 1983 does, however, impose one limited but important duty to commission services in section 117. Where a

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[35] *R (JP) v NHS Croydon Clinical Commissioning Group* [2020] EWHC 1470 (Admin).

[36] National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012, SI No 2996, Part 6A.

[37] 2014 SI No 2871.

[38] See ch 10 for personal budgets.

[39] NHS England, *Mental Health Bulletin, 2022-23 Annual report* (February 2024).

[40] Under ss 2 and 3 respectively. See table 1B of NHS Digital, *Mental Health Statistics 2023-24* (September 2024).

[41] Children's Commissioner for England, *Who are they? Where are they?* (November 2020) p 8. In the post on her website accompanying the report, she also highlighted the poor quality of NHS data in this area: https://www.childrenscommissioner.gov.uk/resource/who-are-they-where-are-they-2020/.

person – of any age – has been detained under one of a number of provisions, in particular, for treatment under section 3, section 117(1) imposes a joint duty on (usually) the relevant integrated care board and the local social services authority:

> to provide or arrange for the provision of, in co-operation with relevant voluntary agencies, after-care services for any person to whom this section applies until such time as the integrated care board or Local Health Board and the local social services authority are satisfied that the person concerned is no longer in need of such services.

14.23 After-care services are services which have the purpose of both:[42]

(1) meeting a need arising from or related to the person's mental disorder; and

(2) reducing the risk of a deterioration of the person's mental condition (and, accordingly, reducing the risk of the person requiring admission to a hospital again for treatment for mental disorder).

14.24 The effect of section 117 of the Mental Health Act 1983 was described by the Supreme Court in *R (Worcestershire County Council) v Secretary of State for Health and Social Care*[43] as follows:

> 7. As reflected in the statutory definition, the provision of after-care services under section 117 is intrinsically linked to the medical treatment which a person compulsorily detained for treatment for mental disorder under the 1983 Act has been receiving in hospital: see *DM v Doncaster Metropolitan Borough Council* [2011] EWHC 3652 (Admin), para 64. As explained by Lord Steyn in *R v Manchester City Council, Ex p Stennett* [2002] UKHL 34, [2002] AC 1127, para 5, it is part of a regime introduced to further a policy of shifting people with mental health conditions from institutional care to care in the community and which "bridged the gap between the institution and unsupported return to the community" (*DM* para 64). It is important to note that section 117 applies only to an "exceptionally vulnerable" class of persons (see *Stennett* at paras 8 and 15) who have been compulsorily detained for treatment under section 3 (or certain other specified provisions) of the 1983 Act. It does not extend to persons who have been informally or voluntarily admitted to hospital under section 131 of the 1983 Act or who have been admitted for assessment under section 2 (which allows for detention for a maximum of 28 days).
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> 8. In practice, the services provided as "after-care" largely comprise health care and social care, including the provision of specialised accommodation. Although these services could be provided under other statutory regimes, section 117 is not a "gateway" to other regimes but imposes a free-standing duty which has the important feature that the services must be provided free of charge: see *Stennett*, paras 7, 10.
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> 9. The House of Lords held in *Stennett* that the duty imposed by section 117 necessarily imports a concomitant power to carry out the duty: see para 11. It also

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[42] Mental Health Act 1983, s 117(6).

[43] *R (Worcestershire County Council) v Secretary of State for Health and Social Care* [2023] UKSC 31, [2023] PTSR 1593.

gives rise to an implied power to make plans and take preparatory steps before the duty to provide after-care arises on release from hospital: see *W v Doncaster Metropolitan Borough Council* [2004] EWCA Civ 378, [2004] LGR 743, paras 49-51. That power is discretionary, but failure to use reasonable endeavours without strong reasons may amount to an unlawful exercise of the discretion: see *R (B) v Camden London Borough Council* [2005] EWHC 1366 (Admin), [2006] LGR 19, paras 58-61.

14.25 Section 117(3) of the Mental Health Act 1983 sets out how to identify which local authority has responsibility in any given case. Which integrated care board has responsibility is set out in the National Health Service (Integrated Care Boards: Responsibilities) Regulations 2022.[44] As noted above, in some cases, the "health" responsibility lies not with an integrated care board, but with NHS England.[45]

14.26 Section 47(1) of the National Health Service and Community Care Act 1990 provides that a local authority must undertake an assessment of a person's needs under section 117 of the Mental Health Act 1983 where it appears to them that the person may be in need of such services. Section 47(3) of the 1990 Act also provides for cooperation between agencies, requiring the local authority to invite assistance from the relevant integrated care board and housing authority if the person appears to have health or housing needs. If at any time during the after-care assessment it appears that the person is under-18 and disabled, the local authority must decide whether the person's needs call for the provision of services under section 2 of the Chronically Sick and Disabled Persons Act 1970. This duty, as we describe further in Chapter 3, can only be identified by reading section 47(2) of the National Health Service and Community Care Act 1990 together with section 4 of the Disabled Persons (Services, Consultation and Representation) Act 1986.

14.27 The Mental Health Act 1983 does not specify how the joint responsibility to provide after-care is to be discharged as between the local authority and either the integrated care board or NHS England. Guidance was issued in March 2024 by the Department of Health and Social Care to address section 117 of the Mental Health Act 1983.[46] There is no specific reference in this guidance to the position of children in their own right, although there is reference to the position of children in reception of section 117 after-care who may be approaching adulthood.

14.28 Finally in this regard, we note the proposals in the draft Mental Health Bill published in 2022 in respect of autistic people and those with a learning disability.[47] The draft Mental Health Bill would have amended the Mental Health Act 1983 so as (in effect) to make it impossible in the civil context to detain someone for treatment on the basis of

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[44] 2022 SI No 635, reg 7. See also NHS England*, Who Pays?* (March 2024).

[45] The National Health Service (Integrated Care Boards: Responsibilities) Regulations 2022, SI No 635, reg 8.

[46] Department of Health and Social Care, *Discharge from Mental Health Inpatient Settings* (March 2024), Annex B. The guidance is both statutory and non-statutory. Whilst it is for the most part statutory, it is non-statutory where it makes reference to how children and young people and their parents, other family members and carers are involved in discharge planning.

[47] Draft Mental Health Bill (2022) CP 699.

autism or learning disability alone.[48] It also included a series of proposals to improve support for autistic people and those with a learning disability. These included putting care, education and treatment review meetings on a statutory footing and proposing new duties on integrated care boards to maintain registers of such individuals with specified risk factors for detention.[49] Such registers would be used to seek to address the potential for individuals with a learning disability or autistic people going into crisis and being detained. Linked to this the draft proposals also placed obligations on both integrated care boards in exercising their commissioning functions and local authorities discharging their market functions under section 5 of the Care Act 2014.[50] The draft Bill did not make reference to obligations in respect of services being provided to children by local authorities. The 2024 King's Speech included a commitment to reforming the Mental Health Act 1983, with the background briefing notes suggesting that it would include proposals "further limiting the extent to which people with a learning disability and/or autistic people can be detained and treated under the Mental Health Act".[51] It did not specifically mention the position of children.

Health care provision in the context of children with special educational needs and disability

14.29 The principles and processes set out above need to be read alongside the Children and Families Act 2014, which has a specific approach to "health care provision" in the context of children with special educational needs and disability.[52]

(1) "Health care provision" is defined in the Children and Families Act 2014 as "the provision of health care services as part of the comprehensive health service in England continued under section 1(1) of the National Health Service Act 2006".[53]

(2) An education, health and care plan (EHCP) prepared by the local authority must specify any health care provision reasonably required as a result of the learning difficulties and disabilities which result in the child having special educational needs.[54] An EHCP may also specify other health care and social care provision reasonably required by the child or young person.[55] If an EHCP specifies health care provision, then unless the child's parent or the young person has made suitable alternative arrangements, the responsible commissioning body must

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[48] The situation would remain different where a person was diverted into the mental health system from the criminal justice system under Part 3 of the Mental Health Act 1983, where the current law would remain unchanged.

[49] The proposed new section 125D(1)(b) of the Mental Health Act 1983 provided that inclusion on the register requires the consent of the person. It did not make express reference to the position of children (for instance, addressing whether or not those with parental responsibility can consent on behalf of a child).

[50] Proposed section 125E of the Mental Health Act 1983.

[51] Prime Minister's Office, *The King's Speech 2024* (July 2024) p 83.

[52] See ch 13 for special educational needs and disability.

[53] Children and Families Act 2014, s 21(3).

[54] Children and Families Act 2014, s 37(1)(d).

[55] Children and Families Act 2014, s 37(3).

arrange the specified health care provision for the child or young person.[56] The responsible commissioning body, in relation to any specified health care provision, "means the body (or each body) that is under a duty to arrange health care provision of that kind in respect of the child or young person". The position is then mirrored in secondary legislation setting out the mandatory requirements for any EHCP.[57]

(3) It might be thought that the responsible commissioning body would always be an NHS body. However, section 21(5) of the Children and Families Act 2014 provides that "health care provision … which educates or trains a child or young person is to be treated as special educational provision (instead of health care provision)". In such a case, the responsibility for commissioning will lie with the local authority.[58]

14.30 For a child with special educational needs and/or a disability there is therefore a particular importance to identifying whether a service is required to meet: (1) a social care need; (2) a health care need; or (3) a "deemed" special educational need.

(1) If the service is "pure" social care, then the obligation to provide it arises out the combination of statute and case law identified in Chapter 7.

(2) If it is specified health care provision, there is a statutory duty on the commissioning body to provide it.[59]

(3) If it is service that is required to meet a "deemed" special educational need, there is a statutory duty on a local authority to provide it, and the SEND Tribunal has the power to direct that it be provided.[60] In the other two situations identified in the sub-paragraphs above, the only judicial body which has the power to direct such provision is the High Court in judicial review proceedings, and any such order would be made very rarely (see Chapter 18).

Transition to adulthood

14.31 We address the transition to adulthood in the social care context in Chapter 15. There are also different types of transition that may arise in the context of health care. The first is in relation to continuing care. The second is in relation to provision being made in respect of health care deemed to be special educational provision for purposes of the Children and Families Act 2014. The third is in relation to services being provided under section 117 of the Mental Health Act 1983. Each of them has their own complexities.

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[56] Children and Families Act 2014, s 42(3), read together with s 42(5).

[57] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 12.

[58] See *East Sussex County Council v TW* [2016] UKUT 528 (AAC), [2017] PTSR 755 at [15] to [26] by Upper Tribunal Judge Jacobs and *East Sussex County Council v KS (SEN) Upper Tribunal Administrative Appeals Chamber* [2017] UKUT 273 (AAC), (2018) 21 CCLR 33 at [66] by Upper Tribunal Judge Ward.

[59] Children and Families Act 2014, s 42(3).

[60] See *NHS West Berkshire Clinical Commissioning Group v The First-tier Tribunal (Health, Education and Social Care Chamber) and others* [2019] UKUT 44 (AAC) at [27] by Upper Tribunal Judge Mitchell. See also ch 18.

(1) Continuing care for children is not the same as NHS continuing health care[61] for adults. There are significant differences between the two, not least that if an adult is eligible for continuing health care, the integrated care board will be solely responsible for funding their care. Further, the decision support tool applicable to adults plays a much more central role in determining eligibility than the equivalent tool does in relation to children. Finally, the *Continuing Care Framework* makes clear that eligibility for continuing care below the age of 18 does not guarantee eligibility for NHS continuing health care as an adult.[62]

(2) Where health care is deemed to be special educational provision for purposes of an EHCP, the relevant transition point in many cases will be at the of age 25, rather than 18 (see further Chapter 13).

THE CONTEXT IN WHICH WE ARE CONSULTING

14.32 The legal frameworks set out above are complicated. As a law reform body we can seek to address (within our terms of reference) how to make them less complicated. Their smooth operation depends, in practice, on significant good will on the part of those involved, something for which it is not possible to legislate.

14.33 We also need to be clear about the context in which we are consulting, because not to do so would be unrealistic. We therefore set out the key features of that context below.

14.34 Our work in the lead up to this consultation has highlighted to us how the good will required to operate the complex legal frameworks in play can sometimes be stretched, especially where budgetary pressures are a consideration. The consequent defence of budgets can lead to public bodies arguing over whether a particular service is one that it falls to a local authority or NHS body to fund. Such arguments are costly, both in financial terms, and in terms of staff time. They also leave children and their parents or carers in limbo. We note here the July 2024 joint report of the Local Government and Social Care Ombudsman and the Parliamentary and Health Service Ombudsman on integrated care.[63] One of the cases highlighted was that of Arthur, a young child with significant medical and care needs. As the Ombudsmen identified, both the local authority and the clinical commissioning group/integrated care board:

> disagreed on what support was required and who should pay for it, with the pressure and uncertainty causing significant stress for Arthur’s family when they were caring for their child with significant needs. It also affected the amount of increased respite care the council was prepared to provide to Arthur’s parents.

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[61] Department of Health and Social Care, *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* (July 2022).

[62] Department of Health, *National Framework for Children and Young People's Continuing Care* (January 2016) para 5.

[63] Local Government and Social Care Ombudsman and the Parliamentary and Health Service Ombudsman, *People not structures: putting people at the heart of integrated care* (July 2024). For more on the Ombudsmen, see ch 18.

> The NHS and the Council did not work together to consider Arthur's needs after the court case,[64] which they should have done. They also did not use the local dispute resolution process which could have resolved this case more quickly. This lack of a holistic approach created uncertainty for Arthur's family, who have had to put in significant time and effort to get the organisations to communicate, eventually approaching an Ombudsman service, which should not have been necessary.[65]

14.35 We are also consulting at a time when there has been an increasing demand for mental health services amongst children and adolescents, placing strain on those services. In February 2024, the Royal College of Psychiatrists identified that:

> In just four years, psychiatrists and their teams have seen a 53% increase in the number of children in mental health crisis, who need emergency support. This includes young people who are suicidal, severely depressed and who have an eating disorder. There were 32,521 referrals to CAMHS [Child and Adolescent Mental Health Services] crisis teams in 2022/23, compared to around 21,242 in 2019/20.
>
> Many of these children have experienced a deterioration in their mental health while on waiting lists, as over-stretched CAMHS teams struggle to meet record demand. According to recently reported [data from NHS England], under-18s who are waiting for follow-up after a GP's referral have already waited on average five months, and in the worst case, almost two years.[66]

14.36 As the Care Quality Commission identifies in its most recent report on monitoring the Mental Health Act 1983:

> Despite additional investment, rising demand and a lack of community support means that children and young people continue to face long waits for mental health support, care and treatment with NHS data reaching a new record with 496,897 open referrals to children and young people's mental health services in November 2023.[67]

14.37 Not all children who require support with their mental health are necessarily "disabled", either by reference to the definition in section 17(10) of the Children Act 1989 or the definition in the Equality Act 2010 (see further Chapter 19). However, a significant proportion will be. Further, delays in the meeting of mental health needs increase the chances that their condition(s) will deteriorate to the point of bringing the child within that definition. As the Care Quality Commission notes:

> Increasing demand and issues with accessing help early on means that too many children are facing long waits for mental health support. These delays are having a

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[64] It is not clear from the report who brought the case, or precisely what the outcome of the case was.

[65] Local Government and Social Care Ombudsman and the Parliamentary and Health Service Ombudsman, *People not structures: putting people at the heart of integrated care* (July 2024) p 8.

[66] Royal College of Psychiatry, *We cannot allow children's mental health illness to become the new norm* (February 2024) https://www.rcpsych.ac.uk/news-and-features/latest-news/detail/2024/02/07/we-cannot-allow-childhood-mental-illness-to-become-the-new-norm----rcpsych.

[67] Care Quality Commission, *Monitoring the Mental Health Act 1983 in 2022/23* (March 2024) p 37.

> huge impact on children, young people and their families. Through our inspections and monitoring visits, providers have told us that children are typically presenting with worse mental health issues than before the pandemic.[68]

14.38 Given the social determinants of mental ill health,[69] in many situations the appropriate response at an early stage may well be that led by the local authority. A failure to provide such a response may lead to an escalation of the child's needs so that the only appropriate response becomes a medical one, including potentially admission to a mental health hospital.

14.39 In the specific context of learning disability and autism, the Joint Committee on Human Rights identified that failures to support children and their families at an early stage was often a reason for detention under the Mental Health Act 1983. The Joint Committee noted in this regard the evidence of the then-Minister for Care, Caroline Dinenage MP:[70]

> All too often, what you have heard is right: young people end up in an in-patient setting as a result of a number of failed opportunities to intervene earlier, provide the right support and maybe diagnose them from an early stage.[71]

14.40 That support may well be support from a local authority, not just from the NHS.

14.41 There will also be situations in which a child has needs which cannot easily be characterised as social care or health care needs. The charity the Nuffield Family Justice Observatory has identified a cohort of children with "complex needs and circumstances".[72] These are:

> children with multiple, overlapping difficulties that are not being met by the services and systems collectively responsible for their care and safety. This includes the many children who are deprived of their liberty due to concerns about their well-being, and who are placed in unregulated settings because there is nowhere else for them to go. These children have multiple emotional and behavioural needs that are often associated with experiences of early and ongoing childhood adversity (such as abuse and neglect, but also poverty and racism) and complex trauma. There may have been repeated failures by children's services, mental health services and education services to provide them with effective help. The children's behaviour may cause significant risk to others (e.g. physical aggression) and to themselves (e.g. self-harm), which is very challenging to manage at home and in residential settings. They often have overlapping difficulties with mental health, emotion regulation, neurodevelopmental conditions (e.g. autism and ADHD), risk of exploitation, and missing education. It is often the combined impact of these multiple, intersecting

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[68] Care Quality Commission, *Monitoring the Mental Health Act 1983 in 2022/23* (March 2024) p 39.

[69] See in this regard Public Health England, *Mental health: environmental factors* (October 2019).

[70] Now Dame Caroline Dinenage.

[71] The Detention of Young People with Learning Disabilities and/or Autism, Report of the Joint Committee on Human Rights (2019) HC 121, HL Paper 10 para 35.

[72] D Bevington, R Duschinsky, R Hiller, L Holmes, E McCrory, H Minnis, and A Simon, *Principles of care for children with complex needs and circumstances* (September 2023), endorsed by the High Court (Family Division) *in Re YR (Deprivation of Liberty - Care Order - Principles of Care)* [2024] EWHC 564 (Fam) at [37].

> (and mutually synergistic) needs – rather than the impact or 'severity' of any individual risk factor – that increases a child's vulnerability, and that systems struggle to effectively respond to.[73]

14.42 Many of these children will be disabled. As the Nuffield Family Justice Observatory note, a failure to respond appropriately to their needs can lead to the point where the only response is, or appears to be, to deprive them of their liberty. We are aware of the broader work that is being done by the" improving cross-sector support for children in complex situations with multiple needs task and finish group".[74] We do not underestimate the scale of that task.

14.43 We noted above the proposals in the draft Mental Health Bill to exclude learning disability and autism from the provisions relating to detention for treatment. If they are carried forward into legislation, it appears to us that there is a risk that they may accentuate the problems identified immediately above. The experience of the Transforming Care programme, designed to bring about the discharge of individuals with learning disability and autistic individuals from mental health hospitals, suggests that providing the right care for them in the community to prevent admission will frequently be both complex and costly.[75] Inevitably, much of that cost will fall on local authorities as opposed to the NHS.[76] This could be seen as "the system" working in terms of making sure that unmet needs do not escalate to the point where the only response is the medical response of detention under the Mental Health Act 1983. However, as "the system" is not unitary, we consider that it is important to be alert to the implications for the different parts of that system.

14.44 Finally, and separately, by way of context, the Children's Commissioner for England highlighted in January 2024 that:

> Even before a child turns 18, professionals speak about a "16 to 18 void" in the NHS which many of the children they support experience – falling between the gaps of children's and adults' services. For example, some 16- and 17-year-olds are placed in adult hospital and mental health wards, which is not always appropriate. Professionals also reflected that sometimes neither children's nor adults' services want to pay for products that are essential to the young people, even those which have been prescribed.[77]

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[73] D Bevington, R Duschinsky, R Hiller, L Holmes, E McCrory, H Minnis, and A Simon, *Principles of care for children with complex needs and circumstances* (September 2023) p 2.

[74] https://www.gov.uk/government/groups/improving-cross-sector-support-for-children-in-complex-situations-with-multiple-needs-task-and-finish-group.

[75] The detention of young people with learning disabilities and/or autism, Report of the Joint Committee on Human Rights (2019) HC 121, HL 10.

[76] Indeed, a greater share of that cost than is the case where a person is detained for treatment under the Mental Health Act 1983 and then discharged. At that point, as set out above, section 117 of the Mental Health Act 1983 imposes a joint funding responsibility upon both the local authority and (in most cases) the integrated care board.

[77] Children's Commissioner for England, *Ensuring smooth transitions for disabled children* (January 2024).

THE CASE FOR REFORM

14.45 The current division between health care and social care appears to be an obstacle to meeting the needs of disabled children. The more complex their needs, the more of an obstacle this division appears to become. The problem is compounded by the lack of clarity as regards the dividing line between the two and also (in the case of the Mental Health Act 1983) the fact that four separate statutory provisions are required to identify that a duty to assess social care needs arises.

14.46 There are limits to what we can consider, both as a law reform body, and also given our terms of reference. The fundamentally different bases upon which health care and social care are delivered are ultimately matters of political policy. It would not be appropriate for us as a law reform body to seek to make proposals in this regard, not least given that the significant implications of making any changes as regards funding of both the NHS and local authorities are ones that should be addressed by elected politicians. Further, given our terms of reference, we cannot seek to make proposals about what is a matter of health service law, rather than disabled children's social care law (or about children's social care more broadly). In this regard, the problems that arise from the division between social care and health care law are not ones that are confined to disabled children, but apply more generally.

14.47 That having been said, we do think that we can properly consider the following.

(1) Clarifying (but not changing) the dividing line between health care and social care in respect of children. Whilst this is a dividing line which in principle is relevant to all children, in practice it most directly affects disabled children. Such children are the group most likely to have both social care needs and health care needs of a nature that at present are identified in the *Continuing Care Framework* as being the responsibility of the NHS.

(2) Simplifying the legal route from section 117 of the Mental Health Act 1983 to the position where a local authority is required to consider a disabled child's social care needs.

OPTIONS FOR REFORM

14.48 There are two options to address the problems set out above. The first would be to address matters by way of clearer guidance. It would be possible for guidance to make clearer which needs are social care needs and which are health care needs. It would also be possible for guidance to explain clearly the route into social care assessment from the Mental Health Act 1983. We can certainly see the merit in this as an approach, and such guidance could undoubtedly help resolve the dispute situations identified (most recently) in the joint Ombudsmen report we note at paragraph 14.34 above.

14.49 However, for the following reasons, we think that the need for clarity and simplicity is so important in this area that legislation is needed.

(1) The dividing line between social care and health care should not be left to guidance alone, but rather should be set out in legislation. This was the

approach that we took in relation to adults,[78] and our initial view is that the same approach should apply in relation to disabled children. A way in which this could be achieved would be by adopting the equivalent of section 22 of the Care Act 2014, which sets out a statutory codification of the dividing line in respect of adults. It also includes a regulation-making power to enable the dividing line between local authority and NHS responsibilities to be changed.

(2) The complex route into assessment under the Mental Health Act 1983 requires statutory simplification, not merely better explanation.

OUR PROVISIONAL PROPOSALS

14.50 Our provisional view is that the current dividing line between health and social care should be placed on a statutory footing, by reproducing the equivalent of section 22 of the Care Act 2014. We should emphasise that in making this proposal, we are not proposing a change in the current dividing line; this is a matter for political policy, not law reform. Rather, we are proposing that the current dividing line be codified. If a regulation-making power is introduced to enable the dividing line between local authority and NHS responsibilities to be changed, it can be moved to reflect changes in Government policy.

Consultation Question 50.

14.51 We provisionally propose that the current dividing line between social care and health care in respect of children, based upon the scale and type of the care being provided, should be placed on a statutory footing, with a regulation-making power to enable that line to be changed in future.

Do consultees agree?

14.52 We also provisionally propose that the statutory mechanism by which a local authority with responsibilities under section 117 of the Mental Health Act 1983 is required to consider their obligations to meet the social care needs of disabled children is simplified. The duty should be made a single duty, rather than arising out of a combination of the National Health Service and Community Care Act 1990, the Chronically Sick and Disabled Persons Act 1970, the Disabled Persons (Services, Consultation and Representation) Act 1986, and the Children Act 1989.

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[78] Adult Social Care (2011) Law Com No 326 paras 11.16 to 11.21.

Consultation Question 51.

14.53 We provisionally propose that there should be a single provision setting out when a local authority with responsibilities under section 117 of the Mental Health Act 1983 is required to assess a disabled child's social care needs.

Do consultees agree?

14.54 We further provisionally propose that guidance on meeting the social care needs of disabled children (which we recommend in Chapter 23)[79] has a specific section – co-produced between local authority and NHS representatives – on the intersection between health care and social care. That section should make the following clear.

(1) How disabled children with health care needs are to be identified (see further in this regard our provisional proposals regarding referral for assessment at paragraph 4.41).

(2) Local authority responsibilities to meet the health care needs of disabled children.

(3) NHS responsibilities to meet the health care needs of disabled children.

(4) Expectations for joint working and joint accountability where local authority and NHS responsibilities overlap in the meeting of such needs.

(5) Mechanisms for dispute resolution, including an expectation that "internal" disputes as between local authority and NHS organisations should not affect the meeting of the needs of the child in the interim.

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[79] As set out there, this guidance would accompany a new framework for assessing and meeting the needs of disabled children we provisionally propose in that chapter. It would be prepared in two versions, one for professionals applying the law, and the other for parents and carers who need to understand their rights under the law.

Consultation Question 52.

14.55 We provisionally propose that guidance include a specific section – co-produced between local authority and NHS representatives – on the intersection between health care and social care. This should make the following clear.

(1) How children with health care needs are to be identified (see further in this regard our provisional proposals regarding referral for assessment at paragraph 4.41).

(2) Local authority responsibilities to meet the health care needs of disabled children.

(3) NHS responsibilities to meet the health care needs of disabled children.

(4) Expectations for joint working and joint accountability where local authority and NHS responsibilities overlap in the meeting of such needs.

(5) Mechanisms for dispute resolution, including an expectation that "internal" disputes as between local authority and NHS organisations should not affect the meeting of the needs of the child in the interim.

Do consultees agree?

Chapter 15: The transition to adult social care

INTRODUCTION

15.1 The transition between children's social care and adult social care engages both issues of law and of the division of labour within local authorities. The legal issues arise because (in England), there are distinct legal frameworks for the provision of social care to children and to adults. The organisational issues arise because, although to the outside world local authorities are indivisible, the distinction between children's services and adult services is often a significant one.[1]

15.2 Disabled children are perhaps the cohort of children who test the law and practice in this area the most. In many cases their needs will be life-long, and they are therefore likely to remain entitled to services from local authorities throughout their life. They are also, in many cases, looked after by parents who remain more heavily involved in decision-making in respect of them than the parents of non-disabled children, even as they move towards adulthood. Such parents do not necessarily stop having (and feeling) responsibility for their children at 18 when, in law, their decision-making authority as parents abruptly ceases.

15.3 We emphasise that in this chapter we focus on the age of 18 because it is the transition point for purposes of social care, the subject of our review. It is also a point at which the law recognises that, in principle, the (now) adult has the right to make their own decisions in a way which they did not before. However, as set out below, the age of 25 is also a transition point for certain purposes.

THE CURRENT LAW

15.4 The law in this area has relatively recently undergone a substantial change, drawing in large part upon our work on adult social care.[2] The Care Act 2014 imposes specific obligations on local authorities to assess and prepare plans to meet the needs of children whose care and support needs are likely to extend beyond their 18th birthday.[3] This will include disabled children. If it appears to a local authority that a child is likely to have needs for care and support after becoming 18, the authority must, if it is satisfied that it would be of "significant benefit"[4] to the child to do so and if the consent condition is met, assess:

(a) whether the child has needs for care and support and, if so, what those needs are; and

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[1] A useful summary of how the divide arose can be found in R Jones, "Social Work across the decades: the birth of the children/adults divide" *Community Care* (June 2024) https://www.communitycare.co.uk/2024/06/12/social-work-across-decades-children-act-1989/.

[2] Adult Social Care (2011) Law Com No 326.

[3] Care Act 2014, s 58.

[4] The benefit relates to the timing of the assessment, not the level of need: Department of Health and Social Care, *Care and Support Statutory Guidance* (March 2024) para 16.10.

> (b) whether the child is likely to have needs for care and support after becoming 18 and, if so, what those needs are likely to be.

15.5 The "consent condition" is met where either:

(1) the child is able[5] to and does consent to what the Care Act 2014 calls a "child's needs assessment";[6] or

(2) if the child is unable to consent, and the local authority is satisfied that carrying out a child's needs assessment would be in the child's best interests.[7]

15.6 The Care Act 2014 requires that, even if a child refuses an assessment, the local authority must nonetheless carry out the assessment if the child is experiencing, or is at risk of, abuse or neglect.[8]

15.7 These provisions are accompanied by detailed statutory guidance.[9] This makes clear that it will generally be of significant benefit to the child to assess "at the point when their needs for care and support as an adult can be predicted reasonably confidently, but will also depend on a range of other factors".[10] In relation to children who have an Education, Health and Care Plan under the Children and Families Act 2014, there is a statutory requirement for any review of that plan to consider from year nine (in other words, when the child is aged 13 to 14):

> what provision is required to assist the child or young person in preparation for adulthood and independent.[11]

15.8 The Care Act 2014 does not itself give powers to (or impose duties on) the local authority to meet the assessed needs of the child whilst they are under-18. These powers are to be found in the legislation governing children, most obviously the Children Act 1989. Rather, the Care Act 2014 places the local authority under different duties. These are to give the child (or, if the child is unable to understand those matters, their parents):[12]

> (a) an indication as to whether any of the needs for care and support which it thinks the child is likely to have after becoming 18 are likely to meet the eligibility criteria (and, if so, which ones are likely to do so), and

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[5] Care Act 2014, s 58(3). The child's ability is judged either by competence (in relation to a child under 16) or capacity (in relation to a child of 16 or 17). See further paras 21.7 and 21.8.

[6] Care Act 2014, s 58(2).

[7] Care Act 2014, s 58(3)(b).

[8] Care Act 2014, s 58(4).

[9] Department of Health and Social Care, *Care and Support Statutory Guidance* (March 2024).

[10] Department of Health and Social Care, *Care and Support Statutory Guidance* (March 2024) para 16.6.

[11] Special Educational Needs and Disability Regulations 2014, SI No 1530, regs 20 (where the child attends a school or other institution) and 21 (where the child does not attend a school or other institution). See also Department for Education and Department of Health, *Special Educational Needs and Disability Code of Practice: 0-25 years* (January 2015) para 8.9.

[12] Care Act 2014, s 59(5).

(b) advice and information about –

(i) what can be done to meet or reduce the needs which it thinks the child is likely to have after becoming 18;

(ii) what can be done to prevent or delay the development by the child of needs for care and support in the future.[13]

15.9 When the child turns 18, the local authority is then required to decide whether to treat that assessment as a needs assessment for the purposes of discharging its adult social care functions.[14] That, in turn, provides the entry point into decision-making about the meeting of the (now) adult's needs for care and support.

15.10 The Care Act 2014 imposes similar obligations in respect of the carers of children who are likely to continue to require services after the child turns 18,[15] and young carers who are likely to have needs for support after becoming 18.[16]

15.11 The Care Act 2014 also introduced section 17ZH into the Children Act 1989, applying to children in need and/or their carers. The drafting of the provision is complicated, but in simple terms its effect is to ensure that services continue to be provided under the Children Act 1989 until a decision is reached that the (now) adult:

(1) does not need care and support;

(2) does need care and support, but is able to meet some or all of those needs themselves;

(3) does need care and support, but the local authority is not under a statutory obligation to meet those needs because they do not meet the eligibility criteria for the provision of adult social care services under the Care Act 2014; or

(4) needs care and support, and the local authority is required to meet those needs.

15.12 Following amendments introduced by the Children (Leaving Care) Act 2000, the Children Act 1989 also imposes a further set of obligations in respect of what are known as care leavers.[17] We addressed these obligations in further detail in Chapter 8. They are primarily designed to provide services and support to children who have been taken into care by local authorities. However, they are also owed to children who have been provided with accommodation under section 20 of the Children Act 1989. An example of such a child was the boy at the centre of the Supreme Court case of *Re D (A Child)*[18] which we discuss in the research paper on deprivation of liberty

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[13] Care Act 2014, s 59(4).

[14] Care Act 2014, s 59(6).

[15] Care Act 2014, ss 60 to 62.

[16] Care Act 2014, ss 63 and 64.

[17] This section draws on S Broach and L Clements, *Disabled Children: A Legal Handbook* (3rd ed 2020) pp 461 to 467, paras 10.52 to 10.64.

[18] *Re D (A Child)* [2019] UKSC 42, [2019] PTSR 1816.

which is available on our website.[19] D was accommodated by the local authority with the agreement of his parents because they could not meet his needs arising from his disabilities at home.[20]

15.13 Other legislation imposes its own obligations as regards those children who have previously been receiving services. In particular, the Children and Families Act 2014 imposes obligations on local authorities in respect of young people up to the age of 25. The statutory *Special Educational Needs and Disability Code of Practice* makes clear that:

> Where young people aged 18 or over continue to have EHC plans, and are receiving care and support, this will be provided under the Care Act 2014. The statutory adult care and support plan should form the 'care' element of the young person's EHC plan. While the care part of the EHC plan must meet the requirements of the Care Act 2014 and a copy should be kept by adult services, it is the EHC plan that should be the overarching plan that is used with these young people to ensure they receive the support they need to enable them to achieve agreed outcomes.[21]

15.14 Separately, turning 18 brings about a further transition which is of particular importance in the case of disabled children with cognitive impairments. In law, any decision-making authority that rests with parents by virtue of the operation of parental responsibility falls away at age 18. Unless the young person has the capacity to appoint them as an attorney under the Mental Capacity Act 2005, or the Court of Protection has appointed the parent as a deputy, the parent has no authority to make decisions for their child. The more severe the cognitive impairments of the young person, the less likely that it is that they will have the capacity to appoint their parent(s) as attorney. The Court of Protection will also only appoint a parent or parents as deputy for personal welfare matters if it is in the best interests of the (now) adult, and such appointments are relatively infrequent.[22]

15.15 As the former Vice-President of the Court of Protection, Mr Justice Hayden, has made clear:

> Whilst there is no special alchemy that confers adulthood on a child on his or her 18th birthday, it nevertheless marks a transition to an altered legal status, which carries both rights and responsibilities. It is predicated on respect for autonomy. The young person who may lack capacity in key areas of decision making remains every bit as entitled to this respect as his capacitous coeval. These are fundamental rights which infuse the [Mental Capacity Act] 2005 and are intrinsic to its philosophy. The extension of parental responsibility beyond the age of eighteen, under the aegis of a [personal welfare deputyship] may be driven by a natural and indeed healthy

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[19] https://lawcom.gov.uk/project/disabled-childrens-social-care/.

[20] *Re D (A Child)* [2019] UKSC 42, [2019] PTSR 1816 at [6] to [11].

[21] Department for Education and Department of Health, *Special Educational Needs and Disability Code of Practice: 0-25 years* (January 2015) pp 20-21; see further and ch 8 of this consultation paper.

[22] *Re Lawson, Mottram and Hopton (appointment of personal welfare deputies)* [2019] EWCOP 22, [2019] 1 WLR 5164.

> parental instinct but it requires vigilantly to be guarded against.[23] The imposition of a legal framework which is overly protective risks inhibiting personal development and may fail properly to nurture individual potential. The data which I have analysed [showing a spike in applications for personal welfare deputyship between the ages of 18 and 24] may, I suspect, reflect the stress and anxiety experienced in consequence of the transition from child to adult services. As a judge of the Family Division and as a judge of the Court of Protection I have seen from both perspectives the acute distress caused by inadequate transition planning. The remedy for this lies in promoting good professional practice. It is not achieved by avoidably eroding the autonomy of the young incapacitous adult.[24]

THE CASE FOR REFORM

15.16 In January 2024, the Children's Commissioner for England highlighted the problems that disabled children face when they turn 18:

> Sharp cliff-edges in support, particularly around the transition from children's to adults' services, are something children experience across a range of services. Professionals at a residential special school my team visited spoke about one young person they had been supporting who recently turned 18.
>
> This young person had been using pull up pads to date, which they found suited them and enabled them to go to the bathroom on their own. However, under adult services, only wrap around pads were being given to this young person. The staff felt the young person's independence was taken away, as they were now no longer able to go to the bathroom on their own.[25]

15.17 In similar vein, in an April 2024 interview, Lord Laming, the chair of the Victoria Climbié inquiry made clear his concerns as to transition. Lord Laming described to the interviewer a severely disabled young adult who, until the age of 18, had been well supported by children's services. As the interviewer put it, Lord Laming further described how when the child got referred to adults' services, upon reaching adulthood, it was as if the young person's history with children's services had been erased. In Lord Laming's words:

> "They started again as if there was no previous contact with this child. An early social history had to be taken and a new file had to be created, etc. And I think to myself, we've got to see the whole person".[26]

15.18 These observations chime with many of the experiences shared with us by stakeholders in the lead up to this consultation. It appears difficult to see why the cliff-

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[23] See also *TN v An NHS ICB & Anor* [2022] EWCOP 53, [2023] COPLR 93 for the rejection, also by Hayden J, of an argument that parental responsibility extended as a matter of law beyond the age of 18 in the case of a (now) adult unable to make their own decisions, in that case about vaccination.

[24] *Re Lawson, Mottram and Hopton (appointment of personal welfare deputies)* [2019] EWCOP 22, [2019] 1 WLR 5164 at [53(b)].

[25] Children's Commissioner for England, *Ensuring smooth transitions for disabled children* (January 2024).

[26] A Koutsounia, "The Victoria Climbié Inquiry chair reflects on social work, 21 years on" *Community Care* (April 2024) https://www.communitycare.co.uk/2024/04/11/the-victoria-climbie-inquiry-chair-reflects-on-social-work-21-years-on/.

edge should exist, because needs do not change on a person's 18th birthday. It appears to us that the reasons for it may include a lack of forward planning, different eligibility criteria being applied by children's and adults' services, and different approaches by the two services to meeting the same needs. However, we welcome further views as to why the cliff-edge appears to be such a problem in so many situations.

Consultation Question 53.

15.19 We invite consultees' views on the cause of the problems faced by disabled children receiving social care in making the transition to adult social care.

15.20 A further, somewhat different theme which emerged in the lead up to this consultation was the lack of preparation by children's services of disabled children and their parents for the legal transition to adulthood. This took two forms.

(1) A problem strongly emphasised by the children and young people's groups we have spoken to was a failure to support children to develop independent living skills. This could include practical things such as supporting the child to learn how to manage money. But it can also be at a deeper level of preparing the child for the fact that they are expected to make their own decisions. We have heard how, inadvertently, disabled children can be infantilised until they reach 18, which then creates problems when they are suddenly expected to be making their own decisions without experience of having done so.

(2) The lack of preparation for the fact that the child's parents would no longer have decision-making authority after the age of 18 (see paragraph 15.14 above).

15.21 We are also, separately, aware of the problems that are repeatedly identified in the safeguarding context where a child transitions to adult services. Not all of these relate to disabled children. However, a significant proportion do. An example drawn to our attention in the lead up to this consultation was the case of Madeleine, who was:

> of mixed ethnicity (White British/Black Nigerian), she was 18 years old when she died and was well known to many services. She had a long history of mental health (CAMHS)[27] support from a very young age, including being an inpatient when she was 9. At 16 her parents were told that CAMHS had 'tried everything' so they should ask for help from social care. Madeleine had a diagnosis of Autistic Spectrum Disorder, 'emotional dysregulation' and Obsessive-Compulsive Disorder. She had an Education, Health and Care Plan but despite this had been excluded from schools because of her behaviour which was challenging. She was first assessed by social care services when she was 12 and at 16 she was taken into care. She experienced 8 different placements in 5 months and was then placed in secure accommodation in Scotland. Shortly before her 18th birthday she moved from there to an Independent Living placement in Croydon. Despite having reached adulthood,

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[27] Child and Adolescent Mental Health Services.

> coordination of her care needs remained the responsibility of [the London Borough of] Wandsworth's Children's Social Care.
>
> On the evening of the 13 August 2020, whilst at her placement, Madeleine took Ketamine. Staff called 111 for advice. A short time later, staff found her suspended from her door. She was taken to hospital and died on 16 August 2020.[28]

15.22 The safeguarding adults review conducted into her death for Croydon's Safeguarding Adults Board identified that:

> Multi-agency support was not robust in either transition planning or in mitigating Transitional Safeguarding issues. In complex cases, transition planning requires careful multi-agency working and this was lacking with Madeleine, particularly around mental health and placement provision. The Transitional Safeguarding issues across the children's and adults' divide were not fully understood for her. In situations like this, practitioners should not walk away and close down involvement when support is declined which is what happened here, but should remain curious and tenacious in seeking ways to engage young people particularly where there are complexities, eg. mental health and substance misuse, which compound their experience of services. Unfortunately there were many gaps in the service that Madeleine received.[29]

15.23 We further note in this regard the recent recommendation made in the context of the second national analysis of safeguarding adults reviews that:

> In light of repetitive findings regarding transition of young people to adult services, [the Department of Health and Social Care] should consider what changes may be necessary in current legislation and guidance to provide a framework that promotes best practice in transitional safeguarding.[30]

15.24 Taking all the matters together above, it seems to us that the policy goal of the Care Act 2014 of securing a seamless transition from children's services to adults' services may not be being achieved, with a particular impact on disabled children. That policy goal depends on the early identification of those disabled children who will require social care services upon reaching adulthood. Our provisional view is that a barrier to this being achieved may be the degree of discretion as to when transition planning should be started. We address the consequence of this below.

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[28] Croydon Safeguarding Adults Board, *Madeleine Safeguarding Adult Review – Seven Minute Briefing* (March 2022). See further, for the full report, F Bateman and C Cocker, *Safeguarding Adults Review: Madeleine* (October 2021).

[29] Croydon Safeguarding Adults Board, *Madeleine Safeguarding Adult Review – Seven Minute Briefing* (March 2022).

[30] S Braye and M Preston-Shoot, *Second National Analysis of Safeguarding Adult Reviews: Final Report Stage 3:* (June 2024) p 14. In respect of transitional safeguarding, see also M Preston-Shoot, C Cocker and A Cooper "Learning from safeguarding adult reviews about Transitional Safeguarding: building an evidence base" (2022) 24(2) Journal of Adult Protection 90; and D Holmes, *Transitional Safeguarding from adolescence to adulthood* (August 2018) https://www.researchinpractice.org.uk/all/news-views/2018/august/transitional-safeguarding-from-adolescence-to-adulthood.

OPTIONS FOR REFORM

15.25 Before we outline options for reform, we should note the potential impact of bringing the Mental Capacity (Amendment) Act 2019 into force. This legislation, based on a project we completed in 2017, would reform the framework for authorising deprivation of liberty of those aged 16 in the health and social care context contained in the Mental Capacity Act 2005.[31] We are conscious that the decision whether to take further steps towards bringing this Act into force is one for Government. However, that Act's provisions would provide another organisational "driver" to secure consideration of transition. It would provide a framework for the administrative authorisation of the deprivation of liberty of 16 and 17 year olds who cannot consent to arrangements for delivering care and treatment to them.[32] All such 16 and 17 year olds would fall within our proposed definition of disabled children; very many would also have conditions lasting into adulthood. In very many cases, the responsibility for authorisation would lie with the local authority; the local authority would also retain responsibility for authorising the arrangements when the child turns 18. At a minimum, therefore, the requirements for authorisation under the 2019 Act would ensure that such children are very firmly on the radar of local authorities. They would, further, be thought about through the lens of the Mental Capacity Act 2005, legislation which assumes increasing importance as a child moves towards and into adulthood.

15.26 At this stage, one option for us is to propose no legal changes at all specifically addressed to the position in relation to transition. Instead, the guidance in relation to disabled children we think is necessary[33] could set out in one place the expectations in respect of the specific transition needs of such children. The statutory guidance accompanying the Care Act 2014 could also be amended.

15.27 We welcome views as to whether this is sufficient to solve the problems we have identified in the context of transition. We note, however that clear guidance has for some considerable time accompanied the Care Act 2014, and our initial view is that it does not seem to be sufficient to achieve the policy goal of that Act. That suggests that the law, itself, may require revisiting.

15.28 One way in which the law could be changed would be to set a statutory age at which transition planning should start for any disabled child who is likely to require services after the age of 18. This would give certainty as to what is required, and when. It would also be enforceable. Conversely, it would remove the current flexibility and discretion for local authorities; and it risks, in some cases, a child being considered at a point when their parents or carers consider that it is "too early".

OUR PROVISIONAL PROPOSALS

15.29 On balance, we consider that the benefits of moving to a statutory age at which transition planning for disabled children should start to outweigh the possible risks.

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[31] Mental Capacity and Deprivation of Liberty (2017) Law Com No 372. See further the research paper on deprivation of liberty in the context of disabled children's social care available on our website at https://lawcom.gov.uk/project/disabled-childrens-social-care/.

[32] Applying the test in the Mental Capacity Act 2005, as to which see para 21.8.

[33] See further ch 23.

What that age should be would ultimately be a matter for Government, but we welcome consultees' views. There are two obvious candidates.

(1) The first is 14, as this is the age by which the current statutory framework provides that the assessment process should have started where the child has an Education, Health and Care Plan under the Children and Families Act 2014.[34]

(2) The second is 16, recognised as a significant age in other legislation, for instance in the Mental Capacity Act 2005.[35]

15.30 If the law were to change to provide a statutory age to start transition planning, it would be necessary to decide what the appropriate remedy should be where a local authority fails to start the process. We consider remedies further in Chapter 18 below. At this stage, we want to understand consultees' views on the principle of having a statutory age for starting consultation, and (if they consider that there should be one), what that age should be.

15.31 The provisional proposal we set out here sits alongside proposals discussed in other chapters, in particular:

(1) a statutory requirement for decision-makers to have regard to the importance of securing transition into adulthood, discussed in Chapter 20; and

(2) a framework to secure the participation of disabled children so as to ensure that their voice is heard clearly from an early stage, discussed in Chapter 21.

15.32 Finally, we note that, given our terms of reference, we can only make provisional proposals in relation to transition planning in respect of disabled children. The potential for inconsistency with the position of other children for whom transition planning may be of importance is something that consultees will need to consider in their responses.

Consultation Question 54.

15.33 We provisionally propose that the Care Act 2014 be amended to provide a statutory age at which transition planning should be started in relation to disabled children.

Do consultees agree?

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[34] Special Educational Needs and Disability Regulations 2014, SI No 1530, regs 20 (where the child attends a school or other institution) and 21 (where the child does not attend a school or other institution). See also Department for Education and Department of Health, *Special Educational Needs and Disability Code of Practice: 0-25 years* (January 2015) para 8.9.

[35] See ch 21.

Consultation Question 55.

15.34 If the Care Act 2014 were to be amended to provide a statutory age at which transition planning should be started in relation to disabled children, we invite consultees' views as to the age at which this should start.

Chapter 16: Identifying need in the local area and securing sufficient services to meet that need

INTRODUCTION

16.1 Identifying the social care needs of the local population is the first step towards making sure that the right services are available, at the right time, so that those needs can be met. Writing in 1972, Alf Morris MP acknowledged the importance of this task, observing that, unless we can "obtain full identification of the severely disabled in Britain… policy making is blind".[1] Despite a series of statutory provisions which are intended to perform this task, in the lead up to this consultation we have been told that services are not always available in the local area to meet the needs of disabled children and their families. In effect, there is a mismatch between supply and demand. In this chapter we consider the legal tools that local authorities have to identify the demand for services in their local area and to arrange a supply of services to meet that demand.

16.2 Policy makers often refer to these topics as aspects of the "commissioning" process. The Department for Education defines commissioning in the following terms:

> when we refer to "commissioning", we mean it as an end-to-end process. It begins by establishing a joint multi-agency understanding of what services and provision are needed by a local area and in what quantity. Then there is a process of planning, engagement, investment and procurement, ensuring there are sufficient of those services and provision (and of suitable quality) to meet local needs. Finally, the local authority and its partners will monitor and review the delivery of these services and provision, leading to a further cycle of design, delivery and review.[2]

16.3 However, with the exception of the Children and Families Act 2014,[3] legislation in this area tends not to use the word "commissioning". Instead, it tends to refer to specific aspects of the commissioning process such as the assessment or identification of need in the local area. We will adopt the same approach and will not use the word "commissioning" unless the context demands it. This is primarily for the sake of clarity, because we are not looking at every element of the commissioning process. In particular, we are not looking at local authority investment or procurement.

16.4 We focus in this chapter on the general, strategic powers and duties that local authorities have to assess the needs of their local population and to make services available – such as a short breaks service – that can serve that population. The duties to assess and meet the needs of individual children are dealt with separately in Chapters 3 and 7.

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[1] A Morris and A Butler, *No feet to drag* (1972) p 11.

[2] Department for Education, *Safeguarding children with disabilities and complex health needs in residential settings: government response* (December 2023) p 31.

[3] See para 16.12 below.

THE CURRENT LAW

The Children Act 1989

16.5 Under the Children Act 1989 and associated regulations, local authorities have a number of general duties to assess the level of disability-related need in their local area and arrange for services to be available to meet those needs. In particular, local authorities must do the following.

(1) Take reasonable steps to identify the extent to which there are children in need (including disabled children) within their area.[4]

(2) Maintain a register of disabled children.[5]

(3) Make available the following services for children in need (including disabled children) living with their families in the area, to the extent they think appropriate:

  (a) advice, guidance and counselling;

  (b) occupational, social, cultural or recreational activities;

  (c) home help (which can include laundry facilities);

  (d) facilities for, or assistance with, travel to and from home, to take advantage of services; and

  (e) assistance to enable children and their families to have a holiday.[6]

(4) Take reasonable steps to identify the extent to which there are parents and carers of disabled children within their area who have needs for support.[7]

(5) Provide services designed to minimise the effect on disabled children in the area of their disabilities, give them the opportunity to lead lives as “normal” as possible and provide breaks for their parents or carers.[8] Those services must include, as appropriate, a range of daytime and overnight care in the home and elsewhere, educational and leisure activities and services to assist parents and carers in the evenings, at weekends and during the holidays.[9]

(6) Take steps that secure, so far as reasonably practicable, a sufficient supply of accommodation in the area for looked after children (some of whom will be disabled).[10] Sufficiency in this context is not just about the number of beds, but

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[4] Children Act 1989, sch 2, para 1.

[5] Children Act 1989, sch 2, para 2.

[6] Children Act 1989, sch 2, para 8.

[7] Children Act 1989, s 17ZD(14).

[8] Children Act 1989, sch 2, para 6.

[9] Breaks for Carers of Disabled Children Regulations 2011, SI No 707, reg 4.

[10] Children Act 1989, s 22G.

about having accommodation that meets children's needs. That requires consideration of matters such as the need for adapted accommodation for disabled children.[11]

16.6 Under section 84 of the Children Act 1989, the Secretary of State has the power to make an order declaring that any local authority has, without reasonable excuse, failed to comply with these duties (and any other duties under the Act). The Secretary of State is aided in this by section 83(3) which permits them to require local authorities to provide information about the performance of any of their functions under the Children Act 1989.

The Local Government and Public Involvement in Health Act 2007

16.7 Under the Local Government and Public Involvement in Health Act 2007, local authorities[12] must carry out and publish an assessment of "relevant needs" in relation to their area.[13] The assessment should be undertaken jointly with the integrated care board(s) (ICB) for the area.[14]

16.8 There is a "relevant need" in relation to an area if it appears to the local authority and the ICB that there is a need, or that that there is likely to be a need, which:[15]

(1) is capable of being met to a "significant extent" by the local authority exercising any of its functions; and

(2) could also be met or affected to a "significant extent" by the ICB or NHS England exercising any of their functions.

16.9 Such an assessment is referred to as a "joint strategic needs assessment". The joint strategic needs assessment should be used as the basis for a "joint local health and wellbeing strategy" setting out how the assessed needs for the area are to be met.[16] In exercising any of their functions, local authorities (among others) should have regard to the joint strategic needs assessment and the joint local health and wellbeing strategy.[17]

16.10 Statutory guidance on joint strategic needs assessments explains that their purpose is to:

> improve the health and wellbeing of the local community and reduce inequalities for all ages. They are not an end in themselves, but a continuous process of strategic assessment and planning – the core aim is to develop local evidence-based

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[11] Children Act 1989, s 22G(2)(b); Department for Children, Schools and Families, *Sufficiency: Statutory guidance on securing sufficient accommodation for looked after children* (March 2010) paras 2.9 to 2.11.

[12] Of the type specified in Local Government and Public Involvement in Health Act 2007, s 103. See Local Government and Public Involvement in Health Act 2007, ss 116(1) and 117.

[13] Local Government and Public Involvement in Health Act 2007, s 116(1) and (5).

[14] Local Government and Public Involvement in Health Act 2007, s 116(4) and (9).

[15] Local Government and Public Involvement in Health Act 2007, s 116(6)-(7).

[16] Local Government and Public Involvement in Health Act 2007, ss 116ZB and 116A.

[17] Local Government and Public Involvement in Health Act 2007, s 116B(1).

> priorities for commissioning which will improve the public's health and reduce inequalities. Their outputs, in the form of evidence and the analysis of needs, and agreed priorities, will be used to help to determine what actions local authorities, the local NHS and other partners need to take to meet health and social care needs, and to address the wider determinants that impact on health and wellbeing.[18]

16.11 The content of the joint strategic needs assessment is not set in stone. Of particular relevance in this context is that there is no statutory requirement that the social care needs of disabled children must be dealt with in a joint strategic needs assessment. Rather, it is a matter of judgement for the local authority and ICB whether a particular need exists in the local area and is capable of being met (or in the case of the ICB, affected) to a significant extent by the local authority or the ICB exercising any of their functions. In that vein, the statutory guidance on joint strategic needs assessments explains that "there is no template or format that must be used and no mandatory data set to be included".[19] However the *Working Together* guidance provides that the needs of children should be a "key part" of the assessment.[20] The *Special Educational Needs and Disability Code of Practice* is more specific, placing significant weight on the joint strategic needs assessment as a tool for commissioning special educational needs and disability (SEND) services. The *Special Educational Needs and Disability Code of Practice* makes repeated references to these assessments, and voices an expectation that:

> The [joint strategic needs assessment] will form the basis of NHS and local authorities' own commissioning plans, across health, social care, public health. This is likely to include specific needs of children and young people with SEN or disabilities.[21]

The Children and Families Act 2014

16.12 The Children and Families Act 2014 contains several further duties relating to the identification of need in the local area, and the arrangement of services to meet those needs. These duties are not limited to the SEND context and apply to disabled children's social care more generally. In particular, under the Children and Families Act 2014, local authorities are required to do the following.

(1) Exercise their functions with a view to identifying all of the children and young people in the area who have a disability.[22] The duty attaches to the exercise of any of the local authorities' functions and not solely those under the Children and Families Act 2014.

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[18] Department of Health, *Statutory Guidance on Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies* (August 2022) p 4.

[19] Department of Health, *Statutory Guidance on Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies* (August 2022) p 6.

[20] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 17.

[21] Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years* (January 2015) pp 56 to 57.

[22] Children and Families Act 2014, s 22.

(2) Work together to make joint commissioning arrangements for education, health and social care provision.[23] These arrangements must include arrangements for considering and agreeing:[24]

(a) the social care provision reasonably required by disabled children in the area; and

(b) what social care provision is to be secured and by whom.

(3) Keep the social care provision for disabled children in the area under review.[25]

(4) Consider, in consultation with disabled children and their parents, whether the social care provision in the area is sufficient to meet the social care needs of the children concerned.[26]

(5) Have regard to their joint strategic needs assessment and joint local health and wellbeing strategy in making joint commissioning arrangements for disabled children's social care and in reviewing the sufficiency of social care provision for disabled children.[27]

THE CASE FOR REFORM

16.13 It seems to us that the Children Act 1989 alone is not sufficient to ensure that the needs of disabled children in the local area are identified, or that sufficient services are provided in the local area so that those needs can be met. First, the Act contains no duty to assess the nature and extent of need in the area. There is a requirement to have a register of disabled children, but no particular requirements as to what that register should contain. Second, the Act requires local authorities to make certain services available for disabled children such as short breaks. But it contains no correlative requirement to ensure that those services are sufficient to meet the needs of the local area.[28]

16.14 Further, it seems to us that the Local Government and Public Involvement in Health Act 2007 does not do a great deal to improve on this position as far as disabled children are concerned. It provides a tool – the joint strategic needs assessment – by which certain social care needs of disabled children can be identified. But there is no requirement to undertake a joint strategic needs assessment focused on disabled children's social care. It is left to the judgement of local authorities to determine whether such an assessment would be appropriate. In any event, the joint strategic needs assessment is, as the name implies, intended to cover needs that can be met jointly by local authorities and ICBs or NHS England. Social care needs which fall exclusively to be met by a local authority are outside of the remit of the joint strategic

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[23] Children and Families Act 2014, s 26(1)-(2).

[24] Children and Families Act 2014, s 26(3).

[25] Children and Families Act 2014, s 27(1).

[26] Children and Families Act 2014, s 27(2)-(3).

[27] Children and Families Act 2014, ss 26(7) and 27(4).

[28] The duty under Children Act 1989, s 22G to secure sufficient suitable accommodation for looked after children provides a limited exception to this general point.

needs assessment. For these reasons, the *Special Educational Needs and Disability Code of Practice* may be overstating the position when it refers to the joint strategic needs assessment forming the basis of local authorities' commissioning plans.[29]

16.15 However, our view is that the lacunae in these two statutory frameworks are filled by the Children and Families Act 2014. The obligations we set out at paragraph 16.12 above seem to us to provide a complete framework for the identification of the nature and extent of social care provision required by disabled children in the area, and for securing sufficient services to meet those needs.

16.16 Research conducted in 2020 for the Department for Education suggested that these duties were providing an effective tool for identifying social care need in the local area. As part of that research, local authorities were asked about the effectiveness of their systems for collecting children's social care data. Of the 90 that responded, almost nine in ten said that their system for collecting data on children in their area "was either quite or very effective, with only 4% saying it was ineffective".[30]

16.17 However, the research question was not focused on disabled children specifically or on the particular duties we have identified under the Children and Families Act 2014. Our work in the lead-up to this consultation has led us to form the initial view that duties set out in the Children and Families Act 2014 are not operating effectively in relation to disabled children's social care. From local authorities we have heard that information about need in the local area is not always gathered in advance from assessment of the local population as whole. Rather, in some instances, it is gathered on an ongoing basis from interactions with families as and when they come into contact with social services. From parents and carers, we have heard concerns that in a number of areas there are insufficient services to meet the assessed needs of disabled children and their families. The most frequently voiced concerns from the parents and carers relate to a lack of appropriate short breaks provision, a lack of carers who can provide personal care in the home and a lack of residential placements.

16.18 In keeping with this, research conducted in 2022 with four local authorities in England based on 93 children with a child in need plan[31] noted that:

> Waiting lists and capacity for internally and externally provided services meant families were unable to access much needed support. This issue was highlighted by professionals in all four local authorities... It was noted that social workers often had to fill gaps in support while families were on waiting lists, although social worker capacity to undertake direct work was often limited. Some parents also referenced that they did not receive any support or that support received wasn't sufficient to resolve the issues it aimed to address. For example, one parent highlighted that support to manage a child with complex needs had not been sufficient, and that they

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[29] See para 16.11.

[30] C Smith and R Moore, *Children's Services Omnibus Wave 5 Research Report* (July 2020) p 31.

[31] Disabled children who receive social care from their local authority are one category of "child in need" who are entitled to a "child in need plan". See paras 11.4 to 11.6 for "child in need plan".

> would have found it helpful to have more respite, less cancellation, as well as support with transport to the respite that was in place.[32]

Furthermore:

> In the case file review for [one of the local authorities], we found that some families felt that there was a lack of suitable service provision for children with disabilities. In two cases, families reported that the support offered through direct payments was insufficient in meeting their child's needs. Sufficiency in services to meet the needs of children and young people with disabilities or complex needs was also highlighted by staff in one local authority (who stated it was a national issue) and by a parent in another local authority.[33]

16.19 This lack of sufficient local social care provision was part of the context to the abuse and neglect of disabled children that took place in the residential settings provided by the Hesley group in the Doncaster area between 2018 and 2021. The phase 1 report of the child safeguarding practice review panel constituted to investigate how and why this abuse was able to take place found that "placement far from home increased the children's vulnerability",[34] explaining that:

> Professionals contributing to the review reported major difficulties in securing long-term placements for children with complex needs and behaviour that challenges. The limited range of options available for families and professionals meant that in practice, a placement some considerable way from a child's home local authority was seen as the only viable option. The average distance from home for the 108 children placed at Hesley's children's residential settings in Doncaster was 95 miles. In phase 2 of the review we will examine ways to improve the operation of the placements market to ensure that children can access provision that meets their needs locally.[35]

16.20 The phase 2 report built on this, noting that:

> The analysis of the journeys into residential placement for a sample of children at Hesley Doncaster found that some children were placed inappropriately and could have had their needs met in their local community, enabling them to remain with their family. Multi-agency commissioning by the local authority, health and education partners in local areas had not been effective in ensuring that children with

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[32] What Works for Children's Social Care, *Understanding services provision for children in need in England* (May 2022) p 44.

[33] What Works for Children's Social Care, *Understanding services provision for children in need in England* (May 2022) p 46.

[34] The Child Safeguarding Practice Review Panel, *Safeguarding children with disabilities and complex health needs in residential settings – phase 1 report* (October 2022) para 1.16.

[35] The Child Safeguarding Practice Review Panel, *Safeguarding children with disabilities and complex health needs in residential settings – phase 1 report* (October 2022) para 1.16.

disabilities and complex health needs were able to access the right support at the right time.[36]

16.21 In the lead up to this consultation, to obtain a better understanding of the tools used by local authorities in England to identify the social care needs of disabled children in the local area, we distributed a survey through the Department for Education to children's services directorates. The results of the survey were limited and inconclusive: only six responses were received. However, accepting that this sample size is too small to draw wider conclusions, it was notable that only half of respondents had assessed the services required by disabled children in their area. Similarly, only half of respondents had assessed the needs of parents and carers in their area. At the very least, this suggests that compliance with the commissioning duties under the Children and Families Act 2014 may not be complete.

16.22 Drawing these threads together, our initial impression is that:[37]

(1) the supply of social care services for disabled children and their families is not always sufficient to meet the need for those services;

(2) the legal duties placed on local authorities to identify, and secure sufficient services to meet, the need for disabled children's social care services in the local area are themselves adequate; but

(3) the legal duties are not always complied with in full.

16.23 This suggests that changing the law may not be the solution. Rather, the solution may lie in monitoring the discharge of the legal duties more closely. That solution does not require legal change. The relevant regulatory body in this context is Ofsted. Ofsted has sufficient legal powers to consider the functions that we list at paragraphs 16.5 and 16.12 above. However, we invite consultees to provide their views and experiences on the various tools available to identify and secure sufficient services to meet needs, whether those tools are being used and, if so, whether they are effective. This will help us to evaluate whether our initial impression is correct, or whether legal change is in fact needed.

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[36] The Child Safeguarding Practice Review Panel, *Safeguarding children with disabilities and complex health needs in residential settings – phase 2 report* (April 2023) para 4.2.

[37] *R (L and P) v Warwickshire CC* [2015] EWHC 203 (Admin), (2015) 18 CCLR 458 provides an example of this: in that case the failure to maintain a register of disabled children prevented the authority from discharging its duty under the Children and Families Act 2014, s 27.

Consultation Question 56.

16.24 We invite local authority consultees to tell us the methods they use to:

(1) identify the nature and extent of social care provision required by disabled children in their area;

(2) ensure that sufficient services are made available to meet those needs; and

(3) keep the sufficiency of service provision under review.

Consultation Question 57.

16.25 We invite consultees' views on, and experiences of, the sufficiency of disabled children's social care provision in the local area.

OPTIONS FOR REFORM

16.26 In the light of our provisional conclusions above, we do not present any options for reform at this stage. This is a matter which we will keep under review during the consultation process.

Chapter 17: Co-operation and joint working

INTRODUCTION

17.1 Co-operation within and between local authorities and the NHS is important in the delivery of disabled children's social care. Meeting the needs of a disabled child may require their special educational needs, health needs and social care needs to be viewed holistically. For example, it may not be possible to meet a child's needs at school if their needs at home are not also met. The education, health and care plan (EHCP) is the statutory embodiment of this principle.[1] Moreover, the boundaries between special educational needs (SEND), health care, and social care are not always fixed or clear.[2] This means that co-operation is essential to ensure that needs are identified and met by the appropriate body. Nevertheless, in the lead-up to this consultation we have been told that the various departments and public bodies responsible for meeting the needs of disabled children do not always co-operate effectively together and can operate in separate silos. This chapter considers the legal framework that governs co-operation and joint working and seeks views on how it is that such problems arise and how we might deal with them.

THE CURRENT LAW

The Children Act 1989

17.2 Section 27 of the Children Act 1989 provides for co-operation between authorities. Under section 27(1), local authorities are entitled to ask for help from various public bodies in exercising their functions under Part 3 of the Children Act 1989. These functions include the powers and duties available to help disabled children. The public bodies who can be asked for help include:

(1) any local authority;

(2) any local housing authority;

(3) NHS England;

(4) any integrated care board; and

(5) any local authority in Wales.

17.3 Any public body which is asked for help under this power is required to "comply with the request if it is compatible with their own statutory or other duties and obligations and does not unduly prejudice the discharge of any of their functions".[3]

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[1] See paras 13.6 to 13.11.

[2] See chs 13 and 14.

[3] Children Act 1989, s 27(2).

17.4 Section 27 of the Children Act 1989 does not impose a duty of co-operation on other departments within a unitary authority.[4] For example, section 27 does not require the education department of a London or metropolitan borough council to co-operate with the social services department of the same authority. But such internal co-operation is required under the statutory guidance which provides that:

> Where requested to do so by local authority children's social care… other parts of the local authority, such as housing, have a duty to co-operate … by assisting the local authority in carrying out its children's social care functions, provided that this is compatible with their own duties and obligations and does not interfere with the performance of their own functions.[5]

17.5 The duty to co-operate under section 27 of the Children Act 1989 is not absolute. As noted above, a public body that is asked for help has latitude to refuse the request based on its own judgement of whether co-operating would be incompatible with its other obligations or unduly prejudice the discharge of its functions. Unsurprisingly, given the discretion that is built into section 27, the courts have signalled a reluctance to monitor and intervene in disputes about co-operation, remarking that:

> The two authorities must co-operate. Judicial review is not the way to obtain co-operation. The court cannot decide what form co-operation should take. Both forms of authority have difficult tasks which are of great importance and for which they may feel their resources are not wholly adequate. The authorities must together do the best they can.[6]

17.6 The courts have also expressed the view that a child or parent who has lost out as a result of a lack of co-operation is not able to bring a legal challenge based on that: the duty is owed as between authorities and not to the parent or child.[7]

The Children Act 2004

17.7 Section 10 of the Children Act 2004 imposes a further duty on local authorities to co-operate to improve the well-being of children. Specifically, local authorities are required to make arrangements to promote co-operation between:[8]

(1) themselves;

(2) other local authorities in the area;

(3) NHS England;

(4) integrated care boards for the area;

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[4] *R (M) v Islington London Borough Council* [2016] EWHC 332, [2016] HLR 19.

[5] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 139.

[6] *R v Northavon District Council ex p Smith* [1994] 2 AC 402, [1994] 3 WLR 403, 410 by Lord Templeman.

[7] *R (T, D and B) v Haringey London Borough Council* [2005] EWHC 2235 (Admin), (2006) 9 CCLR 58 at [97] by Ouseley J.

[8] Children Act 2004, s 10(1) and (4).

(5) schools in the area; and

(6) any other persons or bodies they think appropriate, who deal with children in the area (such as voluntary sector organisations), among others.

17.8 Local authorities are required to put these arrangements in place with a view to improving the well-being of children in the area in relation to:[9]

(1) physical and mental health and emotional well-being;

(2) protection from harm and neglect;

(3) education, training and recreation;

(4) the contribution made by them to society; and

(5) social and economic well-being.

17.9 The various partner organisations set out in paragraph 17.7 are required to co-operate with the authority in making these arrangements.[10] To that end, the local authority and its partner organisations can provide staff, goods, services, accommodation or other resources to each other or to other partners. They can also pay money into a fund out of which expenditure incurred by the authority, or its partners, can be reimbursed.[11] Some stakeholders have suggested to us that Early Help can be delivered using these powers: we are doubtful whether this can be correct, but discuss this point further at paragraphs 3.18 to 3.21.

17.10 The co-operation arrangements made under section 10 must include the establishment of a "children's trust board" for the area, comprising representatives from the local authority and all of its partner organisations.[12] One of the functions of the board used to be the preparation and publication of a "children and young people's plan" setting out its strategy for co-operation.[13] The regulations which required this were revoked in 2010 and have not been replaced.[14] However, some authorities still maintain a children and young people's plan on a voluntary basis.

17.11 The duty under section 10 of the Children Act 2004 complements the duty under section 27 of the Children Act 1989. The latter requires a degree of co-operation in relation to individual children or specific situations. The former requires general arrangements to be put in place to promote co-operation. Neither duty is limited to

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[9] Children Act 2004, s 10(2).

[10] Children Act 2004, s10(5).

[11] Children Act 2004, s 10(5A) and (11).

[12] Children Act 2004, s 12A(1)-(2).

[13] Children Act 2004, ss 12B(1) and 17.

[14] Children's Trust Board (Children and Young People's Plan) (England) Regulations 2010, SI No 591; Children's Trust Board (Children and Young People's Plan) (England) (Revocation) Regulations 2010, SI No 2129.

disabled children. Both apply to children in the area more broadly. But both can be used to facilitate co-operation in relation to disabled children.

The National Health Service Act 2006

17.12 Section 82(1) of the National Health Service Act 2006 requires NHS bodies and local authorities to cooperate with one another "in order to secure and advance the health and welfare of the people of England and Wales". This a broad duty which encompasses co-operation in relation to disabled children's social care. It has been described as a "macro or target" duty which does not necessarily "confer any right on an individual to sue for alleged breach" of the duty.[15] This signifies, again, that this is not an area where the courts will generally intervene.[16]

The Children and Families Act 2014

17.13 The Children and Families Act 2014 contains a number of further duties designed to promote co-operation in the context of SEND which intersect with disabled children's social care. These duties are listed below.

(1) Under section 25(1), local authorities, when exercising their functions relating to SEND, have a duty to promote the integration of education, health and social care provision, in order to improve the well-being of children or young people in the area who have special educational needs or a disability, or the quality of special educational needs provision.

(2) This duty is complemented by a further duty under section 26(1) which requires local authorities, NHS England and integrated care boards to make joint commissioning arrangements for education, health and care provision for disabled children in the area and children with special educational needs. The joint commissioning arrangements must include arrangements for agreeing the social care provision required by the disabilities of children in the area and for securing education, health and care needs assessments.[17]

(3) Under section 28(1), local authorities, NHS England, local integrated care boards and schools in the area (among others), must co-operate with each other in the exercise of the local authorities' special educational needs and disabilities functions.

(4) Under section 28(3), local authorities must make arrangements for ensuring co-operation between the officers of the authority who are responsible for education and training and those who are responsible for social care for children with special educational needs.

(5) Under section 31(1), local authorities are entitled to request co-operation from other local authorities, NHS England and integrated care boards (among

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[15] *R (JP) v NHS Croydon Clinical Commissioning Group* [2020] EWHC 1470 (Admin), (2020) 23 CCLR 535 at [51] by Mostyn J.

[16] See para 17.5 above.

[17] Children and Families Act 2014, s 26(3)-(4). See paras 13.6 to 13.9 for education, health and care needs assessments.

> others) in the exercise of their special educational needs and disabilities functions. The public body that has been asked to co-operate must comply, unless that would be incompatible with their duties or otherwise have an adverse effect on the exercise of their functions.[18] Requests for co-operation should be complied with within six weeks of receipt unless it is impractical to do so for certain specific reasons (for example, because the child to whom the request relates has been absent from the area).[19] A public body that decides not to comply with a co-operation request must provide written reasons for the decision.[20]

17.14 These duties are similar to the duties under the Children Act 1989 and Children Act 2004 in that they facilitate co-operation both in general and in specific cases. However, they are targeted more directly to disabled children's social care, in so far as it arises in the SEND context.[21] In addition, the duties go further, requiring written reasons for a refusal to co-operate and a timeframe for co-operation, and are more specific, dealing with particular subjects such as commissioning.

Working Together to Safeguard Children

17.15 In order to improve joint working between social care services and the SEND system, the statutory *Working Together* guidance encourages local authorities:

> to implement the role of Designated Social Care Officer (DSCO) in each local area. The DSCO will provide the capacity and expertise to improve the links between social care services and the SEND system. Similar to the Designated Clinical Officer (DCO) or Designated Medical Officer (DMO) role in health, the DSCO role will support both operational input (such as the contributions from care to education, health and care assessments) and more strategic planning functions (such as the commissioning of care services such as short breaks) for disabled children and those with SEN.[22]

17.16 The role of the designated social care officer for SEND (known as DSCO) has been developed in conjunction with the Council for Disabled Children.[23] The role is intended to address the variable practice and quality of social care input and engagement with the SEND system and the lack of joint working at a strategic level, among other things. As of March 2023, over 40 local authorities either had a designated social care

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[18] Children and Families Act 2014, s 31(2).

[19] Special Educational Needs and Disability Regulations 2014, SI No 1530 reg 8.

[20] Children and Families Act 2014, s 31(3).

[21] See ch 13 on the intersection between disabled children's social care and SEND.

[22] HM Government, *Working Together to Safeguard Children 2023* (December 2023), para 191. See further Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan: Right Support, Right Place, Right Time (2023) CP 800 ch 4, paras 75 to 76.

[23] Council for Disabled Children, *DSCO Handbook: Implementing the role of the Designated Social Care Officer (DSCO) for SEND* (August 2021). This guidance is not legally binding but represents good practice and advice.

officer in post or were actively recruiting for one[24] and we are told the number is now considerably higher.

THE CASE FOR REFORM

17.17 In the lead-up to this consultation we have been told that the main problems relating to co-operation and joint working are that:

(1) the different departments and public bodies involved in meeting the needs of disabled children have a tendency to operate in silos, and do not always talk to or co-operate with each other;

(2) children and families often have to tell their stories over and again, to different people; and

(3) social care input in the SEND context is often limited. In particular, the social care needs of a disabled child should be assessed as part of an education, health and care needs assessment to determine whether a child requires an EHCP.[25] But this does not always take place and we have been told that the relevant section of the EHCP will sometimes simply record that the child is not known to social care. We have also been told that, in the context of appeals to the SEND Tribunal, local authorities sometimes report that a child is unknown to social care.

OPTIONS FOR REFORM

17.18 In Chapter 3 we provisionally propose that there should be a statutory requirement to assess the social care needs of disabled children, and that this assessment should be combined with other assessments where appropriate. We think this would go some way to dealing with the second and third problems we identify above.

17.19 One option for reform has emerged during our discussions with stakeholders in the lead-up to this consultation. It relates to the designated social care officer and could help to deal with all three problems set out above. A number of stakeholders have told us that:

(1) joint working is easier when there is an individual based in the local authority who is responsible for promoting co-operation, both in general and in individual cases, and who is senior enough to make that happen; and

(2) the designated social care officer role can perform this function.

17.20 But there is a degree of variation across the country in the implementation of this role: it has been implemented in many, but not all local authorities. A potential reform option would be to place the role on a statutory footing, making it mandatory. This would achieve consistency across local authorities and could facilitate the effective

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[24] Community Care, *Government pushes ahead with rollout of SEND social work lead role* (March 2023) https://www.communitycare.co.uk/2023/03/02/government-pushes-ahead-with-rollout-of-send-social-work-lead-role/.

[25] Children and Families Act 2014, s 36(2). See ch 13.

performance of the legal duties we set out above. We seek consultees' views on this option.

Consultation Question 58.

17.21 We invite consultees' views on whether it should be mandatory for local authorities to have a designated social care officer.

17.22 Beyond this, we are not yet at a stage where it is possible to set out a full range of reform options. The problems we identify at paragraph 17.17 above constitute, or may be attributed to, a lack of co-operation. The reasons for this lack of co-operation are not immediately clear. The legal framework we have set out above is undoubtedly complex in that it involves a series of overlapping statutory provisions spread across several different statutes. But simplifying this complex framework – which does not just apply to disabled children – lies outside of the remit of this review. Moreover, this complexity does not appear to be the cause of the problem: all of the professionals we heard from in the lead up to this consultation, whether working in social care, education or health were all well aware of the need to co-operate and were making substantial efforts to do so. However, this is easier said than done and a number of these stakeholders expressed the view that co-operation (or the lack of it) is not a legal issue at all, but a cultural one which often comes down to the skills and resources available to individual social workers and managers. It might also be characterised as a financial or institutional issue reflecting budgetary constraints and arrangements. For example, a recent report commissioned by the Local Government Association and the County Councils Network noted the views of some health leaders that the lack of a "single, joint, place-based budget" spanning education, health and social care can give rise to disputes about who is responsible for meeting a child's needs.[26] We discuss this further at paragraph 14.34, in the context of the intersection between health and social care.

17.23 This is an area where we think that further information is needed before options for reform can be identified. As such, we seek consultees' views and experiences of co-operation (or the lack of it), and the factors that promote and undermine effective joint working.

Consultation Question 59.

17.24 We invite consultees to tell us about their experiences of co-operation and joint working in the social care context, or between social care, education and health.

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[26] Isos partnership, County Councils Network and Local Government Association, *Towards an effective and financially sustainable approach to SEND in England* (July 2024) p 74.

Consultation Question 60.

17.25 We invite consultees' views on the factors that help and hinder effective co-operation and joint working.

Chapter 18: Remedies

INTRODUCTION

18.1 No matter how good the system, there is always the potential for things to go wrong. It is important that there are effective remedies to deal with this situation. Sometimes the most important thing is for the problem in an individual case to be addressed. Sometimes the individual problem flags that there is a wider issue that needs to be resolved. Any system must include effective ways in which to respond to both situations, and must do so in a way which is accessible to those who are affected. In this chapter we examine the current law providing for remedies and set out our provisional proposals for reform.

18.2 As this chapter covers a wide range of remedies, we set out here a brief glossary of some of the terms that we use.

Judicial review	A challenge, brought in the Administrative Court, against the lawfulness of a decision taken by a public body. Judicial review challenges usually address the process by which a decision was reached, rather than the merits of the decision itself (see paragraphs 18.23 to 18.33 below).
Court of Appeal	Appeals from the High Court and Upper Tribunal (see below) are heard by the Court of Appeal.
Court of Protection	The court which has oversight over matters falling within the scope of the Mental Capacity Act 2005 (see paragraph 18.56 below).
High Court	The High Court of Justice is divided into three sections (“Divisions”). For present purposes, the most important are the King’s Bench Division (which includes the Administrative Court) and the Family Division.
Legal aid	Public money made available in certain types of cases to fund legal advice and, in more limited situations, legal representation.
Legal Aid Agency	The public body which administers the legal aid regime, including deciding whether a particular person is eligible for public funding.
Mental Health Tribunal	The common name for the First-tier Tribunal (Mental Health), which hears applications under the Mental Health Act 1983 (see paragraph 18.57 below).

Ombudsman	A person (supported by an office) who has the power to investigate complaints against companies, organisations or public bodies (see paragraphs 18.10 to 18.21 below).
SEND Tribunal	The common name for the First-tier Tribunal (Special Educational Needs and Disability). A statutory tribunal which can hear matters under the Children and Families Act 2014 (see paragraphs 18.34 to 18.52 below).
Supreme Court	Appeals from the Court of Appeal are heard by the Supreme Court.
Upper Tribunal	The appeal body (for almost all purposes) from the SEND Tribunal.

THE CURRENT LAW

Complaints

18.3 The intention of Parliament has always been that things which go wrong in this context should be resolved speedily, cheaply and informally, at a local level if possible.[1]

18.4 To that end, local authorities are under a statutory duty to have a procedure for complaints made in relation to the discharge of their functions under Part 3 of the Children Act 1989.[2] Complaints may be made by any child in need (which will include any disabled child), or by a parent or someone who has parental responsibility for a child in need. They can also be made by any other person that the local authority considers has sufficient interest in the child or young person's welfare, for example a kinship carer such as a grandparent. If a child wishes to make a complaint, local authorities are required to provide them with information about advocacy services and offer help to obtain an advocate.[3]

18.5 The social services complaints procedure has three distinct stages, escalating if the complaint cannot be resolved at the relevant stage. Stage one is internal or "local"; stage two should have one independent member involved; and stage three should be conducted by people independent of the local authority.[4] The procedure is administered by local authorities themselves, rather than by (for instance) His Majesty's Courts and Tribunals Service, as in the case of the SEND Tribunal. It is therefore not a structure entirely independent of the local authorities themselves. Each stage of the complaints procedure must be completed within specific timescales,

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[1] See, for instance, *R (S) v Hampshire County Council* [2009] EWHC 2537 (Admin) at [59] by Walker J.

[2] Children Act 1989 Representations Procedure (England) Regulations 2006, SI No 1738.

[3] Advocacy Services and Representations Procedure (Children)(Amendment) Regulations 2004, SI No 719, reg 4. See also ch 21 on advocacy.

[4] Children Act 1989 Representations Procedure (England) Regulations 2006, SI No 1738, pt 4.

although local authorities remain under a duty to act expeditiously throughout. The regulations are accompanied by statutory guidance, produced in 2006.[5]

18.6 Local authorities have wide powers to remedy their failings in individual cases where complaints are upheld. This could include, for example, reassessing the needs of the child. Local authorities also have the power to provide financial awards – for example, where there has been a quantifiable loss, a loss of a non-monetary benefit, loss of value, lost opportunity, distress, or time and trouble.[6]

18.7 Some complaints involving children's social care are not decided under the procedure set out in paragraphs 18.4 to 18.5 above. There is a degree of ambiguity as to which framework governs complaints relating to the operation of the Care Act 2014 in respect of children requiring ongoing care and support after the age of 18. It could be that it is the Children Act 1989 framework; alternatively, it could be that relating to the Care Act 2014 itself. The relevant statutory provisions and the statutory guidance accompanying the Care Act 2014[7] are both silent on this. The Care Act 2014 complaints framework is contained in the Local Authority Social Services and National Health Service Complaints (England) Regulations.[8] The same regulations also apply to NHS bodies dealing with complaints about the provision of healthcare services (including services for disabled children). By contrast to the position in relation to complaints regarding children's social care, these regulations do not set out any statutory stages or timescales, nor any requirement for an independent person.

18.8 There are also a number of different routes for complaints relating to education. We do not address these further here because the majority of those falling within our terms of reference will relate to children with special education needs whose position we discuss below.[9]

The Ombudsman

18.9 If a complaint is not resolved by the local authority complaints procedure, the complainant can ask for a further investigation by the Local Government and Social Care Ombudsman (the Ombudsman).[10] If a complaint is not resolved by an NHS complaints procedure, the complainant can ask for an investigation by the Parliamentary and Health Service Ombudsman.[11] The two bodies can also carry out

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[5] Department for Education and Skills, *Getting the best from complaints: social care complaints and representations from children, young people and others* (2006).

[6] Local Government Act 2000, s 92.

[7] The relevant paragraph, where one would expect to find the discussion, is Department of Health and Social Care, *Care and Support Statutory Guidance* (March 2024) para 3.55.

[8] SI 2009 No 309.

[9] They are discussed in more detail in S Broach and L Clements, *Disabled Children: A Legal Handbook* (3rd ed 2020) at paras 11.22 to 11.33.

[10] The Ombudsman's powers and duties are set out in the Local Government Act 1974.

[11] The Parliamentary and Health Service Ombudsman's role combines the role of two ombudsmen, the Parliamentary Ombudsman and the Health Service Ombudsman. The Parliamentary Ombudsman's powers derive from the Parliamentary Commissioner Act 1967. The majority of the Health Service Ombudsman's powers derive from the Health Service Commissioners Act 1993.

joint investigations, for example, where the complaint relates to concerns about the delivery of health provision within an education and health and care plan.

18.10 We focus in this section on the Local Government and Social Care Ombudsman because this is the Ombudsman who is most likely to investigate complaints falling within the scope of our terms of reference.

18.11 The remit of the Ombudsman is to investigate:[12]

(1) alleged or apparent maladministration in connection with the exercise of the local authority's administrative functions;

(2) alleged or apparent failure in a service which it was the authority's function to provide; and

(3) alleged or apparent failure to provide such a service.

18.12 In each case, the problem must have led to injustice.[13] "Maladministration" does not have a statutory definition. The Ombudsman website explains that:

> The term "maladministration" is deliberately not defined in law and similarly there is no explicit threshold for what constitutes maladministration. Our jurisdiction allows us to investigate alleged or apparent maladministration or service failure. Our investigations often touch on both, and we interpret maladministration to include service failure. As long as we present our findings clearly, we should not need to go into a detailed explanation of the differences. Case law (*R(ER) v Local Government Ombudsman* [2014] EWCA Civ 1407) has confirmed that we do not have to make separate findings for maladministration and service failure. In our decision statements, we refer to fault rather than maladministration or service failure as this is a simpler term for the public to understand.
>
> …
>
> There is no threshold for maladministration, and we should always identify where something has gone wrong in our reports and decision statements. Regardless of how serious the maladministration is, we should not consider it by itself. We must assess the effect the action had on the complainant (the injustice) and whether a remedy should be provided.
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> Maladministration in broad terms might include:
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> - flaws in policies or decision making
> - poor administrative practice
> - failure to adhere to or consider properly statutory guidelines

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[12] Local Government Act 1974, s 26(1).

[13] Local Government Act 1974, s 26A(1)(a).

- failing to consider properly the exceptional circumstances of an individual or a situation
- not properly considering statutory powers or duties
- failing to give an adequate service.[14]

18.13 The Ombudsman will generally expect the individual first to have exhausted the organisation's own complaints procedure. Before investigating a complaint, the Ombudsman must satisfy herself[15] that the complaint has been drawn to the attention of the local authority in question and the authority has been afforded a reasonable opportunity to investigate and reply to the complaint.[16]

18.14 The Ombudsman cannot consider a complaint where the person concerned has "a right of appeal, reference or review to or before" a tribunal.[17] The demarcation between the Ombudsman and the SEND Tribunal was recently considered by the Court of Appeal in *R (Milburn) v Local Government and Social Care Ombudsman*.[18] Although the case primarily concerned complaints about the local authority's conduct during the course of the appeal to the SEND Tribunal, Lord Justice Stuart-Smith also explained that it was necessary to construe the legislation with a view to ensuring that:

> the Ombudsman does not conduct an investigation which might trespass in any way on the jurisdiction of the tribunal. That is best achieved, in my judgment, by giving the words of section 26(6)(a) [of the Local Government Act 1974] their fullest reasonable meaning. As I have said, the words of section 26(6)(a) are deliberately broader than merely applying to the primary subject matter of an appeal by virtue of the words "reference or review" and the words "to or before" a tribunal. It seems to me that the most natural meaning to be given to section 26(6)(a) is that it excludes the jurisdiction of the Ombudsman when there may be an overlap and consequent risk of trespass between the issues that may be raised for determination in Tribunal proceedings, on the one hand, and that may be raised by the prospective investigation, on the other.[19]

18.15 Where legal proceedings have been started or (in some cases) where steps prior to the issue of formal proceedings such as sending a letter before claim have been taken, the Ombudsman will only consider a complaint about the same matters in exceptional circumstances.

18.16 In considering a complaint, the Ombudsman is not discharging the role of a judge or a tribunal. This means, for instance, that there will not be a hearing before an

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[14] Local Government and Social Care Ombudsman, *Staff Guidance on Jurisdiction* (May 2024) https://www.lgo.org.uk/information-centre/staff-guidance/guidance-on-jurisdiction?chapter=2.

[15] The current Local Government and Social Care Ombudsman is Amerdeep Somal.

[16] Local Government Act 1974, s 26.

[17] Local Government Act 1974, s 26(6)(a).

[18] *R (Milburn) v Local Government and Social Care Ombudsman* [2023] EWCA Civ 207, [2023] PTSR 1250. Permission to appeal the decision was refused by the Supreme Court in March 2024.

[19] *R (Milburn) v Local Government and Social Care Ombudsman* [2023] EWCA Civ 207, [2023] PTSR 1250 at [60].

investigator in the same way as there would be a hearing before a judge or a tribunal, with the opportunity for parties to cross-examine each other's witnesses and test their evidence. Nor will the Ombudsman resolve factual disputes in the same way as a judge. The Ombudsman does not decide what the law means or how it should be applied in the same way as a judge, and does not have the same authority as a judge to determine (as a matter of law) that the authority has applied legislation incorrectly to a particular situation. It should be noted in this regard that the Local Government and Social Care Ombudsman does not have the same powers as, for instance, the Pensions Ombudsman, who has the statutory power both: (1) to consider complaints or maladministration; and (2) to investigate and determine disputes "of fact or law" between certain categories of people.[20]

18.17 The Ombudsman can recommend that the public body:

(1) provides a service the disabled child should have had;

(2) makes a decision that it should have done before;

(3) reconsiders a decision that it did not take properly in the first place;

(4) improves its procedures so similar problems do not happen again; or

(5) makes a payment.

18.18 The recommendations of the Ombudsman are not binding in the same sense as a court order. However, it is very unusual for a public body not to follow them, and we are told that they are followed in the majority of cases. A failure to do so could be challenged by way of judicial review, focusing (usually) on the reasons why the decision was made (see further paragraphs 18.23 to 18.33 below).

18.19 The process is free to complainants and does not expose an individual to the risks of having to pay the costs of the local authority if the complaint is not upheld.

18.20 What is set out above relates to the position where an individual has complained about a problem that relates directly to them. Sometimes, the investigation of such a complaint will identify that others may have been affected who have not complained. The Ombudsman has the power to investigate matters where she considers that a member of the public has, or may have, suffered injustice.[21] A recent example of this is the report into South Gloucestershire Council. In consequence of information received in the course of a complaint about an individual case, the Ombudsman identified in 2023 that over 30% of the disabled children who had been assessed as needing support under section 17 of the Children Act 1989 were either not receiving their full package of agreed care or were not receiving any of the support they required.[22]

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[20] Pensions Schemes Act 1993, s 146.

[21] Local Government Act 1974, ss 24A(2) and 26D, introduced by the Local Government and Public Involvement in Health Act 2007.

[22] Local Government and Social Care Ombudsman, *Report into complaint against South Gloucestershire Council (23 005 373)* (October 2023) para 20.

18.21 However, in contrast to her equivalent in Wales,[23] the Ombudsman does not have the power to investigate potential maladministration or service failure in the absence of any complaint affecting an individual.

The Secretary of State's powers

18.22 Section 84 of the Children Act 1989 gives the Secretary of State the power to make an order declaring that any local authority has, without reasonable excuse, failed to comply with any function imposed on it under the Children Act 1989. Such a power can be used by the Secretary of State to compel compliance by a local authority where it is systemically failing to comply with its statutory duties.[24] However, the Court of Appeal has held that such a power is not to be viewed as a right of appeal or a more appropriate remedy than judicial review in relation to an individual case.[25]

Judicial review

18.23 A claimant may apply to the High Court for a review of the lawfulness of a decision, action or failure to act in relation to the exercise of a public function, including by local authorities and NHS bodies.[26] This can include a claim that the public body has breached section 6 of the Human Rights Act 1998, which makes it unlawful for a public authority to act contrary to a person's human rights.[27]

18.24 Judicial review is available in respect of decisions made under section 17 of the Children Act 1989 or section 2 of the Chronically Sick and Disabled Persons Act 1970. It is not available in relation to decisions falling within the scope of the SEND Tribunal's jurisdiction (as to which see further paragraphs 18.34 to 18.52. It is also unavailable if pursuing a complaints procedure would provide an alternative effective remedy.[28]

18.25 Complainants are usually individuals or organisations (such as voluntary bodies), but it is possible – if rare – for one public body to judicially review another. Any judicial review challenge must be brought promptly and, in any event, within three months after the grounds to make the claim first arose.[29] Most cases involving disabled children will be brought on their behalf by a "litigation friend" because the child will lack the capacity to conduct the proceedings.[30] There is a permission stage in judicial review proceedings: in other words, a judge will decide (in the first instance without a

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[23] See Public Services Ombudsman (Wales) Act 2019 (anaw 3), s 4.

[24] The High Court has recently contemplated the use of the power in such a way in relation to the housing of unaccompanied asylum-seeking children: *R (ECPAT (Every Child Protected Against Trafficking)) v Kent County Council* [2023] EWHC 1953 (Admin), [2024] PTSR 243 at [207] by Chamberlain J.

[25] *R (Sawyers) v Brent London Borough Council* [1994] 1 FLR 203 at 214 by Peter Gibson LJ.

[26] Civil Procedure Rules 1998, SI No 3132, r 54.1(2)(ii). A detailed guide to practice and procedure in judicial review proceedings is issued yearly by the Administrative Court (the relevant part of the High Court which hears such cases).

[27] The relevant rights are defined in s 1 of the Human Rights Act 1998. The Convention rights most relevant in the social care context are arts 2, 3, 5, 8 and 14 of the European Convention on Human Rights.

[28] *R (Cowl) v Plymouth CC* [2001] EWCA Civ 1935, [2002] 1 WLR 803 at [14] by Lord Woolf CJ.

[29] Civil Procedure Rules 1998, SI No 3132, r 54.5(1).

[30] Civil Procedure Rules 1998, SI No 3132, r 21.2. The child will either lack capacity because of their age or their cognitive impairments.

hearing) whether the claim is strong enough to proceed to a full hearing by applying the test of whether it is reasonably arguable.[31]

18.26 Legal aid is available to children, young people and their parents to advise and assist them in respect of judicial review applications in relation to most social care decisions. This is subject to the application by the Legal Aid Agency of both "means" and "merits" tests.[32] "Means" looks to the financial position of the applicant. "Merits" looks to the strength of the prospective claim. Legal aid can take one of two forms: "legal help", and "legal representation". As the names imply, legal help is essentially limited to advice and assistance outside court, whereas legal representation relates to steps up to and including representation in court. There are strict and complicated rules about the payment of legal aid, with payment depending upon the grant of permission by the court to proceed with a judicial review challenge.

18.27 Before bringing proceedings, a pre-action protocol requires the parties to consider a number of things, including whether a method of alternative dispute resolution would be both possible and more appropriate.[33] In 2023, the Court of Appeal held that it is lawful for the court to require parties to civil litigation to take part in alternative dispute resolution, so long as:

> it does not impair the very essence of the claimant's right to proceed to a judicial hearing, and is proportionate to achieving the legitimate aim of settling the dispute fairly, quickly and at reasonable cost.[34]

18.28 The alternative dispute resolution procedure in that case was the local council's internal complaints procedure in relation to planning and environmental matters. Given that there is a statutory complaints procedure in relation to children's social care (see paragraphs 18.4 to 18.8 above) it may be that this judgment is applied by analogy in judicial review proceedings. However, at the time of preparing this consultation paper no reported judicial review cases had been decided on this point.

18.29 The High Court can find that a decision is unlawful on the grounds that it is illegal, irrational or procedurally flawed. In such circumstances, the court has the discretion to order the decision-maker to act, or abstain from acting, in a specified manner or can quash a decision and remit the decision for reconsideration. The court may also make a declaration or grant an injunction preventing or compelling action by a public body. Even if a claimant establishes that the decision is unlawful, this does not mean that the court will necessarily do anything specific. If the court considers that it is highly likely that the outcome for the claimant would not have been substantially different if the conduct complained of had not occurred, then the High Court is barred by statute

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[31] Civil Procedure Rules 1998, SI No 3132, r 54.4.

[32] See the Legal Aid, Sentencing and Punishment of Offenders Act 2012.

[33] Pre-Action Protocol for Judicial Review, available at https://www.justice.gov.uk/courts/procedure-rules/civil/protocol/prot_jrv.

[34] *James Churchill v Merthyr Tydfil County Borough Council* [2023] EWCA Civ 1416, [2024] 1 WLR 3827 at [54] by Sir Geoffrey Vos MR.

from granting any form of remedy.[35] On occasion, the declaration of unlawfulness is considered by the court to be sufficient.

18.30 In many cases, the High Court will not go further than making a declaration and a quashing order; the expectation then being that the public body will act appropriately in light of the judgment, and make the decision again, this time lawfully.[36] The High Court will only very rarely specifically order a public body to act in a particular way such as by providing a service in a specific way.[37]

18.31 In 2022, the High Court was granted the power to suspend a quashing order until a specific date. It can make such a suspension subject to conditions.[38] Whilst there is still limited case law as to the application of this power, it has been used in one case to give the High Court a "continuing remedial role" to resolve an impasse between statutory bodies.[39]

18.32 If the High Court finds that the public body has breached the Human Rights Act 1998, it can grant such relief or remedy, or make such order within its powers as it considers just and appropriate.[40] This can include a financial award. The High Court does not otherwise have the power to make financial awards in applications for judicial review claims.[41]

18.33 The ordinary rule in the High Court is that "costs follow the event".[42] In other words, the successful party can expect to recover their costs from the unsuccessful one. However, in practice, an unsuccessful legally-aided claimant (and any litigation friend if they have one) will not generally have to pay the other side's costs where the correct legal aid certificate is in place.

Special educational needs[43]

18.34 The remedies set out above are generic, in the sense that they have not been created specifically to address the issues that might arise in the context of meeting and assessing the needs of disabled children. By contrast, a specific framework exists in respect of the assessing and meeting of special educational needs under the Children and Families Act 2014.

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[35] Senior Courts Act 1981, ss 31(2A) and (2B).

[36] *Craig v HM Advocate* [2022] UKSC 6, [2022] 1 WLR 1270 at [46] by Lord Reed.

[37] See *Gunter v South Western Staffordshire Primary Care Trust* (2006) 9 CCLR 121 at [19] by Collins J; see also for a broader discussion *R (Imam) v Croydon London Borough Council* [2023] UKSC 45, [2023] 3 WLR 1178 at [44] by Lord Sales.

[38] Senior Courts Acts 1981, s 29A(1) and (2), inserted by Judicial Review and Courts Act 2022, s 1.

[39] *R (ECPAT (Every Child Protected Against Trafficking)) v Kent County Council* [2023] EWHC 2199 (Admin), [2024] PTSR 243 at [53] by Chamberlain J.

[40] Human Rights Act 1998, s 8(1).

[41] It does not appear that the High Court has jurisdiction to hear a claim for damages for disability discrimination under the Equality Act 2010. There is no authority specifically on this point, but this was the effect of the decision of the Court of Appeal in *R v South Bank University ex p Coggeran* [2000] ICR 1342.

[42] Civil Procedure Rules 1998, SI No 3132, r 44.2.

[43] See ch 13.

18.35 The framework starts with independent dispute resolution procedures. Since 2014, local authorities must make arrangements with a view to avoiding or resolving disagreements with parents of disabled children in relation to education, health and care (EHC) needs assessments, the preparation and review of education, health and care plans (EHCPs), and re-assessments.[44] The process must be independent of the local authority. Its use is voluntary and must be with the agreement of all parties.

18.36 Parents and young people have a right to request mediation where a decision is made against which an appeal to the SEND Tribunal may be brought.[45] The right to mediation also extends to mediation in relation to the health and social care parts of the EHCP. There is also a requirement to "consider mediation" and obtain a mediation certificate from a mediation adviser before an appeal to the tribunal can be lodged.[46] The mediation adviser must be contacted within two months after written notice of the decision is received.[47] Mediation must be conducted by an independent person and the public body arranging it must ensure that it is attended by someone who has authority to resolve the issues in dispute.[48] It may be attended by any advocate or other supporter who the child's parent or the young person wishes to attend.[49] This can include legal representation although each party would have to pay for it themselves. The mediator must take reasonable steps to ascertain the wishes of the child or young person.[50]

18.37 If the mediation issues are limited to healthcare provision, the healthcare commissioning body must arrange the mediation and ensure it is conducted by an independent person, and must participate in the mediation.[51] If the mediation includes any educational and social care issues, then the local authority must arrange it within 30 days of being informed that the parent or young person wishes to pursue mediation.[52] The body responsible for arranging mediation must pay travel costs, loss of earnings, child care and any overnight expenses at a prescribed rate provided prior agreement is obtained where required and upon receipt of supporting evidence of the expenses claimed.[53] Where the mediation reaches an agreement, the outcome must be recorded in writing in a "mediation agreement".[54] Where the agreement requires the local authority or responsible commissioning body to do something, it must do that

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[44] Children and Families Act 2014, s 57.

[45] Children and Families Act 2014, s 52.

[46] Children and Families Act 2014, s 55(1)(3).

[47] The Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 33. If a parent fails to comply with this requirement, and the time for obtaining a mediation certificate has elapsed, leave to appeal to the tribunal may still be sought. See the Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 34 and Tribunal Procedure (First-tier Tribunal) (Health, Education and Social Care Chamber) Rules 2008, SI No 2699, r 19.

[48] The Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 37.

[49] The Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 38.

[50] The Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 40.

[51] The Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 35.

[52] The Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 36.

[53] The Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 41.

[54] The Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 42.

thing either within the timescales set out for complying with a tribunal order on the same issue, or, where that does not apply, within two weeks of the date of the mediation agreement.[55]

18.38 The Department for Education consulted in 2022 on a proposal to make SEND mediation mandatory.[56] Following that consultation, in its 2023 Special Educational Needs and Disabilities and Alternative Provision Improvement Plan, the Department indicated that:

> We will continue to explore options for strengthening mediation and will test and evaluate approaches further before deciding whether to bring forward legislation to make these strengthened processes statutory and make mediation mandatory. We will be more effective at using data on how mediation is carried out locally to inform intervention activity and will take action where local areas are not participating in mediation as required.[57]

18.39 Subject to the requirement to consider mediation as outlined above, the SEND Tribunal has the power to hear appeals against a decision:[58]

(1) not to secure an EHC needs assessment;

(2) that an EHCP is not necessary;

(3) about the content of specific parts of the plan, although not in relation to those parts concerned with meeting the child's "pure" social care needs;

(4) not to reassess a child's needs;

(5) not to amend or replace an EHCP following a reassessment; and

(6) to cease to maintain an EHCP.

18.40 An appeal can be brought by a parent in respect of a child who is still of compulsory school age.[59] Where the child is over compulsory school age,[60] the appeal can be brought by the child if they have capacity to do so or, if they lack the capacity to do so, by an "alternative person".[61] The alternative person will be either a representative, or

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[55] The Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 42.

[56] SEND Review: Right support, right place, right time: Government consultation on the SEND and alternative provision system in England (2022) CP 624 pp 34 to 35.

[57] Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan: Right Support, Right Place, Right Time (2023) CP 800 p 77.

[58] Children and Families Act, s 51.

[59] Children and Families Act, s 51(1).

[60] In other words, the end of the academic year in which they turn 16.

[61] Children and Families Act 2014, s 80; Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 64. See ch 21 for the concept of capacity. The legislation effects "a statutory substitution of the alternative person for the young person": *Hillingdon London Borough Council v WW* [2016] UKUT 253 (AAC), [2016] ELR 431 at [13] by Upper Tribunal Judge Jacobs.

where there is no representative, the young person's parent (or, if the parent also lacks capacity, a representative of the parent).[62]

18.41 In general, and by contrast to the position in relation to judicial review proceedings, the only form of legal aid available for SEND Tribunal cases is legal help, as opposed to representation. The exception to this is if the case falls within the Legal Aid Agency's "exceptional funding" criteria. The majority of parents do not receive legal aid and represent themselves at the Tribunal.

18.42 When determining the appeal, the SEND Tribunal's powers include ordering the local authority to do any of the following:[63]

(1) arrange an EHC needs assessment or re-assessment;

(2) make and maintain an EHCP plan or continue to make an EHCP; or

(3) maintain an EHCP plan with specified amendments in respect of the special educational needs and provision set out in the EHCP. The Tribunal does not have the power to make orders in relation to social care needs and provision.

18.43 The statutory power of the SEND Tribunal to direct a local authority to provide a specific service derives ultimately from reforms introduced in the 1990s. Prior to then, under the Education Act 1981, parents could appeal to a local appeal committee in respect of the content of statements of special educational needs, the predecessor to EHCPs. The committee's decision was not binding on the local educational authority but there was a further right of appeal to the Secretary of State, who could issue a binding decision including as to service provision.[64] It was increasingly recognised that there was a need for a judicial approach that could offer "a clear, timely and effective means of redress" for parents' grievances.[65] The Education Act 1993 established a new tribunal, the Special Educational Needs Tribunal, which inherited the Secretary of State's power (amongst other matters) to order a local authority to provide services. Such a power, as we set out further below, is unusual. However, the consequences of the decision to give the Tribunal the power to direct service provision do not appear initially to have been in the forefront of people's minds. This is perhaps because it was seen as building on a route which had led to the Secretary of State for Education, and it would not have been controversial for the Secretary of State to direct the allocation of public money.

18.44 However, the consequences of the decision taken in the 1990s as regards the powers of the then Special Educational Needs Tribunal have been significant. Whilst framed in different language, the modern SEND Tribunal has retained the same powers to

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[62] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 64(2).

[63] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 43.

[64] Education Act 1981, s 8(1) and (6). There was also a separate route of appeal under s 5 of the same Act to the Secretary of State against a failure to issue a statement of special educational needs; the Secretary of State had the power to require the local education authority to reconsider the decision.

[65] Department for Education, *Special Educational Needs: Access to the System – A Consultation Paper* (1992), para 20, quoted in N Jones and E Smith, "Resolving Disputes about Special Educational Needs and Provision in England" (2009) 10 *Education Law Journal* 113.

make orders about service provision. The statistics maintained by the Ministry of Justice do not tell us how often the SEND Tribunal makes such orders. However, it appears from the work that we have done leading up to this consultation that the SEND Tribunal regularly requires local authorities to provide services in a particular fashion. That differs from the approach of other judicial bodies. As set out above, the High Court in judicial review proceedings would only very rarely make a mandatory order directing such provision; none of the other judicial bodies we discuss at paragraphs 18.53 to 18.57 below have the power to do so. We return to the mismatch at paragraph 18.92 below.

18.45 Local authorities must comply with decisions of the Tribunal within specified time limits.[66] A failure to do so can (depending on the circumstances) be challenged by way of judicial review. In a recent judicial review, the High Court made clear that there is an "absolute and non-delegable" duty on the local authority to provide the EHCP as ordered by the Tribunal.[67] It also emphasised that "'speed must be of the essence'… given the critical impact of lack of educational provision on a child's wellbeing and future".[68]

18.46 Following a pilot, the Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations (the Recommendations Regulations)[69] came into force on 3 April 2018. They allow the SEND Tribunal to make non-binding recommendations in respect of certain health and social care matters within EHCPs and set down how the relevant public bodies are to respond. The Recommendation Regulations require the relevant public body to give reasons for any decision not to follow the recommendation, or any part of it.[70]

18.47 Non-statutory guidance issued by the Department of Health makes clear that:

> Although any recommendations made by the Tribunal on health and social care elements of an [EHCP] are non-binding and there is no requirement to follow them, they should not be ignored or rejected without careful consideration. Any reasons for not following them must be explained and set out in writing to the parent or young person. It is important to be aware that, should [a local authority] or responsible health commissioning body decide not to follow the recommendations of the

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[66] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 44. See also *East Sussex County Council v TW* [2016] UKUT 528 (AAC), [2017] PTSR 755 at [23].

[67] *R(L) v Hampshire County Council* [2024] EWHC 1928 (Admin) at [70], in which the High Court made a mandatory order requiring the EHCP as ordered by the Tribunal to be provided within five weeks.

[68] See *R(L) v Hampshire County Council* [2024] EWHC 1928 (Admin) at [59], quoting *H v East Sussex County Council* [2009] EWCA Civ 249, [2009] ELR 161 at [13] by Waller LJ.

[69] SI 2017 No 1306.

[70] Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations 2017, SI No 1306, reg 7(3)(c).

Tribunal, parents and young people can complain to the Ombudsmen[71] or seek to have the decision judicially reviewed.[72]

18.48 The case of *R (AT and BT) v London Borough of Barnet* shows what can happen when a local authority does not follow the Tribunal's recommendation.[73] In that case, a local authority not only failed to respond within the statutory time-frame but also then failed to provide sufficiently cogent reasons for departing from the recommendations of the SEND Tribunal.[74] The court quashed the local authority's response and required it to provide a response properly engaging with the Tribunal's recommendations. We note, however, that this result was only achieved following judicial review proceedings to challenge the local authority's failure to follow the recommendations of the SEND Tribunal. The Tribunal does not, itself, have any ability to impose a sanction for a failure to follow a recommendation; that is a matter which requires a person such as a parent or carer to be willing and able to take steps themselves.

18.49 In *VS and RS v Hampshire County Council v National Autistic Society*,[75] the Upper Tribunal clarified that the SEND Tribunal's function is not to determine provision under section 2 of the Chronically Sick and Disabled Persons Act 1970. Upper Tribunal Judge Ward also noted that the power to make recommendations in respect of social care provision is a "considerable difference" from the power to determine enforceable rights relating to educational provision.[76] Later in his judgment, he emphasised that the regulations expanding the powers of the SEND Tribunal on appeals:

> do not provide a single route of redress for all disputes there may be concerning the health and social care needs of, or provision for, a child or young person with special educational needs. Rather, they are a further attempt to mitigate some of the effects of those differing duties and governance arrangements by providing an opportunity to raise all the concerns about an [EHCP] in one place.[77]

18.50 It is therefore clear that, in terms of the SEND Tribunal's jurisdiction and powers, much turns for the child, their parents and carers on whether provision is special educational provision or "pure" social care provision (see further Chapter 13). To recap.

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[71] The reference is to Ombudsmen in the plural, because, depending on the nature of the complaint, it could lie to either the Local Government Ombudsman or the Parliamentary and Health Service Ombudsman. See para 18.9 above.

[72] Department for Education, *SEND Tribunal: extended appeals: Guidance for local authorities, health commissioners, parents and young people* (September 2021) p 12.

[73] *R (AT and BT) v London Borough of Barnet* [2019] EWHC 3404 (Admin), [2021] ELR 62.

[74] The requirement for sufficiently cogent reasons was read in by the High Court, rather than coming from the Regulations: see at [13] by Philip Mott QC sitting as a Deputy High Court Judge.

[75] *VS and RS v Hampshire County Council v National Autistic Society* [2021] UKUT 187 (AAC), [2022] 1 WLR 753.

[76] *VS and RS v Hampshire County Council v National Autistic Society* [2021] UKUT 187 (AAC), [2022] 1 WLR 753 at [35].

[77] *VS and RS v Hampshire County Council v National Autistic Society* [2021] UKUT 187 (AAC), [2022] 1 WLR 753 at [54].

(1) If the problem is "pure" social care provision, there is no right of appeal to the SEND Tribunal.

(2) Even if the SEND Tribunal is able to consider the social care provision problem as part of an existing appeal, it can only make recommendations, rather than order the local authority to provide services.

18.51 One point about which we heard differing views in the work leading up to this consultation was as to the SEND Tribunal's powers where the local authority has not carried out any assessment of the child's wider social care needs.[78] The problem arises as a result of the wording of the Children and Families Act 2014 and the Recommendations Regulations.[79]

(1) If the local authority has not carried out an EHC needs assessment, the Tribunal could order it to do so. It would appear that in so doing, the Tribunal can make clear that the EHC needs assessment should include a social care assessment so that it complies with section 36(2) of the Children and Families Act 2014.[80] However, if there has been an EHC assessment, but there has been no assessment of the child's social care needs, we have some doubts as to whether this falls within the scope of the matters that can be appealed under section 51 of the Act. That section is directed to where there has been no assessment (section 51(a)), or to the decisions based on that assessment. The problem in the scenario we have just described is that there has been an EHC needs assessment, but it is incomplete. On the face of it, this is not a matter catered for directly by the legislation.

(2) During the pilot which proceeded the coming into force of the extended appeals process described above at paragraph 18.46 it appears that at least some SEND Tribunal judges considered they could make a non-binding recommendation that the local authority carry out a social care assessment.[81] We understand that at least some Tribunal judges still make such recommendations. However, we have some doubts whether the Recommendations Regulations in fact provide for this to be done where no social care assessment at all has been carried out. The Recommendations Regulations provide for recommendations to be made as to the amending of the social care needs relating to the child's disability specified in the EHCP.[82] The

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[78] In other words, not those needs which are deemed to be social care needs giving rise to special educational needs. As set out above, it is clear that the SEND Tribunal has power to deal with a failure to carry out such an assessment.

[79] SI 2017 No 1306.

[80] Under s 36(2), an "EHC needs assessment" is an assessment of the educational, health care and social care needs of a child or young person.

[81] IFF Research and Belmana, *Evaluation of the national trial extension of Special Educational Needs and Disability (SEND) Tribunal powers* (July 2021) para 4.4.1. This noted the main categories of recommendations made under the pilot regulations, of which 33% included "assessments or referrals and subsequent delivery of any provision identified". "Social care assessments" were noted as being amongst the most common.

[82] Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations 2017, SI No 1306, reg 4(2)(b), read together with Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 12(1)(d).

> Recommendations Regulations clearly provide for the situation where the local authority has considered the child's social care needs, but has not done so in a way which satisfies the Tribunal. However, they do not so obviously provide for the situation where the local authority has simply not considered the child's needs at all. In *MM v Royal Borough of Greenwich*, Upper Tribunal Judge Stout expressed the view that the Tribunal had no power to order or recommend that such an assessment be carried out (although she considered that the Tribunal could make such orders as part of its case management powers).[83]

18.52 The usual order for costs in a tribunal is that each party meets their own costs. There are exceptions to this where a party or its representative has acted unreasonably in bringing, defending or conducting the proceedings.[84]

Other courts

18.53 For completeness, there are four other situations in which a judicial body regularly becomes involved with disabled children. In all of them, the need for such involvement may represent the consequence of an earlier failure properly to assess and meet the needs of the child. To that extent, therefore, they can be seen (albeit indirectly) as a "remedy".

18.54 The first situation is where an application is brought to the Family Court by a local authority under either Part 4 or Part 5 of the Children Act 1989. Part 4 provides for care orders. Part 5 provides for child assessment and emergency protection orders. On such an application, the Family Court does not have the power to direct service provision by the local authority, for instance by way of requiring it to put in place services which might alleviate the need for the child to be taken into care.[85]

18.55 The second situation is where an application is brought to the High Court to authorise the deprivation of liberty of a child. This could either be under section 25 of the Children Act 1989 to authorise placement in secure accommodation, or by way of an application under the inherent jurisdiction. The High Court does not have the power to direct service provision on the part of the public body. It can, as a last resort, refuse to authorise the deprivation of liberty, which may prompt action on the part of the public body to identify an alternative solution.[86]

18.56 The third situation is where an application is brought to the Court of Protection to authorise the deprivation of liberty of a 16- or 17-year-old who lacks the mental capacity to consent to their confinement. As with the High Court, the Court of Protection cannot direct service provision on the part of any public body. Our work leading up to this consultation has, however, made clear to us that in some cases being before the Court of Protection can unlock service provision. This is particularly

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[83] *MM v Royal Borough of Greenwich* [2024] UKUT 179 (AAC) at [108(f)].

[84] Tribunal Procedure (First-tier Tribunal) (Health, Education and Social Care Chamber) Rules 2008, SI No 2699, reg 10.

[85] See by analogy *Holmes-Moorhouse v Richmond upon Thames London Borough Council* [2009] UKHL 7, [2009] PTSR 698 at [30] by Lord Neuberger.

[86] See the two judgments of Poole J (exercising the inherent jurisdiction of the High Court) in *Nottinghamshire County Council v LH, PT and LT* [2021] EWHC 2584 (Fam) and *Nottinghamshire v LH, PT and LT (No. 2)* [2021] EWHC 2593 (Fam).

so in situations where there has been an impasse between different public bodies (or, sometimes, different parts of the same public body) as to how to assess or meet the needs of the child. By bringing the relevant public bodies together and requiring them to explain their reasoning, our impression is that the Court of Protection can exert considerable "soft power" to move matters forward.

18.57 The fourth situation is where a child has been detained under the Mental Health Act 1983 and the situation has come before the Mental Health Tribunal. This could have been because a failure to meet the child's social care needs in a timely fashion has led to a deterioration in their mental health and the need for admission.[87] The situation could then come before the Mental Health Tribunal in a number of ways, including where the child has the competence to bring their own application.[88] Depending on the circumstances, one of the child's parents could also have brought the application as the child's nearest relative. The Mental Health Tribunal is required to consider whether the relevant criteria for admission are still met.[89] It does not have the power to direct the provision of services in the community, even where such have been identified as necessary to enable the person to be discharged.

A possible further appeal structure

18.58 The Care Act 2014 included a provision to introduce a new system to allow appeals against certain adult social care decisions made by local authorities.[90] This followed the Law Commission's recommendation that the Government consider further the area of redress and, in particular, the need for a "community care tribunal".[91] Having carried out consultation, the Government initially decided in 2016 to implement an independent review structure. The consultation paper published in 2015 prior to this decision made clear that this was not intended to be a formal judicial process, but rather a (centrally funded) system of appointment by local authorities of an independent reviewer able to make recommendations.[92] In 2021, the previous Government confirmed that it did not intend to introduce such a system immediately, albeit that it was keeping the position under ongoing review.[93]

THE CASE FOR REFORM

Introduction

18.59 It can be seen from the review of the current law above that in any given situation, there may well be more than one route to bring a complaint or a challenge. Each route will have its own timelines, and each may produce a different result. We illustrate this

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[87] See further ch 14.

[88] As to competence, see ch 6.

[89] Mental Health Act 1983, s 72.

[90] Care Act 2014, s 72.

[91] Adult Social Care (2011) Law Com No 326 para 12.38.

[92] Department of Health, *The Care Act 2014 Consultation on draft regulations and guidance to implement the cap on care costs and policy proposals for a new appeals system for care and support* (2015) para 15.13.

[93] People at the Heart of Care: Adult Social Care Reform White Paper (2021) CP 560 para 5.18. A judicial review challenging the lawfulness of the decision not to implement the system was dismissed in 2023: *R (HL) v Secretary of State for Health and Social Care* [2023] EWHC 866 (Admin), (2023) CCLR 237.

in the table below, using as an example the situation where the parents or carers of a disabled child consider that the local authority has not properly assessed the child's social care needs.[94]

Route	Time frame	Outcome if complaint or challenge upheld
Local authority statutory complaints procedure	Stage one (local resolution). Response required 10 working days from receipt of the complaint, with 10 further working days in more complex complaints. Stage two (formal investigation by an independent person). A report must be sent to the complainant within 25 working days. If the report will take longer, social services must let the complainant know of the delay and explain why. The extension can be for a maximum of 65 working days. In such a case, 100 working days will have passed since the start of stage one (assuming that the complainant starts the stage two process immediately). Stage three (consideration by a review panel). The complainant must request a review panel within 20 working days of the stage two response. The panel must meet within 30 working days of the request being made and must then issue its report within five working days. The local authority must then write to the person making the complaint to give them a final response within 15 working days of receiving the panel's report. Assuming that the complainant requests a review panel immediately upon receipt of the stage two response, 145 working days (29 weeks, or over six	The complaint process results in a recommendation that the local authority reassess the child's needs. The local authority could also provide financial redress.

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[94] The statutory provisions containing the time frames are set out in the relevant sections above.

	months) will have passed since the start of the process.	
Complaint to Local Government and Social Care Ombudsman	Note: this cannot usually be used as a route unless the local authority's own complaints procedure has been completed first. The Ombudsman does not have a statutory time frame for the completion of investigations. Its website provides that the office seeks to take a first look at a complaint within one day.[95] If the complaint is "ready" for the office, it will be allocated to an investigator who will decide within four weeks whether the office will investigate it in detail.	If the complaint is upheld, the Ombudsman could recommend that the local authority reconsiders its decision. It could also recommend that the local authority provides a specific service that the disabled child should have had. It could also recommend a payment be made to reflect the impact of the maladministration.
Judicial review	The challenge has to be brought promptly, and in any event within three months of the decision in question. There is no statutory timeframe for the determination of the proceedings. There is a specific procedure for considering urgent cases, which can only be used where there is a "genuine need for the application to be considered urgently".[96]	The High Court can quash the decision of the local authority, order it to be retaken or, in exceptional circumstances, direct that it makes the decision in a specific way.

18.60 The mere fact that there are different routes does not necessarily require law reform. Each route may be serving a different purpose. However, it is clear from what we have heard in the lead up to this consultation that trying to identify which route to follow, and how to follow it, can be stressful and time-consuming for children, parents and carers. We have heard how this can be particularly so given that they are trying to navigate the system at a time when something either has or appears to have gone wrong. In some cases, parents and carers have told us, this has led to:

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[95] https://www.lgo.org.uk/make-a-complaint/how-we-deal-with-your-complaint.

[96] The Administrative Court Judicial Review Guide 2024 (October 2024) para 17.2.1.

(1) the Ombudsman declining to consider complaints as they are out of time, or the internal complaints mechanisms have not been used; or

(2) parents being unable to bring judicial review claims as they are out of time.

18.61 The work that we have done in the lead up to this consultation also highlighted to us that there is often a mismatch between what parents and carers think or expect that a particular procedure may achieve, and what it can actually do. This is particularly so when parents discover that the SEND Tribunal cannot deal with all of the problems the parents wish to raise. This is not necessarily a problem with the law, but it is undoubtedly a problem with how the law is explained to people.

Problems with the different routes of complaint and challenge

18.62 Each of the routes set out above has problems or difficulties associated with them.

18.63 A number of persistent problems with the operation of local authority children's social care complaints procedures have been identified by the Ombudsman. These include failing to recognise that a complaint is, in fact, a statutory complaint; taking unnecessarily long to resolve complaints; and refusing to complete all stages of the procedure. The Ombudsman identifies a specific problem with local authorities either delaying or refusing to complete all stages of the procedure either because of a lack of resources or because the local authority does not think that there is merit to the complaint.[97]

18.64 Whilst the Ombudsman has the power to make recommendations, she cannot direct that a local authority provide services in a particular way. We have also heard in the lead up to this consultation from those who feel that the process can be slow, which is exacerbated (in particular) for those who are autistic by a lack of clearly defined timescales. We have also heard from parents and carers that the fact that an upheld complaint so often results in sending the matter back to the local authority does not actually give them what they wanted, giving rise to the perception that the remedy is inadequate.

18.65 As observed in our scoping paper on adult social care, judicial review has limitations as a remedy for many social care disputes of a factual nature.[98] In significant part this is because it is simply not designed to resolve such disputes, and in the vast majority of cases proceeds on the basis that the facts as established by the initial decision-maker are correct. As Mr Justice Collins identified almost 20 years ago in *Gunter v South Western Staffordshire Primary Care Trust*, judicial review is an "unsatisfactory means" of dealing with cases where there are judgements to be made and factual issues in dispute:

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[97] Local Government and Social Care Ombudsman, *Children's statutory complaints process: Guide for Practitioners* (November 2023) pp 1 and 9.

[98] Law Commission, Adult Social Care: Scoping Report (2008) para 4.344.

> At best, it can identify failures to have regard to material considerations and a need for a reconsideration. Very rarely if ever will it result in mandatory orders to the body which has the responsibility to reach the relevant decision.[99]

18.66 Further, for many, judicial review is not an accessible remedy for the two reasons set out below.

(1) Where legal aid is available, the operation of the means test frequently means that even those of relatively modest means are not eligible. It can also be complicated and difficult to resolve whether it is the child's means or those of their parents which are relevant.[100]

(2) Even where the child, parent or carer is eligible for legal aid, it may not be possible to find a legal aid solicitor who is able to assist. The Law Society of England and Wales has identified that 71% of people in 2024 do not have access to a local legal aid provider with the relevant community care contract.[101] There is also an overlap between areas with high rates of disability and low numbers of legal aid solicitors. The North-East, for instance, has the highest rate of disability in England,[102] but some of the lowest numbers of solicitors providing legally-aided community care assistance.

18.67 It is of note that there have only been two reported decisions squarely addressing challenges to assessment or meeting of the needs of individual disabled children in the past five years.[103] This is by comparison with the SEND Tribunal where, in the same period, the number of decided cases has risen from 2,614[104] (in the academic year September 2018-August 2019) to 7,968[105] (in the academic year September 2022 – August 2023). We consider it unlikely that the very low relative number of reported judicial review decisions as compared to SEND decisions reflects the relative level of discontent as regards the discharge by local authority functions under their social care and special educational needs functions. It is more likely, in our view, that

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[99] *Gunter v South Western Staffordshire Primary Care Trust* [2005] EWHC 1894 (Admin), 86 BMLR 60 at [19] by Collins J.

[100] Coram Children's Legal Centre, *Response to the Ministry of Justice Review of Civil Legal Aid* (February 2024) at pp 13 and 14.

[101] The Law Society, *Community care – legal aid deserts* (February 2024) https://www.lawsociety.org.uk/campaigns/civil-justice/legal-aid-deserts/community-care.

[102] Office for National Statistics*, Disability by age, sex and deprivation, England and Wales: Census 2021* (February 2023).

[103] *R (TS) v The London Borough of Hackney* [2023] EWHC 3063 (Admin), (2024) CCLR 117 (a challenge to the lawfulness of assessment under ss 17 and 20 of the Children Act 1989); and *R (LB) v Surrey County Council* [2022] EWHC 772 (Admin), (2022) CCLR 381 (a challenge to a failure to keep provision under Children Act 1989, s 17 under review). There have been other judicial reviews reported relating to such matters as the closure of specific services, but these fall into a different category for purposes of the comparison being drawn here.

[104] Out of 7,002 registered appeals. The annual statistics do not break down which out of the registered appeals are withdrawn on the basis of concessions by the local authority agreed by the appellant young person/parent: Tribunal Statistics Quarterly: July to September 2023 (December 2023).

[105] Out of 13,658 registered appeals. See above.

it represents the relative accessibility of the SEND Tribunal as opposed to judicial review.

18.68 The SEND Tribunal has significant powers in respect of those matters within its jurisdiction, including in some cases to require a specific educational service to be provided. That having been said, some stakeholders have expressed the view that this power is ineffective in some circumstances. Coram Children's Legal Centre has noted that they are seeing an increase in the failure of local authorities to implement EHCPs even after successful appeals, but there are insufficient numbers of solicitors to represent families in judicial review proceedings.[106]

18.69 The SEND Tribunal has considerable "soft power" as regards wider social and health care matters, but it can only deploy this alongside consideration of an appeal relating in some way to special educational needs. Further, whilst the intention of Parliament was that the SEND Tribunal would be an accessible, low-cost forum, some stakeholders have expressed the view that this has not been the case. Parents may incur direct costs in obtaining expert reports or (in some cases) legal representation and indirect costs by having to spend time on preparation.[107] The stress for parents, as well as the cost, of going through the Tribunal process was specifically highlighted by the House of Commons Education Committee in its 2019 inquiry into special educational needs and disabilities.[108]

18.70 In cases where public authorities are seeking judicial authorisation to deprive a child of their liberty, the judge can undertake a process of "negotiation" with the public authority to tease out whether an alternative is available. That negotiation can be robust.[109] But ultimately the court cannot direct service provision. It is also difficult to escape the impression that there is a degree of arbitrariness as to the cases which end up before the courts in this way. It depends both on the public authority recognising that the situation gives rise to a deprivation of liberty, and that it needs to take steps to obtain authorisation. As we set out in the research paper on deprivation of liberty, which is available on our website,[110] these matters are not always recognised or understood.

18.71 Finally, the inability of the Mental Health Tribunal to direct service provision to "unblock" situations where a person is stuck in hospital because of a lack of community provision was identified as a problem by the independent review of the Mental Health Act 1983. The review recommended that the Tribunal be given a power

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[106] Coram Children's Legal Centre, *Response to the Ministry of Justice Review of Civil Legal Aid* (February 2024) p 10.

[107] J Jemal and A Kenley, *Wasting money, wasting potential: the cost of SEND Tribunals* (September 2023).

[108] Special Educational Needs and Disabilities, Report of the House of Commons Education Committee (2019) HC 20.

[109] For examples, see the two judgments of Poole J in *Nottinghamshire County Council v LH, PT and LT* [2021] EWHC 2584 (Fam) and *Nottinghamshire v LH, PT and LT (No. 2)* [2021] EWHC 2593 (Fam).

[110] https://lawcom.gov.uk/project/disabled-childrens-social-care/.

to direct such provision.[111] The draft Mental Health Bill published in response did not contain such a power.[112]

The mismatch in remedies

18.72 One of the most significant problems that we have encountered in our consideration of the law in this area is the mismatch between the remedies available under the Children and Families Act 2014 compared to those under the Children Act 1989. To recap, in relation to the former, the SEND Tribunal can look at whether a local authority has made the right decision, and, if it considers it has not, require the local authority to take steps including directing the local authority to provide specific services. In relation to the latter, the High Court can be asked to consider the lawfulness of the decision-making process, but will only direct a local authority to act in a specific way in exceptional circumstances.

18.73 Where a child is both a child in need for the purposes of section 17 of the Children Act 1989 and a child with special educational needs, the child is being considered by one local authority, and indeed one directorate (children's services) of that local authority. Further, the child has one EHCP, maintained by that local authority, with one goal, which is to meet their education, health and care needs. The point of the EHCP system is to view the child's needs holistically and recognise that meeting their social care needs is as important as meeting their special educational needs. Meeting social care needs is important in its own right. It also maximises the chances that the child's educational needs are met. It is therefore arguable that the lack of parity in the remedies available frustrates the policy goal of the EHCP system. It might also be thought to give rise to arbitrariness, given that in many situations the same service (for instance, accommodation) could be seen as either provision for special educational needs or social care.[113]

18.74 The extension of the SEND Tribunal's powers to make recommendations about social care and health care can undoubtedly help some children by the exercise of "soft power". But it cannot help those disabled children who cannot obtain the social care services they need and who cannot access the SEND Tribunal. This might be because they do not need an EHCP. Or it might be that because, while they have an EHCP and are content with the special educational provision within it; their concern is as to the social care provision. We have also heard how in some cases the fact that the SEND Tribunal cannot consider standalone challenges in relation to social care creates a perverse incentive for appeals to be maintained longer than they "should". This arises where the real problem is the wider social care provision, but where there is an incentive to maintain the appeal as regards the educational provision so as to be able to access the Tribunal's recommendation-making power.

18.75 The consequence of the matters set out above is that it is not always predictable whether a child, their parent or carer is able to obtain an effective remedy as regards social care provision.

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[111] *Final Report of the Independent Review of the Mental Health Act 1983* (December 2018) p 123.

[112] Draft Mental Health Bill (2022) CP 699.

[113] For a recent example, see *R (LS) v London Borough of Merton* [2024] EWHC 584 (Admin).

OPTIONS FOR REFORM

18.76 Many of the problems set out above are general ones which affect anyone who is unhappy with the service they have received from their local authority, or from public bodies more generally. However, our terms of reference are limited to considering social care for disabled children. The options below are focused on this cohort.

18.77 In terms of making local authority complaints procedures better for disabled children, we are conscious that there are limits to what we can propose given our terms of reference. One option could be the introduction of the equivalent of an internal review process under the Housing Act 1996. This allows a person who is unhappy with a decision to have it looked at afresh by a more senior review officer. The review officer will not have been involved in the initial decision and has the power to remake the decision if they agree that it was wrong.[114] An equivalent process could be created for disabled children's social care law: a right of review to a "disability review officer". However, we are conscious that setting up such a procedure could give rise to complicated overlaps with the statutory complaints procedure for wider children's social care matters.

18.78 More fundamentally, we do not consider that we yet have the data in order to allow us to identify whether the problems with complaints procedures we have identified in preparatory work are legal ones or practical ones. We therefore want to explore this issue further with consultees.

Consultation Question 61.

18.79 We invite consultees' views of the statutory complaints procedure (either through making or handling a complaint).

18.80 In terms of the Ombudsman, it seems to us that the problems that have been raised with us in the period leading to this consultation are not necessarily problems with the law as opposed to its application, or the expectations that people have of it.

18.81 We note that there have previously been recommendations that the relevant Ombudsman bodies be given power to launch investigations on their own initiative.[115] We can see the force in this as a tool to remedy systemic problems. We do not make a specific provisional proposal in this regard because we consider that to do so would be to go considerably beyond the terms of reference of our project.[116] Moreover, the Ombudsman appears to be making effective use of her power to conduct wider

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[114] Housing Act 1996, ss 202 and 203; Homelessness (Review Procedure etc) Regulations 2018, SI No 223.

[115] Most recently in P Tyndall, C Mitchell and C Gill, *Value for Money Study Report of the independent peer review of the Parliamentary and Health Service Ombudsman* (2018) at pp 10 to 11, noting that 71.4% of respondents to a survey by the International Ombudsman Institute had "own initiative" powers of investigation.

[116] In 2011 we recommended that the Government establish a wide-ranging review of the public services ombudsmen's role within the administrative justice system. See Public Services Ombudsmen (2010) Law Com No 329 p 17.

investigations where she has received a complaint shedding light on a potential systemic problem. An “own initiative” power would always have to be used based upon information received. That information could come from press reports or from cases determined before the courts, but in very many cases we anticipate that the information would be coming as a result of a complaint. In practice, therefore, changing the law might not substantially change the current position, so long as the Ombudsman is and remains appropriately alert to the potential that an individual complaint might reveal a wider issue.

18.82 One option we have considered is to recommend that the Ombudsman be given the express power to determine disputes of fact or law. This would have the effect of giving Ombudsman decisions binding effect in the same way as the relevant decisions of the Pensions Ombudsman. We have not pursued this further, because our provisional view is that this would be to go significantly beyond our terms of reference.

18.83 However, so that we can make sure that we have the fullest possible picture of the role of the Ombudsman, we want to hear consultees’ experiences.

Consultation Question 62.

18.84 We invite consultees to tell us about experiences of complaints to the Local Government and Social Care Ombudsman. Do consultees consider that the current system enables timely and appropriate resolution of such complaints?

18.85 If a “community care tribunal” is ever introduced in the adult social care field under the Care Act 2014, then it could potentially hear cases involving “pure” social care for disabled children. However, such a tribunal does not appear to be on the horizon at present. Giving it a jurisdiction over children would also give rise to some difficult questions as to how the jurisdiction of such a tribunal would interact with that of the SEND Tribunal. We do not therefore consider such a tribunal further at this stage. But it would be important, for the sake of parity, to consider this option if a community care tribunal were to be introduced.

18.86 We are limited by our terms of reference as to any proposals that we can make in respect of judicial review. It would not be practical to suggest changes to the substantive or procedural rules relating to judicial review, a route of challenge which is of general application, which relate only to disabled children. We are also conscious that judicial review more broadly has been considered recently by an independent review, and that review resulted in legislation.[117] Legal aid matters are also outside the scope of our terms of reference, although we emphasise the point we make at paragraph 18.86 above as to the difficulties that are caused where children, parents and their families are unable to access specialist assistance.

18.87 Further, even if we could make proposals in respect of judicial review so as to make it more accessible, they would not address the issue of the mismatch in remedies that

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[117] Independent Review of Administrative Law (2021) CP 407, responded to in the Judicial Review and Courts Act 2022.

we have identified at paragraphs 18.72 to 18.75 above. What disabled children, their parents and carers require where a local authority has not complied with its legal obligations to assess and meet their needs is, as a last resort, access to a judicial body which can take effective steps to remedy the situation. In principle, the SEND Tribunal is able to do so in relation to the assessment and meeting of special educational care needs. We consider that there may be a case for giving the SEND Tribunal, whose jurisdiction already includes aspects of disabled children's social care, the equivalent powers in respect of the social care needs of disabled children. We develop this further in the next section.

18.88 Finally, we have been struck by the power given to the Equality and Human Rights Commission to enable it to bring legal proceedings where they are "relevant to a matter in connection with which the Commission has a function".[118] This is a power that the Commission can use in respect of an individual situation, or in relation to a systemic problem. In the course of the debates leading to the passage of the Children and Families Act 2014, the previous Government's position was that the Children's Commissioner for England implicitly had such a power.[119] An attempt to make such a power express was resisted by the Government on the basis that it:

> would raise expectations that the commissioner will take up legal challenges on behalf of any individual or group who brings a matter to the commissioner's attention. The Office of the Children's Commissioner is clearly not resourced to operate in that way, and it could end up wasting time defending decisions not to take up particular cases.[120]

18.89 We recognise the resourcing issue, and that the Children's Commissioner has multiple other commitments. We also recognise that, even if we could make a provisional proposal, we could only do so in relation to her powers in relation to disabled children. This would give rise to an inconsistency in respect of her (express) powers in relation to other children in need. However, we do think that there may be circumstances where the rights of disabled children in a particular area are being adversely affected by a local authority's actions or inactions and no other person is able to assist. An example of such a situation would be where a local authority has failed to commission adequate services. At that point, given her statutory function to protect and promote the rights of children in England,[121] the Children's Commissioner could colloquially be described as the last line of defence for such children. Making her powers to intervene express would make this clear. We seek consultees' views on this.

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[118] Equality Act 2006, s 30.

[119] *Hansard* (HL), 29 January 2014, vol 751, col 1334.

[120] *Hansard* (HL), 29 January 2014, vol 751, col 1335.

[121] Children Act 2004, s 2(1).

Consultation Question 63.

18.90 We invite consultees' views on whether the Children's Commissioner should be given an express power to initiate legal proceedings in respect of the social care needs of disabled children.

OUR PROVISIONAL PROPOSALS

18.91 We want to know more about how complaints procedures are currently working, and we see that there is an important place for them in resolving issues as informally and (ideally) quickly and cheaply as possible.

18.92 However, we do not consider that we can properly leave matters at that. Our terms of reference expressly require us to consider the alignment of the law relating to social care for disabled children with other parts of the statute book concerning social care, support for special educational needs and children's rights more generally. We cannot therefore ignore the significant mismatch in the remedies available as regards "pure" social care and social care linked to special educational needs provision. In this regard, it is important to be clear that there is a distinction in this context between bodies empowered to make recommendations and bodies empowered to make binding decisions. At present, the only body empowered to make binding decisions as regards "pure" social care is the High Court, using powers that are rarely exercised. Conversely, the SEND Tribunal is empowered to make binding decisions about social care linked to special educational needs provision, and regularly does so. There is, therefore, a mismatch in remedies which appears to us to have a real impact on the rights of disabled children.

18.93 Parliament could empower the Ombudsman to make binding determinations as to the discharge of local authority functions in relation to disabled children, but our provisional view is that it lies beyond our terms of reference to make such a recommendation. This is because it would require too substantive a change in the Ombudsman's approach by requiring her to discharge (in effect) a judicial function for an important but (relatively) small part of her work.

18.94 At this stage, it appears to us that a way in which to address this mismatch could be:

(1) to expand the jurisdiction of the SEND Tribunal to hear appeals against assessment and service provision decisions in relation to the social care needs of disabled children (including decisions not to assess); and

(2) to expand the powers of the SEND Tribunal on such appeals to direct that assessments are carried out (if they have not been), to direct that decisions are remade, and, if necessary, to direct service provision.

18.95 However, we recognise that it would represent a considerable expansion of both the SEND Tribunal's jurisdictions and its powers. We are also mindful that, in principle, resource allocation is predominantly meant to be a matter for democratically elected politicians, rather than for the courts.[122] That having been said, as set out above, Parliament has already seen fit to empower the SEND Tribunal to make resource allocation decisions as regards the special educational needs of disabled children. It is not entirely easy to identify a principled reason why the Tribunal should not also have the same powers in relation to the social care needs of disabled children. We welcome views on the justification for this differential treatment.

18.96 We recognise, further, that there would be very considerable practical implications of implementing our provisional proposals, especially given that the SEND Tribunal is under significant strain currently. We consider our other provisional proposals would maximise the chances that decisions are made correctly first time around, and hopefully mean that there would only ever be a limited number of appeals. That would undoubtedly be desirable given the costs (both in human and financial terms) of going through Tribunal proceedings. However, even if only a relatively small number of challenges were made to "pure" social care decisions, the number of such decisions that are made each year inevitably means that the absolute numbers of appeals to the SEND Tribunal would rise. Absent the necessary increase in resources available to the Tribunal, this would run the risk that challenges would not be heard in a timely fashion. Taking this path would also carry the risk that the SEND Tribunal's ability to hear appeals relating to its current "core business" of special educational needs provision would be hampered.

18.97 We note one consequence of this approach would be that it would no longer be possible to challenge the relevant decisions by way of judicial review. This would have implications for the availability of legal aid, given that (as set out at paragraph 18.41 above), public funding of legal representation is not ordinarily available before the SEND Tribunal. Decisions about the availability of legal aid are not ones for us to make. However, the potential implications for the availability of legal aid are something that consultees should keep in mind when considering their views about the route of challenge being to the SEND Tribunal.

18.98 Our provisional view is that there are valid arguments of principle in favour of extending the jurisdiction and powers of the SEND Tribunal, but that the practical implications are both significant and difficult to assess. This could militate in favour of a pilot scheme, as was set up in respect of the SEND Tribunal's powers on "extended appeals". That would, in turn, provide a clear evidence base upon which a final decision could be taken as to the expansion of the SEND Tribunal's jurisdiction and powers.

18.99 However, before reaching any settled views, we want to hear consultees' views about remedies generally. We particularly want to understand whether any changes, or combinations of changes, to the other remedies set out above could sufficiently close the gap so that the mismatch we have identified is rendered notional rather than real.

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[122] A strong recent statement of this principle by Supreme Court can be found in *R (AM (Belarus)) v Secretary of State for the Home Department* [2024] UKSC 13, [2024] 2 WLR 1075 at [59] by Lord Sales.

Consultation Question 64.

18.100 We invite consultees' views on the changes necessary in order for families to have an effective and independent mechanism to challenge and rectify decisions about disabled children's social care.

Consultation Question 65.

18.101 We invite consultees' views on extending the powers and jurisdiction of the SEND Tribunal as a potential option to challenge and rectify decisions about disabled children's social care.

18.102 Whilst the questions of extending the SEND Tribunal's powers more broadly may be difficult; we think that it is clear that any doubt as to its powers in relation to "extended" appeals should be resolved. Our provisional view is that it should be made clear in the relevant regulations[123] that the SEND Tribunal has the power to recommend on any "extended" appeal that a local authority carries out a social care assessment where one has not already been carried out.

Consultation Question 66.

18.103 We provisionally propose that the Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations are amended. This amendment should make clear that the SEND Tribunal has the power on an "extended" appeal to recommend that a local authority carries out a social care assessment where one has not been carried out.

Do consultees agree?

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[123] Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations 2017, SI No 1306.

PART 5 – WIDER ISSUES

Chapter 19: The definition of disability

INTRODUCTION

19.1 As we noted in Chapter 1, the definition of disability in the Children Act 1989 is out of date and we think that it needs to be replaced. No-one we spoke to in the lead up to this consultation sought to defend the current definition. In this chapter we explain what we think is wrong with the current definition and make provisional proposals about the definition that should replace it.

THE CURRENT LAW

The Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970

19.2 At present, the Children Act 1989 gives the following definition of disability:

> For the purposes of this Part, a child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed.[1]

19.3 The same definition of disability applies for the purposes of the Chronically Sick and Disabled Persons Act 1970.[2]

The Equality Act 2010

19.4 In contrast, section 6 of the Equality Act 2010 provides that a person has a disability if:

(1) they have a physical or mental impairment; and

(2) the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

19.5 "Substantial" means "more than minor or trivial".[3] The effect of an impairment is "long-term" if:[4]

(1) it has lasted for at least 12 months;

(2) it is likely to last for at least 12 months; or

(3) it is likely to last for the rest of the life of the person affected.

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[1] Children Act 1989, s 17(11). There have been no prescriptions of additional disabilities since the Act was passed.

[2] Chronically Sick and Disabled Persons Act 1970, s 2 refers to local authority functions under Children Act 1989, pt 3 in relation to disabled children.

[3] Equality Act 2010, s 212.

[4] Equality Act 2010, s 6(6) and sch 1, para 2.

19.6 The Equality Act (Disability) 2010 Regulations[5] modify the definition of disability to be found in the Equality Act 2010 in three relevant ways.[6] The first is by changing the definition of “substantial and long-term” for children under six:

> For the purposes of the Act, where a child under six years of age has an impairment which does not have a substantial and long-term adverse effect on the ability of that child to carry out normal day-to-day activities, the impairment is to be taken to have a substantial and long-term adverse effect on the ability of that child to carry out normal day-to-day activities where it would normally have that effect on the ability of a person aged 6 years or over to carry out normal day-to-day activities.[7]

19.7 This provision recognises that the impact of impairments for some (but not all) younger children may not be felt as dramatically as for older ones. As children develop, so does their range of normal day-to-day activities, potentially increasing the impact of their impairment.

19.8 The second relevant modification of the definition in the Equality Act 2010 (Disability) Regulations 2010 relates to addiction. Regulation 3 excludes from the scope of the Equality Act 2010 addiction to alcohol, nicotine, or any other substance, save where the addiction arose as a result of the administration of medically prescribed drugs or other medical treatment. Addiction is treated as “not amounting to an impairment for the purposes of the Act”.

19.9 The third relevant modification of the definition of disability is contained in regulation 4(1) of the Equality Act 2010 (Disability) Regulations 2010. This excludes from the definition of disability:

(1) a tendency to set fires;

(2) a tendency to steal;

(3) a tendency to physical or sexual abuse of other persons;

(4) exhibitionism; and

(5) voyeurism.

As with addiction, these conditions are treated as “not amounting to an impairment for the purposes of the Act”.

19.10 In 2019, the Upper Tribunal concluded that, in the context of education, the exclusion of children with a “recognised condition that is more likely to result in a ‘tendency to physical abuse’” from the definition of disability amounted to unlawful discrimination

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[5] SI 2010 No 2128.

[6] This modification also applies for purposes of the Children and Families Act 2014, by virtue of the operation of Children and Families Act 2014, s 83(3).

[7] Equality Act 2010 (Disability) Regulations 2010, SI No 2128, reg 6.

contrary to the European Convention on Human Rights.[8] As a result, the Tribunal held, the exclusion should not be applied in that particular context.

The Children and Families Act 2014

19.11 The Children and Families Act 2014 uses the definition of disability contained in the Equality Act 2010 to identify children with special educational needs.[9] Specifically, the definition of special educational needs in the 2014 Act includes children who have a disability – as defined in the Equality Act 2010 – which prevents or hinders them from making use of facilities of a kind generally provided for others of the same age in mainstream education, and which requires special educational provision.[10]

THE CASE FOR REFORM

19.12 There are two key reasons for reforming the definition of disability for the purposes of assessing and meeting the social care needs of disabled children.

19.13 The first reason for proposing reform to the definition in section 17 of the Children Act 1989 is that, as we note in in Chapter 1, it can be traced back to the immediate post-Second World War period. It uses language that is out of date and that many find offensive. Moreover, the language reflects the medical model of disability: in other words, that disability is the problem which the person has and which they try to overcome. By contrast, the modern approach is founded upon the social model. In broad terms, this means that a person is disabled not by any impairment they might have, but because of society's failure to respond to their needs in such a way as to enable them to live life on an equal basis with others.

19.14 The social model underpins the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).[11] The UNCRPD was concluded in 2006 and was signed by the United Kingdom in 2009. Disabled people[12] played a significant part in its drafting. It has not been incorporated into the law of England and Wales,[13] but represents an international consensus on the rights of disabled people.

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[8] *C v The Governing Body of a School (SEN)* [2018] UKUT 269 (AAC), [2019] PTSR 857 at [90] to [93] by Upper Tribunal Judge Rowley.

[9] See para 13.4 for a full list of the various definitions used in special educational needs law.

[10] Children and Families Act 2014, ss 20(1) to (2) and 83(3).

[11] The Committee on the Rights of Persons with Disabilities, the body of experts that oversees the UNCRPD, uses "human rights" model of disability, rather than "social model" of disability. For a discussion of the human rights model see G Quinn and T Degener, "The Moral Authority for Change: Human Rights Values and the World Wide Process of Disability Reform", in G Quinn and T Degener (eds), *Human Rights and Disability: The Current Use and Future Potential of Human Rights Instruments in the Context of Disability* (2002) p 14. For a discussion of the differences between the human rights and social model see A Lawson and A Beckett, "The social and human rights models of disability: towards a complementarity thesis" (2010) 25(2) *The International Journal of Human Rights* 348.

[12] The Convention on the Rights of Persons with Disabilities talks of "persons with disabilities". In line with the accepted position in England, we use the term "disabled people". See the note on language in para 1.16.

[13] *R (SC) v Secretary of State for Work and Pensions* [2021] UKSC 26, [2022] 2 AC 223 at [77] to [96]. See further para 20.21.

19.15 The second reason for reform is that a significant number of children currently have two different definitions of disability applied to them. One is applied for the purposes of identifying their social care needs under the Children Act 1989. The other is applied to decide whether they are eligible for services to meet their special educational needs under the Children and Families Act 2014. Having two different definitions of disability adds to the difficulty of identifying the number of children who are, or should be, recognised as disabled. We chose the word "significant" at the start of this paragraph with care, because on the basis of the data available to us we cannot identify the number of disabled children who have two definitions applied to them. The children in need statistics and the special educational needs statistics are not cross-referenced. This makes it difficult to identify whether individual children who are understood to have a disability for the purposes of the Children and Families Act 2014 are also understood to be disabled for the purposes of the Children Act 1989.[14] Such a disjointed approach, exemplified by different definitions and different databases, heightens the risk that children are not identified as disabled when they should be (including by their parents and carers). This was recognised as a problem in 2008;[15] nothing that we have heard in the lead up to this consultation has suggested that it does not remain a problem.

OPTIONS FOR REFORM

19.16 In reforming the definition of disability in the context of disabled children's social care the only viable option we have identified is to adopt the definition contained in section 6 of the Equality Act 2010. This provides that a person has a disability if this has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. This definition is relatively well-known and easy to understand. It is widely used in guidance and cross-governmental policy. And it is the definition which applies to determine whether a child has a disability for the purposes of the Children and Families Act 2014.[16] To produce an entirely different definition would risk confusion. Nevertheless, in the work leading up to this consultation we have come across a number of concerns about the use of this definition which we address below.

19.17 The first was a concern from some stakeholders that using the definition in section 6 of the Equality Act 2010 would require a formal diagnosis of an impairment (to use the language of the Act). However, the courts have been clear that this not correct. We are therefore of the opinion that a formal diagnosis would not be legally required and that this concern does not undermine this option.[17] However, it does suggest that the

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[14] A 2019 report by the Department for Education, based upon internal data analysis, identified that in the school year 2015-6, 105,000 children were both children in need and were considered to have special educational needs (Department for Education, *Children in need of help and protection: Data and analysis* (2018) p 30). However, the report did not identify the proportion of those children who were both children in need because of their disability and were considered to have special educational needs.

[15] J Porter and others, *Disability Data Collection for Children's Services* (2008) https://research-information.bris.ac.uk/ws/portalfiles/portal/190240573/Report.pdf.

[16] Children and Families Act 2014, s 83(3).

[17] A point recently restated in *Young v Commissioner of Police of the Metropolis (Disability Discrimination; Meaning of Disability)* [2024] EAT 55 at [14] by Jason Coppel KC, sitting as a Deputy High Court Judge.

lack of requirement for a diagnosis is not well-known. This is a matter that might usefully be dealt with in guidance.

19.18 The second concern relates to the use of the word impairment in section 6 of the Equality Act 2010. We know that some find this word offensive as it suggests to them that there is something wrong with the disabled person, reflecting the medical and not the social model of disability. This touches on an extensive debate about whether it is truly possible (or even desirable) to produce a model of disability which does not require consideration of the person's impairments.[18] It is not for us, as a law reform body, to resolve that debate. But we note that the UNCRPD itself includes references to impairments. It is also fair to say that this debate has not been a particular concern among the children, young people, parents and carers we have heard from so far. The children and young people we have heard from were not overly concerned with the language of the definition. What they wanted society to do was to stop viewing disability as a negative. The parents and carers we have heard from have generally been more focused on practical matters such as whether it is necessary to have a formal diagnosis before being able to access services.

19.19 The third concern – which also applies to the current definition under the Children Act 1989 – relates to whether and how trauma should be considered from a disability perspective. This was a particular concern of the adoptive parents we have heard from. Where the *effect* of trauma gives rise to an impairment falling within the Equality Act 2010, that is a disability. But that avoids the question of whether and when trauma *itself* can be considered an impairment. Whilst we acknowledge this concern, this is not a matter for us as a law reform body. It requires an assessment of difficult and complicated questions engaging clinical, social work and policy considerations.

19.20 The fourth concern is whether or not the definition in section 6 of the Equality Act 2010 fully meets the requirements of the UNCRPD. This issue was examined by the House of Lords Select Committee convened in 2015-16 to consider the impact of the Equality Act 2010. In its final report, it noted that there was "considerable inconsistency" between the witnesses giving evidence to it on this point.[19] The House of Lords Select Committee did not draw any final conclusions as to the compatibility of the Equality Act 2010 with the UNCRPD, nor did it recommend changing the definition of disability contained in the Equality Act 2010. In 2021, the House of Lords liaison committee carried out a follow-up inquiry into the 2016 report.[20] Again, it did not recommend any amendments to the definition of disability contained in the Equality Act 2010. In these circumstances we do not think it is appropriate for us to seek to settle this debate. The issue is politically contested and has wider ramifications which fall outside of the scope of this project.

19.21 It is for these reasons that we think that adopting the definition of disability in section 6 of the Equality Act 2010 is the only real option. The more difficult question is whether the three modifications to the definition in section 6 which are contained in the Equality

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[18] See T Shakespeare, *Disability Rights and Wrongs Revisited* (2nd ed 2014).

[19] The Equality Act 2010: the impact on disabled people, Report of the Select Committee on the Equality Act 2010 and Disability (2015-16) HL 117, para 53 (footnotes omitted).

[20] The Equality Act 2010: the impact on disabled people: Follow-up report, Report of the House of Lords Liaison Committee (2021-22) HL 60, para 8.

Act 2010 (Disability) Regulations 2010 should also be applied to disabled children's social care either in whole or in part. Dealing with these modifications in turn, there are a number of reasons why they might not be appropriate in the context of disabled children's social care.

(1) *The modified definition of "substantial and long-term" that applies to children under six.*[21] As we explain above, this modification recognises that the impact of an impairment on a very young child who is only just learning to carry out normal day-to-day activities may not be as significant as it is on an older child. But our work in the lead up to this consultation has also suggested that the converse can also be true. A young child, under six, may have a serious developmental condition which – in practical terms – is disabling for them and means that they require support. There may, however, be a reasonable likelihood that the impact on them will become much less significant for them as they get older, especially if they are provided with the necessary support at an early stage. But if the impact is compared to the impact it would have on an older child, it may not satisfy the modified definition of "substantial and long-term" contained in the Equality Act 2010 (Disability) Regulations 2010.

(2) *The exclusion of addiction from the definition of disability.*[22] This would exclude children who are born with addictions from the scope of disabled children's social care. More generally, the application of this exclusion to disabled children's social care raises difficult political and moral questions – which are not for us – such as whether children should be held responsible for becoming addicted and whether this should outweigh the societal responsibility for bringing the child to adulthood.[23]

(3) *The exclusion of physical abuse and other forms of challenging behaviour from the definition of disability.*[24] We have heard from parents and carers in the lead up to this consultation who are seeking support from social services because they are struggling to deal with challenging behaviour on the part of their disabled child. Often this will happen because the child has difficulty in communicating or regulating their emotions. The consequence of this is that they react violently toward their parent or carer or their siblings. The services that the parent or carer is seeking in these instances might be a short break or support to help the child develop their communication skills. The exclusion of physical abuse from the definition of disability which is contained in the Equality Act 2010 (Disability) Regulations 2010, if applied to disabled children's social care, might preclude services being provided in these instances. This exclusion, applied in the education context, has attracted the criticism of a House of Lords Select Committee convened in 2015-6 to consider the impact of the Equality Act 2010. The Committee considered that the exclusion undermined the principle that schools should be encouraged and supported to make the kinds of

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[21] See para 19.5 above.

[22] See para 19.7 above.

[23] As to society's responsibilities, see *Re G (Education: Religious Upbringing)* [2012] EWCA Civ 1233, [2013] 1 FLR 677 at [80] to [81] by Munby LJ.

[24] See para 19.9 above.

adjustments that can help to address the educational inequalities faced by disabled children and young people, including those whose disability gives rise to challenging behaviour.[25] And it was this exclusion, applied in the education context, that the Upper Tribunal decided was unlawful in the case we refer to in paragraph 19.10 above, which involved a child with autism, anxiety and Pathological Demand Avoidance who was excluded from school as a result of aggressive behaviour.

19.22 These points militate against applying the modifications to the definition of disability in the Equality Act 2010 (Disability) Regulations 2010 to disabled children's social care.

19.23 However, excluding the modifications in the 2010 Regulations would mean there is still inconsistency in the law. This is because the definition of disability for the purposes of disabled children's social care law would remain different to the definition used in special educational needs law. We address this further below.

OUR PROVISIONAL PROPOSALS

19.24 We provisionally propose that the definition of disability contained in section 6 of the Equality Act 2010 should apply to disabled children's social care, but without the exclusions contained in the Equality Act 2010 (Disability) Regulations 2010. That is, a child should be regarded as disabled for these purposes if:

(1) they have a physical or mental impairment; and

(2) the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

19.25 We provisionally propose, however, that the following conditions should not be excluded from being impairments:

(1) addiction;

(2) a tendency to set fires;

(3) a tendency to steal;

(4) a tendency to physical or sexual abuse of other persons;

(5) exhibitionism; and

(6) voyeurism.

19.26 We provisionally favour the definition in section 6 of the Equality Act 2010 because, as we explain above, it is well-known and understood and widely applied, and we have not identified any viable alternative options. However, for the reasons set out at paragraphs 19.21(2) and (3) above, our provisional view is that the exclusions contained in the Equality Act 2010 (Disability) Regulations 2010 are not appropriate for disabled children's social care. The definition of disability contained in the Children

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[25] The Equality Act 2010: the impact on disabled people, Report of the Select Committee on the Equality Act 2010 and Disability (2015-16) HL 117, para 503.

Act 1989 does not contain any equivalent exclusions and we think it could have significant ramifications – which go beyond law reform – for those exclusions to be introduced into disabled children's social care law. It is primarily the outdated language of the Children Act 1989 which we are seeking to change and not the underlying, inclusionary approach.

19.27 We recognise that our provisional proposal would mean that there is inconsistency as between disabled children's social care law and special educational needs law when it comes to defining disability. This is a factor which consultees should keep in mind in deciding whether our provisional proposal is the right one. There is, however, already inconsistency in this area, and the language and approach of our provisional proposal would reduce the inconsistency by coming closer to the definition used in special educational needs law than is currently the case. Separately, the points that we have made at paragraph 19.21 may apply equally to the approach to disability for the purposes of special educational needs; this is not a matter, however, about which we can make provisional proposals.

Consultation Question 67.

19.28 We provisionally propose that a child should be regarded as disabled for the purposes of disabled children's social care law if:

(1) they have a physical or mental impairment; and

(2) the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

Do consultees agree?

Consultation Question 68.

19.29 We provisionally propose that the statutory definition of disability should clarify that social care services should not be denied to a child purely on the basis that their impairment gives rise to:

(1) addiction;

(2) a tendency to set fires;

(3) a tendency to steal;

(4) a tendency to physical or sexual abuse of other persons;

(5) exhibitionism; and

(6) voyeurism.

Do consultees agree?

19.30 Whether the modified definition of definition of "substantial and long-term" that applies to children under six contained in Equality Act 2010 (Disability) Regulations 2010 should be applied to disabled children social care law strikes us as being more finely balanced. As we explain at paragraph 19.21(1) above, it appears that this modification may be appropriate for some children but not for others. Again, if a different approach is adopted, this would mean maintaining inconsistency between disabled children's social care law and special educational needs law. We seek consultees' views on this issue.

Consultation Question 69.

19.31 We invite consultees' views on whether the definition of "substantial and long term" requires adaptation for younger children in the context of disabled children's social care law.

Chapter 20: Statutory principles

INTRODUCTION

20.1 In our work leading up to this consultation, one issue that came up repeatedly was whether there should be a set of statutory principles that should be applied to decision-making in this area. In this chapter, we discuss what statutory principles are, and why they are of importance in the context of social care for disabled children. One important preliminary point when reading this chapter is that, as we go on to explain in Chapter 23, we think that putting in place the provisional proposals we make here would be impossible without a new framework specifically addressing the social care needs of disabled children.

WHAT ARE STATUTORY PRINCIPLES?

20.2 Statutory principles are legislative provisions which set out how the legislation is to be applied to specific situations. The term covers a wide range of provisions, which differ in their legal effect and nature. A principle can be drafted in such a way that gives it primacy; such as the welfare principle of the Children Act 1989, that requires the child's welfare to be the paramount consideration (see below)[1] or the best interests principle of the Mental Capacity Act 2005.[2] Alternatively, principles can set out statutory assumptions, which are phrased in mandatory terms but contain general caveats or are broadly worded to give decision-makers sufficient flexibility. For instance, section 1(2) of the Mental Capacity Act 2005 provides that a person must be assumed to have capacity unless it is established that they lack capacity.

20.3 In our adult social care consultation paper, we set out a number of propositions about principles. We think that they apply equally in this context, and we set them out here, modified to relate more precisely to this project.[3]

(1) A principle appearing in legislation must be capable of acting as a proposition of law. To do so it should be clear and precise. It should not be merely rhetorical.

(2) Each principle must be capable of doing some legal work. This would mean the outcome of a decision made under the Act would or might be different in the absence of the principle.

(3) Principles should assist decision-makers acting under the legislation and should not give rise to actionable rights.[4]

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[1] Children Act 1989, s 1(1).

[2] Mental Capacity 2005, s 1(5).

[3] Adult Social Care (2010) Law Commission Consultation Paper No 192 para 3.14.

[4] That having been said, a failure to have regard to a principle when required to by statute can be something that a court can take into account: see in the context of the well-being principle in Care Act 2014, s 1(2), *R (Davey) v Oxfordshire County Council & Ors* [2017] EWCA Civ 1308, [2018] PTSR 281 at [52] by Bean LJ.

(4) Statutory principles should not provide an overly restrictive decision-making framework, reducing individual practitioners' discretion to an inappropriate level. This is important in the context of disabled children's social care, which relies heavily on professional judgement.

(5) The principles must not be inconsistent with each other, and each principle must be of truly general application to the rest of the statute, or of general application subject only to limited and specified exceptions.

(6) Principles must not be inconsistent with any relevant provision elsewhere in legislation (subject to specified exceptions, if any). For example, a social care assessment of a person over 16 who lacks capacity to make the relevant decisions must be carried out in accordance with the principles of the Mental Capacity Act 2005.

(7) Principles should not simply repeat other provisions or principles stated elsewhere in legislation. For example, it would be unnecessary to include a principle that local authorities must respect and promote the human rights of disabled people, since the Human Rights Act 1998 already requires public authorities to respect the human rights of everyone in the United Kingdom. However, there may be an exception to this general rule if an existing legal provision is relevant but is not clearly stated or expressed in terms relevant to disabled children's social care.

20.4 One way of looking at this is that a principle must serve the function of telling a decision-maker what to do in a broad sense. For example, section 1(1) of the Children Act 1989[5] tells a court determining an issue governed by that provision that the child's welfare must be paramount.

20.5 Principles can be distinguished from rules telling decision-makers to have regard (or particular regard) to a list of factors. Such rules tell the decision-maker what factors they need to take into account when making a decision. But they stop short of giving the decision-maker the type of guidance that is provided by a principle.

20.6 The two can sometimes be combined, by setting out a principle combined with a checklist of factors:

> which must be considered when giving effect to the principle. These factors [do] not operate as legal rules but …, for example, direct the decision maker to consider a particular point or establish certain assumptions, which are either phrased in mandatory terms, but contain general caveats, or are broadly phrased to give decision makers sufficient flexibility.[6]

20.7 We set out below a number of relevant principles which exist in domestic and international law in this area before we turn to the question of whether and how such principles could apply in the context of our project.

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[5] See para 20.8 below.

[6] Adult Social Care (2011) Law Com No 326 para 4.22.

Domestic law

20.8 Section 1(1) of the Children Act 1989 sets out the principle that:

> when a court determines any question with respect to:
>
> (a) the upbringing of a child; or
>
> (b) the administration of a child's property or the application of any income arising from it,
>
> the child's welfare shall be the court's paramount consideration.

20.9 This principle, however, does not apply to decisions concerning the provision of social care for disabled children. Decisions relating to social care are made under section 17 of the Children Act 1989, found in Part 3 of that Act. Section 1(1) does not apply directly to Part 3 of the Children Act 1989.[7] In *R(HC) v Department for Work and Pensions*[8] the Supreme Court observed that section 17 of the Children Act 1989 has the "primary objective" of promoting the welfare of the children concerned. But this is not quite the same as saying that in any individual decision under section 17 the child's welfare is the paramount consideration. If it were, then decision-makers could not take into account resource implications in terms of meeting their obligations under section 17, contrary to the position established by case law.[9]

20.10 Section 11 of the Children Act 2004 implements the principle contained in article 3 of the United Nations Convention on the Rights of the Child,[10] namely that the best interests of the child shall be a primary consideration.[11] It requires that bodies including local authorities[12] must make arrangements for ensuring that:[13]

> (a) their functions are discharged having regard to the need to safeguard and promote the welfare of children; and

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[7] The suggestion in the *Children's Social Care National Framework* that the first principle of children's social care is that the child's welfare is paramount is not correct (Department for Education, *Children's Social Care National Framework* (December 2023) p 14). In support of that proposition, the Framework document refers to the Children Act 1989, s 22(3). However, s 22(3) imposes a duty on local authorities in respect of looked after children safeguard and promote their welfare (as to looked after children, see para 3.15. This not the same as saying that the child's welfare is paramount; further, not all children to whom services are provided under pt 3 are looked after children.

[8] *R(HC) v Department for Work and Pensions* [2017] UKSC 73, [2019] AC 845 at [37] by Lord Carnwath.

[9] *R (G) v Barnet London Borough Council* [2003] UKHL 57, [2004] 2 AC 208 at [35] by Lord Nicholls.

[10] See further para 20.22 below.

[11] See *ZH (Tanzania) v Secretary of State for the Home Department* [2011] UKSC 4, [2011] 2 AC 166 at [23] by Lady Hale. In *Nzolameso v City of Westminster* [2015] UKSC 22, [2015] PTSR 549, the Supreme Court confirmed that the duty applies to decision-makers in individual cases: see [24] by Lady Hale.

[12] Except in respect of their functions under s 175 of the Education Act 2006, which relate to the discharge of education functions.

[13] This means that the local authority must be able to "demonstrate that due regard has been had to the dimensions of a child's best interests for the purposes of s.17 [of the Children Act] 1989 in the context of the duty in s.11 of the Children Act 2004 to have regard to the need to safeguard and promote the welfare of children": *R (C) v Southwark* [2016] EWCA Civ 707, (2016) 19 CCLR 347 at [12] by Ryder LJ.

(b) any services provided by another person pursuant to arrangements made by the person or body in the discharge of their functions are provided having regard to that need.

20.11 Two other statutes in this area contain what are described in the legislation as principles.[14]

(1) Section 19 of the Children and Families Act 2014, under the heading "Local authority functions: general principles",[15] sets out a series of matters to which local authorities must have regard "in particular" when discharging their functions towards children and young people in England with special educational needs or disabilities:

(a) the views, wishes and feelings of the child and his or her parent, or the young person;

(b) the importance of the child and his or her parent, or the young person, participating as fully as possible in decisions relating to the exercise of the function concerned;

(c) the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions; and

(d) the need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes.

(2) Section 1(1) of the Children and Social Work Act 2017, entitled "corporate parenting principles", provides that a local authority in England must, in carrying out functions in relation to relevant children and young people,[16] have regard to the need:

(a) to act in the best interests, and promote the physical and mental health and well-being, of those children and young people;

(b) to encourage those children and young people to express their views, wishes and feelings;

(c) to take into account the views, wishes and feelings of those children and young people;

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[14] The Mental Capacity Act 2005 may also be relevant in the discharge of some functions towards older children. See further ch 21.

[15] The section itself being called "Local authority functions: supporting and involving children and young people".

[16] Children and Social Work Act 2017, s 1(2). Relevant children for these purposes are those described at paras 8.18 to 8.26.

(d) to help those children and young people gain access to, and make the best use of, services provided by the local authority and its relevant partners;

(e) to promote high aspirations, and seek to secure the best outcomes, for those children and young people;

(f) for those children and young people to be safe, and for stability in their home lives, relationships and education or work; and

(g) to prepare those children and young people for adulthood and independent living.

20.12 Despite what the two statutes say, we do not think that these provisions meet the definition of statutory principles which we have set out above. Whilst they set out factors to which decision-makers must have regard, they do not give guidance of the nature that we have identified as required by principles.

20.13 The *Children's Social Care National Framework* sets out six "principles of children's social care".[17] These are not statutory principles. Instead, they are policy statements which provide an important context for the statutory principles that we are considering. The first four principles set out in the Framework are that:

(1) children's welfare is paramount;[18]

(2) children's wishes and feelings are sought, heard and responded to;

(3) children's social care works in partnership with families; and

(4) children are raised by their families, with their family networks or in family environments wherever possible.

20.14 The other two principles set out in the Framework are broader in nature, namely that local authorities work with other agencies to effectively identify and meet the needs of children, young people, and families; and that local authorities consider the economic and social circumstances impacting children, young people, and families.

20.15 We also have considered both statutes that were enacted drawing upon our earlier work on adult social care.[19] Both of these contain principles, although not expressly described as such.

20.16 In England, the Care Act 2014 includes what is often called the well-being principle, namely that "the general duty of a local authority, in exercising a function under this Part in the case of an individual, is to promote that individual's well-being".[20] It then sets out a series of matters to which local authorities must have regard in particular

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[17] Department for Education, *Children's Social Care National Framework* (December 2023) p 14.

[18] See also fn 7 above.

[19] Adult Social Care (2011) Law Com No 326.

[20] Care Act 2014, s 1(1).

when exercising relevant functions of the Act.[21] The well-being principle primarily applies to adults, but applies in certain contexts to children.[22]

20.17 In Wales, the Social Services and Well-Being (Wales) Act 2014 includes a similar well-being principle.[23] The Act applies to both adults and children. Section 6 of the 2014 Act sets out what those discharging relevant functions under the Act must do, including a duty to "in so far as is reasonably practicable, ascertain and have regard to the individual's views, wishes and feelings",[24] and then to have regard to the following matters:

(1) the importance of promoting and respecting the dignity of the individual;[25]

(2) the characteristics, culture and beliefs of the individual (including, for example, language);[26] and

(3) the importance of providing appropriate support to enable the individual to participate in decisions that affect him or her to the extent that is appropriate in the circumstances, particularly where the individual's ability to communicate is limited for any reason.[27]

20.18 When discharging functions in relation to a child, section 6 of the Social Services and Well-Being (Wales) Act 2014 also requires the decision-maker to:[28]

> (a) have regard to the importance of promoting the upbringing of the child by the child's family, in so far as doing so is consistent with promoting the well-being of the child, and
>
> (b) where the child is under the age of 16, must ascertain and have regard to the views, wishes and feelings of the persons with parental responsibility for the child, in so far as doing so is -
>
> (i) consistent with promoting the well-being of the child, and
>
> (ii) reasonably practicable.

20.19 The Social Services and Well-Being (Wales) Act 2014 also expressly requires decision-makers to have "due regard" to Part 1 of the United Nations Convention on the Rights of the Child (UNCRC) which contains the substantive rights enjoyed by children.[29] This reflects the operation of the Rights of Children and Young Persons

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[21] Care Act 2014, s 1(3).

[22] See ch 15 in relation to cases involving children transitioning to adulthood.

[23] Social Services and Well-Being (Wales) Act 2014 (anaw 4), s 5.

[24] Social Services and Well-Being (Wales) Act 2014 (anaw 4), s 6(2)(a).

[25] Social Services and Well-Being (Wales) Act 2014 (anaw 4), s 6(2)(b).

[26] Social Services and Well-Being (Wales) Act 2014 (anaw 4), s 6(2)(c).

[27] Social Services and Well-Being (Wales) Act 2014 (anaw 4), s 6(2)(d).

[28] Social Services and Well-Being (Wales) Act 2014 (anaw 4), s 6(4).

[29] Social Services and Well-Being (Wales) Act 2014 (anaw 4), s 7(2).

(Wales) Measure 2011, a legislative provision which does not have a direct counterpart in England.

20.20 We have, finally, looked at a set of what are described as principles contained in draft guidance for assessing the needs of disabled children and their families developed by parent groups and published in 2023.[30] We have found them – and the other recommendations set out in the draft guidance – very helpful in terms of developing our provisional proposals. However, statutory principles should seek to guide decision-makers in how they approach their task, not prescribe what they should do in the way that the draft guidance proposes.

International law

20.21 We need also to consider both the UNCRC and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which have been signed and ratified by the United Kingdom.[31] Neither of these have been incorporated into English law and cannot therefore be relied upon directly before the English courts.[32] However, the position is different when it comes to proposing new legislation or amending existing legislation. At that point, we suggest that the expectation is that any move should be towards, rather than away from, the treaty obligations the United Kingdom has taken upon itself. In respect of the UNCRC, we note that the new version of the *Working Together* guidance specifically identifies that “the UK Government ratified the UNCRC in 1991 and, by doing so, recognises children’s rights including to expression and receiving information”.[33]

20.22 The UNCRC has provisions that apply to all children. The most important for present purposes are set out below.

(1) Article 3, which says: “[i]n all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration”.

(2) Article 12, which imposes an obligation on the United Kingdom to: “assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child”.

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[30] *Draft Guidance: Assessing the Needs of Disabled Children and their Families* (July 2023) https://www.lukeclements.co.uk/wp-content/uploads/2023/07/Final-Draft-Guidance-02.pdf.

[31] The United Kingdom signed the United Nations Convention on the Rights of the Child on 19 April 1990 and ratified it on 16 December 1991; the United Kingdom signed the United Nations Convention on the Rights of Persons with Disabilities on 30 March 2007 and ratified it on 8 June 2009.

[32] *R (SC) v Secretary of State for Work and Pensions* [2021] UKSC 26, [2022] AC 223 at [77] to [96] by Lord Reed. The UNCRC has been incorporated into Scottish law in United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024, and into the law of Wales in the Rights of Children and Young Persons (Wales) Measure 2011.

[33] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 16. See also para 1.40.

20.23 The UNCRC has an article applying to disabled children (article 23). However, it is not as detailed as the provisions contained in the UNCRPD. The most important of the provisions in the UNCRPD are as follows.

(1) Article 3(h), which provides that one of the “general principles” of the Convention is of respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

(2) Article 7(2), which provides that "[i]n all actions concerning children with disabilities, the best interests of the child shall be a primary consideration".

(3) An obligation imposed on the United Kingdom under article 7(3) to ensure that children with disabilities have: “the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right”.

(4) An obligation imposed on the United Kingdom by article 23 to ensure that children with disabilities have equal rights with respect to family life, and “with a view to realising these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities”, to provide early and comprehensive information, services and support to children with disabilities and their families. Article 23(4) also provides that in no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents. Where the immediate family is unable to care for a child with disabilities, article 23(5) also imposes a requirement on the United Kingdom to undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

20.24 The Committee on the Rights of the Child and the Committee on the Rights of Persons with Disabilities are the treaty bodies established to oversee the two conventions. In 2022, they issued a joint statement on the rights of children with disabilities which emphasises the consistency between the two conventions and that:

> all children, for the full and harmonious development of their personalities should grow up in a family, in an atmosphere of happiness, love and understanding. Both Committees are deeply concerned about the institutionalisation of children with disabilities and call on States Parties to end institutionalisation on the basis of disability and to promote the development of support for children in a family in the community. The Committees recall that, in accordance with both Conventions, States Parties have the obligation to adopt clear and targeted strategies for de-institutionalisation, with specific time frames and adequate budgets, in order to eliminate all forms of discrimination and segregation of children with disabilities. Specific attention should be paid to children with intellectual or psychosocial disabilities and children requiring high levels of support, who are usually at a higher risk of institutionalisation. The Committees call on States parties to provide inclusive and supportive services for children with disabilities and their families in the

community in accordance with article 23 para. 5. of the CRPD, and article 23, para. 1 of CRC.[34]

20.25 The precise legal weight which should be attributed to statements of such treaty bodies is a matter of some debate, with the Supreme Court in more recent years taking a more restrictive view of their status than before.[35] We do not therefore take the statement set out above as binding as a matter of English law. But it is in line with the Government policy underpinning our terms of reference. It also aligns with what has been described to us in our work leading up to this consultation: a failure to meet the needs of disabled children at home leads to an escalation of those needs, so that the only response appears to be to place them in an institution, whether that be a residential placement or a hospital.

THE CASE FOR STATUTORY PRINCIPLES

20.26 In our consultation paper on adult social care, we examined in some detail the arguments for and against setting out principles in statute law, as opposed to guidance.[36] At that point, we identified a number of potential reasons for having statutory principles. In particular, principles can do the following.

(1) Articulate and clarify the underlying aims of the legislation, for the benefit both of decision-makers and of courts interpreting that legislation.

(2) Emphasise principles that already exist but are not consistently recognised or applied.

(3) Assist decision-makers to ensure the consistent application of the legislation.

(4) Perform an important educational function by promoting positive images of marginalised groups of people.

(5) Set out ethical standards that apply for the purposes of the legislation.

20.27 We also identified that these advantages are best achieved through statutory principles which have stronger legal force. Further, and importantly, such principles can be fully debated and only amended by Parliament.

20.28 We consider that all of these remain sound reasons for having principles set out in legislation. We note that the importance of including principles in legislation requiring the exercise of equally difficult judgements was restated in 2022 by the Parliamentary committee convened to consider the draft Mental Health Bill.[37]

20.29 However, there does remain an important potential counterargument: namely that principles may have little impact in practice. Whether and how principles make a

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[34] Joint Statement on the Rights of Children with Disabilities (March 2022) para 10.

[35] *R (AB) v Secretary of State for Justice* [2021] UKSC 28, [2022] AC 487 at [64] to [67] by Lord Reed, concerning the status of General Comments published by the Committee on the Rights of the Child.

[36] Adult Social Care (2010) Law Commission Consultation Paper No 192 paras 3.5 to 3.13.

[37] Draft Mental Health Bill, Report of the Joint Committee on the Draft Mental Health Bill (2022-2023) HC 696, HL 128 para 39.

difference can be difficult to evaluate, especially as it can be difficult to disentangle the effect of specific principles from the effectiveness (or otherwise) of the implementation of the legislation within which they are contained.[38] However, the evaluation of the Social Services and Well-Being (Wales) Act 2014 conducted in 2023 on behalf of the Welsh Government,[39] whilst taking a somewhat broad brush approach to the concept of statutory principles, nonetheless suggested that:

> A focus on well-being[40] as an aim for social care services is received as a positive direction by people both accessing and delivering services. It appears to have positively impacted the working cultures and capacity for innovation of organisations responsible for social care delivery. Its conceptual function operates as an ideology that rallies professionals around the individual and families.[41]

20.30 Similarly, research funded by the National Institute of Health Research identified in relation to the Care Act 2014 that:

> The foundational principles of the Act – a commitment to well-being, prevention and reforming the funding of care – continue to shape care policy, though there is still uncertainty as to how the social care system will realise these foundational principles.[42]

20.31 We return at the end of this chapter to steps that we consider would be required to ensure that any principle or principles that we do suggest are effective. However, our provisional view is that the arguments that we considered in the context of our work in adult social care remain sound, and that any new framework that might be adopted should include a statutory principle or principles.

OUR PROVISIONAL PROPOSALS

20.32 We provisionally propose that decision-making in this context should be governed by the principle that the best interests of the child be the primary consideration for decision-makers. This would be consistent with both the existing domestic statutes and international human rights obligations that we discuss at paragraphs 20.8 to 20.25 above. It would also maintain the important distinction discussed at paragraph 20.9 above between situations where a child’s best interests are paramount, and those where they are either “the” or “a” primary consideration. It would mean that local authorities would be able to consider their resources alongside the child’s best

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[38] This is the tenor of the discussion of the principles contained in chapter 3 of the report of the Select Committee convened by the House of Lords to conduct post-legislative scrutiny of the Mental Capacity Act 2005: Mental Capacity Act 2005: post-legislative scrutiny, Report of the House of Lords Select Committee on the Mental Capacity Act 2005 (2013-2014) HL 139.

[39] M Llewellyn and others, *From Act to Impact? Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014* (2023).

[40] Social Services and Well-Being (Wales) Act 2014 (anaw 4), s 5 requires that a person exercising functions under the Act must seek to promote the well-being of people who need care and support and carers who need support.

[41] M Llewellyn and others, *From Act to Impact? Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014* (2023) para 5.62.

[42] E Burn, S Redgate, C Needham, and S Peckham, “Implementing England’s Care Act 2014: was the Act a success and when will we know?” (2024) 8(1) *International Journal of Care and Caring* 47.

interests, and would not be required always to choose the most expensive option where the child's best interests can still be upheld with a less expensive option.

20.33 We have then identified a set of nine considerations to which decision-makers must have regard when applying this overall principle. Having a principle together with a checklist of considerations is an approach taken in the Children Act 1989,[43] as well as the Care Act 2014.[44] We set out each of these considerations below, together with an explanation of why we provisionally consider that each would serve an important function.

(1) *The importance of promoting the upbringing of the child by the child's family, in so far as doing so is consistent with promoting the best interests of the child.*

This reflects the provisions of article 23 of the UNCRPD, the provisions of section 17(1) of the Children Act 1989 and also reflects the approach of the Social Services and Well-Being (Wales) Act 2014.

(2) *The importance of the child participating as fully as possible in decisions relating to the exercise of the function concerned.*

(3) *The importance of the child being provided with the information and support necessary to enable participation in those decisions, having regard to their particular needs.*

(4) *The views, wishes and feelings of the child.*

These three considerations mirror the provisions of section 19 of the Children and Families Act 2014, and also the approach of the UNCRC and UNCRD. See further as regards the participation of the child Chapter 21, where we develop these points further, and also set out provisional proposals which help secure such participation.

(5) *The views, wishes and feelings of the child's parent*s *and carers and their knowledge of their child's condition and needs*.

This mirrors but expands upon sections 19(a)-(c) of the Children and Families Act 2014. It makes distinct provision for parents and carers to recognise that the parents and carers are very often "experts in their children".[45] It also makes explicit the implicit recognition in section 19 of the Children and Families Act 2014 that the views, wishes and feelings of the child and their parents may not always be identical.

(6) *The need to support the child and their parent carers in order to facilitate the development of the child and to help them achieve the best possible outcomes at each stage of their life.*

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[43] Children Act 1989, s 1(1) (the principle) and 1(3) (the checklist).

[44] Care Act 2014, s 1(1) (the principle) and 1(3) (the checklist).

[45] See further paras 21.49 to 21.50.

This mirrors the provisions of section 19 of the Children and Families Act 2014, but does not limit the focus primarily to educational outcomes. It also includes carers and makes express that the needs of disabled children change over time.

(7) *The importance of preventing or delaying the development of the needs for care and support*.

This mirrors the approach taken in relation to adults in section 2(1)(a) of the Care Act 2014. It reflects the fact that, for children, just as much (indeed often if not more) as for adults, prevention is always invariably better than seeking to respond after the event.

(8) *The need to prepare the child for adulthood and independent living.*

This reflects the provisions of section 1(1) of the Children and Social Work Act 2017. The children and young people we have spoken to as part of the work leading up to this consultation also made very clear that this was the single most important thing that they wished that they had had more help with.

(9) *The characteristics, culture and beliefs of the child (including, for example, language).*

This provision, which we have taken from the Social Services and Well-Being (Wales) Act 2014, is important for securing the preservation of all aspects of the identity of disabled children. This is also important for compliance with the provisions of article 3(h) of the UNCRPD.

20.34 We do not think that that there is a hierarchy between the items in this checklist, or a presumption as to how they should be balanced. This is because we recognise that they may, at times, be in tension with each other: for example, the wishes of a disabled child may conflict with the wishes of their parent or carer. We do not think that we could be prescriptive about how conflict between the various factors should be resolved. That kind of balancing exercise should be left to the good sense and experience of social workers and the law should not prescribe the outcome of that exercise. The most the law can reasonably say is that they are matters which should be taken into consideration.

20.35 We also think that there is a test which should be applied to all decisions. This is whether the purpose being served by the proposed decision or action can be as effectively achieved in a way which is less restrictive of the child's rights and freedom of action. Versions of such a test appear elsewhere in legislation.

(1) Section 1(6) of the Mental Capacity Act 2005, in which it is described as a principle, a description usually adopted by others.[46] The legislation in fact requires the decision-maker to have regard to whether the purpose in question can be as effectively achieved in a way that is less restrictive of the person's

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[46] See, for instance, Lady Hale's description of it as the "least restrictive alternative principle" in *N v ACCG* [2017] UKSC 22, [2017] AC 549 at [27].

rights and freedom of action. Applying the logic of paragraph 20.6 above, it may be that, in fact, section 1(6) should not strictly be described as a principle.

(2) Section 1(3)(h) of the Care Act 2014, in the statutory checklist supporting the well-being principle. The requirement is to have particular regard to the need to ensure that any restriction on the individual's rights or freedom of action that is involved in the exercise of the function is kept to the minimum necessary for achieving the purpose for which the function is being exercised.

20.36 We think that the test that is set out above would not conflict with any of the considerations that we have set out at paragraph 20.29 above; it is also one that would be relevant to decision-makers' consideration of all of them and helping them navigate through any conflict between them. We therefore provisionally propose that it serve as a final check for decision-makers to apply, requiring them to balance all the rights in play and helping to do the following.

(1) To secure that children are brought up in the home and by their families in so far as is consistent with their other rights, thereby upholding their rights under article 8 of the European Convention Human Rights (ECHR) and article 23 of the UNCRPD.

(2) To ensure that proper focus is always placed on the child's right to autonomy as an aspect of the right to respect for their private and family life under article 8 of the ECHR, by requiring proper consideration before that autonomy is overridden in service of some other good.

(3) To ensure that measures giving rise to the deprivation of liberty of a child contrary to article 5 of the ECHR are only used as a last resort, whether such measures are imposed in the home environment or in an institution. As set out in the research paper on deprivation of liberty, which is available on our website,[47] the law has been clarified over the last decade, in particular in two decisions of the Supreme Court.[48] In consequence, it is now clear there will be many circumstances in which local authorities will either directly or indirectly be involved in situations where children are deprived of their liberty. Our "least restrictive alternative" check would ensure that decision-makers properly consider these matters.

20.37 Drawing the threads above together, therefore, we provisionally propose that the law in this area should be based on:

(1) an overarching principle that the best interests of the child be the primary consideration for decision-makers;

(2) a set of nine considerations to which decision-makers must have regard; and

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[47] https://lawcom.gov.uk/project/disabled-childrens-social-care/.

[48] *P v Cheshire West and Chester Council* [2014] UKSC 19, [2014] AC 896 and *Re D (A Child)* [2019] UKSC 42, [2019] PTSR 1816. This clarification came after the work that we did on adult social care, and both the Care Act 2014 and the Social Services and Well-Being (Wales) Act 2014 (anaw 4) were enacted.

(3) a final check that decision-makers must apply as to whether the purpose being served by the proposed decision or action can be as effectively achieved in a way which is less restrictive of the child’s rights and freedom of action.

20.38 We are interested in consultees’ views on our provisionally proposed approach. The list of nine considerations that we have set out at paragraph 20.32 above is relatively long, although it is comparable in length to that in the Care Act 2014. We would be interested in the experience of consultees as to the operation and practical effect of the list in the Care Act 2014.

Consultation Question 70.

20.39 We provisionally propose that decision-making as to the assessment and meeting of the social care needs of disabled children should be:

(1) an overarching principle that the best interests of the child be the primary consideration for decision-makers;

(2) a set of considerations to which decision-makers must have regard in applying that principle; and

(3) a final check that decision-makers must apply as to whether the purpose being served by the proposed decision or action can be as effectively achieved in a way which is less restrictive of the child’s rights and freedom of action.

Do consultees agree?

Consultation Question 71.

20.40 We are provisionally proposing the following list of considerations to which decision-makers should have regard:

(1) the importance of promoting the upbringing of the child by the child's family, in so far as doing so is consistent with promoting the best interests of the child;

(2) the importance of the child participating as fully as possible in decisions relating to the exercise of the function concerned;

(3) the importance of the child being provided with the information and support necessary to enable participation in those decisions, having regard to their particular needs;

(4) the views, wishes and feelings of the child;

(5) the views, wishes and feelings of the child's parents and carers and their knowledge of their child's condition and needs;

(6) the need to support the child and their parent carers in order to facilitate the development of the child and to help them achieve the best possible outcomes at each stage of their life;

(7) the importance of preventing or delaying the development of the needs for care and support;

(8) the need to prepare the child for adulthood and independent living; and

(9) the characteristics, culture and beliefs of the child (including, for example, language).

Do consultees agree?

Consultation Question 72.

20.41 We invite consultees' views on the operation and practical effect of the list in section 1(3) of the Care Act 2014.

20.42 We have considered whether there should be a requirement for decision-makers to have regard to the specific position of children under 16, as appears in the Social Services and Well-Being (Wales) Act 2014. On balance, we do not at this stage think that there needs to be. We note that Parliament did not include a specific provision to this effect in the Children and Families Act 2014. As we discuss further in Chapter 21, we consider that setting out a clearer test for assessing a child's ability to participate in decision-making will clarify the relative weight to be given to the views of the child as opposed to those of others. However, we are interested in views as to whether the application of the approach we have set out at paragraphs 20.28 to 20.37 above should vary according to the age of the child.

Consultation Question 73.

20.43 If the approach that we have set out in this chapter to participation were to be adopted, we invite consultees' views as to whether and how it should vary according to the age of the child.

MAKING THE APPROACH THAT WE HAVE SET OUT ABOVE EFFECTIVE

20.44 Whilst we provisionally consider that there is value in setting the approach outlined above in any legislation, so as to give a clear direction for its operation, this is insufficient. In order to make the approach effective, it would need to be reflected in guidance published to accompany the legislation, form part of training, and also form an integral part of the oversight of the discharge by local authorities of their powers and duties.

20.45 We also provisionally consider that the approach that we have set out could facilitate the development of materials for disabled children to be able to assert their own choices and rights. This links to the importance of participation which we discuss in the next chapter. It would also be in keeping with article 4(3) of the UNCRPD which requires states closely to consult with and actively involve persons with disabilities (including children) in the development and implementation of legislation and policies.

Chapter 21: Participation

INTRODUCTION

21.1 In this chapter, we address two distinct issues falling under the umbrella heading of participation.

(1) The participation of the child in the process of assessing and meeting their needs. See paragraphs 21.3 to 21.47 below.

(2) The participation of parents and carers in the process of assessing and meeting the needs of the child. See paragraphs 21.48 to 21.59 below.

21.2 Each form of participation is important. However, what we have learned through our work preparing for this consultation has been consistent with the long-standing evidence of problems with each. We address those problems and our proposed solutions in this chapter. We address advocacy as a support for participation in Chapter 22. Both Chapter 22 and this chapter need to be read with Chapter 23, where we set out our provisional proposals for a new legal framework for assessing and meeting the social care needs of disabled children. As we develop there, we consider that it would be very difficult to make the changes that we suggest in relation to participation without a new legal framework.

THE PARTICIPATION OF THE CHILD

21.3 As we have set out in Chapter 20 the participation of children is considered to be very important, both in domestic law and international human rights law.

21.4 The word "participation" can, however, cover two distinct concepts. It could mean looking to the child to make their own decisions. It could also mean taking the child's views into account when reaching a decision about them. Sometimes it is not easy to distinguish the two, or the two might be linked. For instance, a decision that a disabled child needs help with washing and dressing involves both a decision about that child, and a decision by that child to consent to the touching involved in washing and dressing them.[1] It might also include a decision about what to do if the child cannot make their own decision, either because of their age or their cognitive functioning.

21.5 However, even if the two aspects of participation may be linked, both aspects of the concept raise different issues. They also both need to be considered separately if "the participation of the child" is not simply to be an empty phrase. We discuss children making their own decisions at paragraphs 21.6 to 21.35. Taking into account children's views is discussed at paragraphs 21.36 to 21.47.

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[1] In general, touching someone without their consent is both a civil and a criminal wrong.

The child making their own decisions

The current law

21.6 At present, English law does not, in general, allow children (whether disabled or otherwise) to make their own decisions in the social care context. There are, however, exceptions to this rule, which we set out in the table below, alongside the tests that apply to determine whether a particular child can make the decision in question. There are two preliminary points to make in relation to the table.

(1) Where we say “statutory test”, we mean a test set down in legislation. Where we say “judicially-determined test”, we mean that the courts have decided what the test is (in some cases, by drawing upon a test which is to be found in legislation even if the legislation does not directly govern the position).

(2) We discuss the concept of competency at paragraph 21.7 and the test for capacity under the Mental Capacity Act 2005 at paragraph 21.8.

Decision	Test to determine whether a particular child can make the decision
About local authority accommodation A child aged 16 or 17 may agree to being accommodated by a local authority even if their parents object or wish to remove them.[2]	No test There is no statutory test to determine when a child should be recognised as having the ability to “agree” to accommodation being provided. The courts have not decided what, if any, test applies.
About direct payments A local authority may provide support by way of direct payments to a 16 or 17 year old disabled child where a number of conditions are satisfied.[3] Where a person who satisfies the criteria asks for direct payments, the local authority should make them.[4] The ability to ask for such direct payments is contingent on the local authority assessing the 16 or 17 year old as requiring services in the first place.	Statutory test Whether the child is “capable” of managing a direct payment by themselves or with such support as may be available.[5] Guidance that we now understand to have been withdrawn (but not replaced) provides that “capability” includes but goes further than having the mental capacity to consent to payments.[6]
About assessment of the needs of a child who is likely to have needs for care and support after they turn 18 The child must consent before the assessment can proceed[7] (although an assessment is required even if the child	Statutory test The child must either have capacity or be competent to consent to the assessment being carried out.[9] The Care Act 2014 does not specify what test is applied to determine either capacity or competence to consent to the assessment.

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[2] Children Act 1989, s 20(11).

[3] Children Act 1989, s 17A(2)(c). See paras 10.8 to 10.13.

[4] See Department of Health, *Guidance on direct payments: for community care, services for carers and children’s services* (England) (2009) para 25. We understand that this has been withdrawn (but not replaced). See also S Broach and L Clements, *Disabled Children: A Legal Handbook* (3rd ed 2020) paras 3.109 and 3.100.

[5] The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, SI No 1887, reg 4(a).

[6] Department of Health, *Guidance on direct payments: for community care, services for carers and children’s services* (England) (2009) para 66.

[7] Care Act 2014, s 58.

[9] Care Act 2014, s 58(3).

refuses if the child is experiencing, or is at risk of, abuse or neglect).[8]	
About special educational needs[10] When a child reaches the end of compulsory school age (the end of the academic year in which they turn 16), they have the following rights: 1. To request an assessment for an education, health and care plan.[11] 2. To make representations about the content of their plan.[12] 3. To request that a particular institution is named in their plan.[13] 4. To request a personal budget for elements of their plan.[14] 5. To appeal to the First-tier Tribunal (Special Educational Needs and Disability) about decisions concerning their plan.[15]	Statutory test The Children and Families Act 2014 provides that the young person's ability to exercise the relevant rights depends upon them having the capacity to do so, applying the test in the Mental Capacity Act 2005.[16]
To consent to being touched for purposes of delivering care Examples of such touching include being provided help with washing, dressing, personal hygiene, eating, drinking or moving around.	Judicially-determined test It is widely understood that the test is that of competence for those aged under 16. It is also generally understood that the test for capacity set down in the Mental Capacity Act 2005 should be used for those aged 16 and above.

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[8] Care Act 2014, s 58(4).

[10] See ch 13.

[11] Children and Families Act 2014, s 36(1).

[12] Children and Families Act 2014, s 38(2)(b)(i).

[13] Children and Families Act 2014, s 38(2)(b)(ii).

[14] Children and Families Act 2014, s 49(1).

[15] Children and Families Act 2014, s 51(1).

[16] Children and Families Act 2014, s 80(5).

To consent to any surgical, medical or dental treatment This would cover most medical treatments, except for treatment for mental disorder governed by the treatment framework in the Mental Health Act 1983 (as to which see further below in this table).	Judicially-determined test There is no statutory test to determine whether a child has the (cognitive) ability to consent to surgical, medical or dental treatment. However, if they do, then the Family Law Reform Act 1969 provides that their consent is effective from the age of 16.[17] That means that there is no need to seek consent from a parent before medical treatment can be provided. The courts have confirmed that it is the Mental Capacity Act 2005 which applies to determine whether the child can consent.[18] If the child is under 16, then the courts look at whether the child is competent. If the child is competent to make the decision, treatment can be provided on the basis of the child's consent.[19]
To consent to admission to hospital for assessment and treatment of mental disorder Children aged 16 and 17 are in principle able to consent to admission as a so-called "informal" or "voluntary" patient under the Mental Health Act 1983.[20]	Statutory test The 16 or 17 year old must have the mental capacity to consent to admission applying the test in the Mental Capacity Act 2005.[21]

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[17] Family Law Reform Act 1969, s 8(1).

[18] *An NHS Trust v X* [2021] EWHC 65 (Fam), [2021] 4 WLR 11 at [57] by Sir James Munby.

[19] *Gillick v West Norfolk and Wisbech Health Authority* [1986] AC 112; *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11.

[20] Mental Health Act 1983, s 131.

[21] Mental Health Act 1983, s 131(5).

To make decisions about medical treatment for mental disorder The treatment framework in Parts 4 and 4A of the Mental Health Act 1983 recognises the ability of children to make decisions about medical treatment for mental disorder. Their decision is not determinative of whether the treatment is provided, but goes (broadly) to the procedural safeguards surrounding the treatment.	Statutory test In relation to inpatient medical treatment for mental disorder, the test is whether the child is capable of understanding its nature, purpose and likely effects.[22] Where treatment is being provided in the community under a community treatment order: (1) if the child is 16 or 17, the test is that set out in the Mental Capacity Act 2005;[23] (2) if the child is under 16, the child must be competent (the term not being defined in the statute).[24]
To consent to a confinement that would otherwise be a deprivation of liberty See the research paper on deprivation of liberty which is available on our website[25] for an explanation of confinement, consent and the concept of deprivation of liberty.	Judicially-determined test The courts have decided that the test is that of competence for those under 16,[26] and the test for capacity contained in the Mental Capacity Act 2005 for those aged 16 and above.[27]

21.7 The test of competence is one developed by the courts. In *Gillick v West Norfolk and Wisbech Health Authority*,[28] the Judicial Committee of the House of Lords held that a child with sufficient understanding, maturity and intelligence[29] to make the decision is "competent" to consent to the proposed intervention. The *Gillick* case was concerned with medical treatment, but it has been applied more broadly (amongst many other examples, in relation to the test for a child's ability to make a decision about changing their surname).[30] An assessment of whether a child is *Gillick* competent will factor in

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[22] Mental Health Act 1983, s 57(2)(a) (treatment requirement consent and a second opinion); s 58(3)(a) (treatment requiring consent or a second opinion); s 58(4)(c)(i) (electro-convulsive therapy).

[23] Mental Health Act 1983, ss 64B(1)(b) and (2)(a), read together with s 64C(2)(a) and s 64K(2) and (3).

[24] Mental Health Act 1983, s 64E(3)(b).

[25] https://lawcom.gov.uk/project/disabled-childrens-social-care/.

[26] *A Local Authority v D and others* [2016] EWHC 3473 (Fam), [2017] 2 FLR 875 at [52] to [54] by Keehan J.

[27] *Re D (A Child)* [2019] UKSC 42, [2019] PTSR 1816 at [26(iii)] by Baroness Hale.

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

[29] Their Lordships talked of all three of these terms, even if guidelines subsequently often only refer to two out of three (for instance maturity and understanding).

[30] *Re S (Change of Surname)* [1999] 1 FLR 672.

whether they can truly understand what is in their interests,[31] but it is also possible for a competent child to seek to make a decision that is against their best interests.[32]

21.8 The test of capacity contained in the Mental Capacity Act 2005 is a statutory one, although it draws on a test originally developed by the courts.[33] It looks first and foremost at whether the person can make a specific decision at a specific point in time, rather than (for instance) what they know, or whether or not they have a particular diagnosis. It looks at the person's ability to understand, retain, use and weigh the information relevant to the decision that they need to take, and to communicate their decision. If the person cannot do one of these things, the next question is whether that inability is caused by a material impairment of or disturbance in the functioning of their mind or brain.[34] If it is, then the person will lack the capacity to make the decision. There is a statutory presumption that the person has the capacity to make the decision.[35]

The case for reform

21.9 The Independent Review of Children's Social Care noted that:

> Over the last 30 years, changes have been made to the children's social care system in an attempt to strengthen how children's views can be heard. This has been enshrined through further legislation, and enacted in practice by adding checks and balances at key points of decision making and through dedicated roles being created to balance the best interests of children or advocate on their behalf. Many of these roles have been layered on top of each other over time, collectively making the system feel reassured that it is acting in a safe and compassionate way. However, it is too often ineffective in achieving this aim in practice.[36]

21.10 The work we have done preparing for this consultation has led us to agree that the aim of strengthening the voice of the child in decision-making in this area has not been achieved. We think based on that work that this is in part because of the way in which the law is applied to disabled children, especially those who have communication difficulties.

21.11 However, we also consider that a significant part of the problem is that the "layering" process noted in the report of the independent review is not a substitute for a clear framework which sets out:

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[31] *Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11 at 26E by Lord Donaldson MR; *Re E (a minor) (wardship: medical treatment)* [1993] 1 FLR 386 at 391 by Ward J.

[32] *Re S (A Child) (Child as Parent: Adoption: Consent)* [2017] EWHC 2729 (Fam), [2019] Fam 177 at [59] and [62] by Cobb J.

[33] See Mental Incapacity (1995) Law Com No 231 ch 3; see also A Ruck Keene, N Kane, S Kim and G Owen, "Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection" (2019) International Journal of Law and Psychiatry 56.

[34] Mental Capacity Act 2005, ss 2 and 3. See also *A Local Authority v JB* [2021] UKSC 52, [2022] AC 1322 at [47] to [79] by Lord Stephens.

[35] Mental Capacity Act 2005, s 1(2).

[36] J MacAlister, *The independent review of children's social care – Final Report* (May 2022) p 176.

(1) which decisions children can take for themselves; and

(2) the basis upon which children can take such decisions.

21.12 As we explained in the table following paragraph 21.6, when a child with special educational needs reaches the end of compulsory school age, the Children and Families Act 2014 gives them the right to make a number of important decisions about their education, health and care plan. It appears difficult to see why the arguments in favour of allowing children to make decisions about their educational needs do not apply to their social care needs. This is especially so given the extent of the overlap between those with disabilities requiring assessment under section 17 of the Children Act 1989 and requiring assessment for the provision of services under the Children and Families Act 2014.

21.13 In its provision for direct payments,[37] the Children Act 1989 does already contain a limited recognition that (at least some) disabled children have a right to make their own decisions about one aspect of their life if they are capable of doing so. We find it difficult to see a justification for why such children are not also allowed to make other decisions about their social care provision.

Options for reform

21.14 We do not think that it would be possible to achieve the changes that are required to secure the participation of disabled children in the meeting of their social care needs by way of guidance alone. This is both because of our general reservation about the appropriateness of relying on guidance (see further paragraphs 23.4 to 23.9) and because guidance cannot provide the statutory framework we consider is necessary:

(1) to set out what decisions disabled children can make in the context of the assessment and meeting of their social care needs; and

(2) to set out the basis upon which such children's ability to make those decisions is to be assessed.

21.15 We therefore do not consider this option further, but rather focus on the question of what changes in the law might be required to secure the goal of participation in the context of disabled children's social care. This gives rise to a series of questions as to what the law should provide.

(1) Should it set out what decisions children can make, or simply say that they can make *any* decision? The latter would go beyond our terms of reference and would not reflect the fact that there will be situations where the child's decision could never be determinative as it is not a matter for them, but for the local authority. It is therefore, in reality, not a viable option. This suggests that the law should set out a series of decisions that children can make in this context. But what should those decisions be?

(2) At what age should the law recognise that, in principle, a child could make a relevant decision? The Children and Families Act 2014 gives specific rights to

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[37] See the table at para 21.6 above.

children to make relevant decisions concerning assessment and development of education, health and care plans after the end of the academic year in which they turn 16. However, the Act does not give equivalent rights to those below 16. Maximising consistency with the Children and Families Act 2014 would suggest choosing this approach. However, maximising participation would suggest taking a broader approach. Such a broader approach would recognise the fact that children below the age of 16 may also have the ability to make relevant decisions – something which is already recognised by the law in other areas.

(3) What test should the law apply to determine whether a particular child could make a relevant decision? Capacity would appear to be the obvious option for a child aged 16 and above, and competence for a child below the age of 16. However, as we set out below, enshrining competence in any legal framework which might be put in place to respond to our proposals risks causing problems.

(4) How should the law protect children from making bad decisions in this context? The Children and Families Act 2014 does not provide any protection; the Care Act 2014 and the Social Services (Well-Being) Wales Act 2014 do.

21.16 Implementing decisions made about the child's care needs may well require consideration of how to proceed if they do not have the ability to consent to the touching that this may involve, or to other interferences with their autonomy. However, our initial view is that we cannot address those issues here because they raise wider questions falling outside of our terms of reference. This reinforces the view that we expressed in 2017 that Government should consider the question of children's competence and capacity more broadly.[38] It cuts across so many areas of the law that it is not possible to look at it properly within one discrete area in isolation.

Our provisional proposals

What decisions a child can take

21.17 Our provisional view is that we should follow the approach set out in the Children and Families Act 2014 and that the law should set out a series of decisions that a child (of any age, with the relevant ability) could take. Drawing on the decisions set out in the Children and Families Act 2014, but modifying them for our purposes, would lead to the position where the law would provide that children (of any age, with the relevant ability) can:

(1) request an assessment of social care needs (see further Chapter 3);

(2) make representations in the course of the assessment of those needs (see further Chapter 4);

(3) make representations about the content of any plan developed to meet those needs (see further Chapter 11);

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[38] Mental Capacity and Deprivation of Liberty (2017) Law Com No 372 para 7.40.

(4) opt-out of advocacy support where a duty to provide such advocacy is engaged (see further Chapter 22);

(5) request that services are provided by way of direct payments (see further Chapter 10); and

(6) make use of the relevant remedies that are available where a local authority has failed to assess or meet their needs appropriately (see further Chapter 18).

The age at which children can make decisions

21.18 Whilst recognising that it would come at the cost of inconsistency with the Children and Families Act 2014, we provisionally think that the goal of maximising participation is sufficiently important that the law should not set a lower age limit for children to have the right to make relevant decisions. This would mean that a child of any age, if they have the ability to do so, could make the decisions set out at paragraph 21.17 above.

Consultation Question 74.

21.19 We provisionally propose that legislation should provide that children (of any age) who have the ability to do so, can:

(1) request an assessment of social care needs (see further Chapter 3);

(2) make representations in the course of the assessment of those needs (see further Chapter 4);

(3) make representations about the content of any plan developed to meet those needs (see further Chapter 11);

(4) opt-out of advocacy support where a duty to provide such advocacy is engaged (see further Chapter 22);

(5) request that services are provided by way of direct payments (see further Chapter 10); and

(6) make use of the relevant remedies that are available where a local authority has failed to assess or meet their needs appropriately (see further Chapter 18).

Do consultees agree?

The test to determine whether an individual child can make a relevant decision

21.20 Whilst we have set out a list of decisions we provisionally think children should, in principle, be able to take, we do not suggest that *all* children would be able to take such steps. Some will simply be too young. Others may have a condition which means that they cannot make the decision. We need therefore to consider how any legislation could enable decision-makers to identify whether the particular child they are working with has the ability to take the step in question.

21.21 The position in relation to those aged 16 and over would appear self-evident, namely the test of capacity contained in the Mental Capacity Act 2005. That is the test which is applied in the Children and Families Act 2014 to answer essentially the same question. It is also the test which is of most general, though not universal, application to those aged 16 and over. Adopting the approach in the Mental Capacity Act 2005 would mean:

(1) that there was a presumption that the child had the capacity to make the relevant decision(s);[39]

(2) that a child could only be found to lack capacity to make the relevant decisions if all practicable support to help them to do so had been taken to them without success.[40]

(3) that the child could not be treated as unable to make the decision(s) merely because the decision(s) they made were unwise;[41] and

(4) that a child could only be found to lack the capacity to make the relevant decision(s) if their inability to understand, retain, use or weigh the relevant information, or communicate their decision, was caused by an impairment of or disturbance in the functioning of their mind or brain.[42]

Consultation Question 75.

21.22 We provisionally propose that the test for whether a child aged 16 or 17 is able to make the decisions set out in the question above should be the test contained in the Mental Capacity Act 2005.

Do consultees agree?

21.23 In respect of those below the age of 16, the question is more complicated, because there is no statutory test we can adopt. Unlike the concept of mental capacity, the concept of competence is purely a common law test. There are therefore two options.

(1) For the legislation simply to refer to competence without giving a further definition.

(2) For the legislation to spell out how the ability of the child to make the relevant decisions should be evaluated.

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[39] In line with the presumption of capacity in s 1(2) of the Mental Capacity Act 2005.

[40] In line with the “support principle” in s 1(3) of the Mental Capacity Act 2005.

[41] In line with the principle set out in s 1(4) of the Mental Capacity Act 2005.

[42] In line with the approach set out in s 2(1) of the Mental Capacity Act 2005.

21.24 It is important to understand the implications of both potential options. By referring simply to competence in the legislation relating to the assessment and meeting the needs of disabled children, Parliament would be telling decision-makers to adopt the common law definition, which is ultimately one determined by the courts. That is the approach taken in the Mental Health Act 1983 to decision-making about mental health treatment in the community.[43] It is also the approach that we took in our work on surrogacy in the context of accessing information on the surrogacy register.[44] Guidance could set out factors for decision-makers to apply when considering whether a child had or lacked competence, but there would be no statutory test to apply.

21.25 The other alternative is for the legislation to set out what it means for a child to have the ability to make the relevant decisions. This would mean that professionals would look to the legislation (amplified by guidance) to tell them what they need to do to test the ability of a child that they are working with. We were told in the work leading up to this consultation of the difficulties that at least some local authority social workers experienced in understanding the concept of competence. The difficulties experienced by professionals in understanding and applying the concept were also highlighted by the independent review of the Mental Health Act 1983[45] and the Parliamentary committee convened to consider the draft Mental Health Bill put forward by the previous Government.[46] Whilst professionals should have training, they will not necessarily be legally qualified, nor always able to access legal advice at speed. Clarity seems to us to be particularly important in this context, which means our provisional view is that legislation should set out a test. To the extent that we are provisionally proposing a slightly different approach to that we set out in our surrogacy project, we consider that such is justified by the particular demands of this area.

21.26 If legislation were to set out a test, which we provisionally think is the right option for the purposes of our project, we think that it would not be appropriate for the legislation to seek to codify the *Gillick* test. In other words, we do not think that it should say that it is defining the concept of *Gillick* competence. Our project is concerned with only one – albeit very important – area of the law. The test of *Gillick* competence is one that is used in many other areas, and we cannot within the terms of reference of our project seek to set out a test which would apply in all of those other contexts.

21.27 Rather, we think that the legislation should set out its own test that relevant professionals should apply to determine whether a child can make the relevant decisions. The most obvious candidate would be the functional test contained in the Mental Capacity Act 2005. That would require examination of whether the child can understand, retain, use and weigh the information relevant to the decision that they need to take, and whether they can communicate their decision. For the avoidance of

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[43] Mental Health Act 1983, ss 64E and 64F. See also Care Act 2014, s 12(6) in relation to the “consent condition” for carrying out assessments involving children.

[44] Building families through surrogacy: a new law (Volume II) (2023) Law Com No 411; Scottish Law Commission No 262 at paras 13.137 to 13.146.

[45] *Independent Review of the Mental Health Act 1983: supporting documents* (December 2018) p 296 and *Final Report of the Independent Review of the Mental Health Act 1983* (December 2018) p 174.

[46] Draft Mental Health Bill, Report of the Joint Committee on the Draft Mental Health Bill (2022-23) HC 696, HL Paper 128 para 216.

doubt, however, this would not represent the simple translation of the test in the Mental Capacity Act 2005, for two reasons.

(1) Unlike the position when the Mental Capacity Act 2005 is being applied to children aged 16 and over, there should be no presumption that the child can make the decision. Rather, and in line with the approach at common law contained in *Gillick*, it should be for the child to show that they have that ability. This recognises that, for all children, there is a maturation process. Below the age of 16, the burden is on the child to show their ability. Above the age of 16, and in line with the approach set out at paragraph 21.8 above, the burden shifts to others to show that the child does not have the ability.

(2) The Mental Capacity Act 2005 requires consideration of *why* the person cannot functionally make the decision in question, and whether that is caused by an impairment of or disturbance in the functioning of their mind or brain. In the context with which we are concerned, that it is not the relevant question. This is because the reason why the child may not be able to make the decision may be as simple as the fact that they are still very young. The focus would therefore solely be on whether the child can functionally make the decision in the way identified above.

21.28 The approach set out immediately above is, broadly, the approach adopted in Scotland in the Education (Additional Support for Learning) (Scotland) Act 2004. This sets out a statutory test for determining the ability of a child under 16 to make relevant decisions which is modelled directly on the relevant parts of the test for those aged 16 and over.[47] It is a test which coexists with the common law *Gillick* test of competence that operates in other areas of the law in Scotland. From speaking to those with experience of the Scottish legislation in the lead up to this consultation, we have the impression that the test set out in the 2004 Act has worked well since it came into force in January 2018 in the context of appeals to the equivalent of the Special Educational Needs and Disability Tribunal.

21.29 There would undoubtedly be similarities between the test that we are setting out here and the common law *Gillick* test of competence. Our work leading up to this consultation suggests that many practitioners do, in practice, already use the functional test set out above to assess whether a child is competent. Further, some judges have already incorporated it in their consideration of whether a child is *Gillick* competent. Mr Justice Cobb, for instance, considered the test of competence to a child parent to consent to the adoption of their child in *Re S (child as parent: adoption: consent)*.[48] In doing so, he regarded it as “appropriate, and indeed helpful to read across to, and borrow from, the relevant concepts and language of the Mental Capacity Act 2005”.[49]

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[47] Education (Additional Support for Learning) (Scotland) Act 2004, s 3(1)(b). This mirrors the definition of capacity for those aged 16 and above in the Adults with Incapacity (Scotland) Act 2000, s 1(6).

[48] *Re S (child as parent: adoption: consent)* [2017] EWHC 2729 (Fam), [2019] Fam 177 at [16].

[49] *Re S (child as parent: adoption: consent)* [2017] EWHC 2729 (Fam), [2019] Fam 177 at [16]. A similar approach was taken by MacDonald J in *An NHS Trust v ST (Refusal of Deprivation of Liberty Order)* [2022]

21.30 However, it is important to understand that the test we are proposing would be a statutory test, applying for a particular purpose; it would not replace *Gillick* outside the specific context with which we are concerned. Unless other statutes were amended to include the test we are provisionally proposing, it would be a matter for judges considering situations in which the common law test applied whether or not they drew upon that statutory test in refining the common law approach.[50]

21.31 We have set out above the two options for a statutory test to determine whether a child under 16 could make relevant decisions within the framework that we provisionally propose. Whilst we think there does need to be a statutory test, we want to understand consultees' views about the relative merits of the two options that we have set out before we reach a final view.

Consultation Question 76.

21.32 We invite consultees' views as to whether legislation should provide that the test for whether a child aged under 16 is able to make the decisions set out in the question above is:

(1) competence (and not provide any further definition of the term); or

(2) the child's ability to understand, retain, use and weigh the relevant information, and to communicate their decision.

Should the law protect children against bad decisions?

21.33 One implication of our approach is that children with the ability to do so may wish to exercise their rights in a way that others find problematic. Children, like adults, can make bad decisions. This is an inevitable consequence of giving real effect to the concept of participation. This gives rise to the question of whether and how the law should limit their participation to protect them from the consequences of a bad decision. Participation is important, but no-one has suggested to us that this should be at the expense of allowing children to come to harm.

21.34 The Care Act 2014 addresses this situation in the context of "transitional" assessments. It provides that where a child refuses a child's needs assessment and

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EWHC 719 (Fam). When considering whether the child (aged 14) was *Gillick* competent, it was noted that she was able to understand simple information relevant to the decision but "was considered unable to retain the information or use and weigh it, in order to make a relevant decision" [26]. The Court of Appeal in *Bell & Anor v The Tavistock and Portman NHS Foundation Trust* [2021] EWCA Civ 1363, [2022] PTSR 544 observed that they did not "think that the comparison between the exercise of assessing *Gillick* competence and the process envisaged under the Mental Capacity Act 2005 … assists" (at [83] by Lord Burnett). However, it appears that these comments were addressed at the requirement to identify an impairment of or disturbance in the functioning of their mind or brain, rather than the aspects of the test concerned with the child's ability to understand, retain, use and weigh relevant information.

[50] This is similar to the position as regards the Mental Capacity Act 2005, which does not apply save where statute provides that it does, albeit that judges can adopt the definition for the purposes of a test governed by the common law where they consider it to be appropriate. See *Local Authority X v MM (adult)* [2007] EWHC 2003 (Fam), [2009] 1 FLR 443 at [80] by Munby J and *Re Clitheroe* [2021] EWHC 1102 (Ch), [2021] COPLR 380 at [51] to [72] by Falk J.

the consent condition is accordingly not met, the local authority must nonetheless carry out the assessment if the child is experiencing, or is at risk of, abuse or neglect.[51] The Social Services and Well-Being (Wales) Act 2014 takes a similar approach, but makes further provision for the situation where the duty to assess has come to an end because the child has refused such an assessment. That duty is then re-engaged if the child subsequently asks for an assessment and the local authority is satisfied that the child has sufficient understanding to make an informed decision about having an assessment.[52] We think that a similar approach should be taken in any legislative framework for assessing and meeting the needs of disabled children.

Consultation Question 77.

21.35 We provisionally propose that the law should provide that a local authority must carry out an assessment of the social care needs of a disabled child where the child is seeking to opt out of such an assessment if the child is experiencing, or is at risk of, abuse or neglect.

Do consultees agree?

Taking the views of the child into account

The current law

The statutory framework

21.36 We now turn to the situation where a local authority has to make a decision about social care for a disabled child, and the child's participation is limited to having their views taken into account.

21.37 The most significant instance of this is contained in section 17 of the Children Act 1989. This did not initially include any express requirement to secure the participation of the child in the process of assessing and meeting their needs. However, with effect from 1 March 2005, section 17(4A) was introduced by the Children Act 2004[53] to provide that:

> (1) before determining what (if any) services to provide for a particular child in need in the exercise of functions conferred on them by this section, a local authority shall, so far as is reasonably practicable and consistent with the child's welfare –
>
> > (a) ascertain the child's wishes and feelings regarding the provision of those services; and
> >
> > (b) give due consideration (having regard to his age and understanding) to such wishes and feelings of the child as they have been able to ascertain.

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[51] Care Act 2014, s 58(4).

[52] Social Services and Well-Being (Wales) Act 2014 (anaw 4), s 24(a).

[53] Children Act 2004, s 53(1).

21.38 A similar duty was introduced for local authorities undertaking child protection investigations.[54] These duties complement requirements relating to the wishes and feelings of children who are, or may be, looked after,[55] including those who are provided with accommodation under section 20 and children taken into police protection.[56]

21.39 The Children and Families Act 2014 provides a stronger statutory participation component than the Children Act 1989. The 2014 Act requires local authorities to have particular regard to the wishes and feelings of the child[57] when discharging relevant functions (for our purposes, the assessment and meeting of special educational needs).[58] It also goes further by requiring the local authority to have particular regard to:[59]

> (b) the importance of the child … participating as fully as possible in decisions relating to the exercise of the function concerned; and
>
> (c) the importance of the child … being provided with the information and support necessary to enable participation in those decisions.

Statutory guidance

21.40 The *Working Together* guidance emphasises that:

> Anyone working with children should see and speak to the child, listen to what they say, observe their behaviour, take their views seriously, and work with them and their families and the people who know them well when deciding how to support their needs. Practitioners should also be aware that children may find it difficult to always speak about what they need, what is happening to them or what has happened to them. Legal duties under the Equality Act 2010 must be complied with, including putting special provision in place to support dialogue with children who may not be able to convey their wishes and feelings as they may want to. This might include, for example, those who have communication difficulties, unaccompanied children, refugees, those children who are victims of modern slavery and/or trafficking and those who do not speak English or for whom English is not their first language.[60]

21.41 We have addressed in Chapters 3 and 4 above the assessment process itself, but for present purposes we observe that the *Working Together* guidance gives little concrete

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[54] Children Act 1989, s 47(5A), introduced by Children Act 2004, s 53(3).

[55] Children Act 1989, s 22(4).

[56] Children Act 1989, s 46(3)(d).

[57] Consistent with the position set out in para 1.22 above, we use the word “child” here, although the Children and Families Act 2014 talks of children and young people, depending upon their age.

[58] Children and Families Act 2014, s 19(a).

[59] Children and Families Act 2014, s 19.

[60] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 14 (footnote omitted).

detail as to how practitioners should secure the participation of the child, with the exception of noting that:

> Observation can be an important way to get the perspective of babies, infants, and non-verbal children. In the case of disabled children, practitioners should consider whether any specialist communication support is required and consider how advocacy services can support the child to communicate their views.[61]

21.42 The *Children's Social Care National Framework* provides as one of its six principles of children's social care that "children's wishes and feelings are sought, heard, and responded to".[62] The *Framework* provides somewhat more detail than *Working Together*, providing as an "expectation for practice" as regards responding to voices of children, young people and families that:

> Every area makes sure that practice is flexible and adaptive so that the perspectives of children, whatever their age or ability, can be heard, including, where required, through the provision of independent advocacy. This includes consideration of the wishes and feelings of children who are not yet old enough to talk or who, for reasons of disability, cannot communicate verbally or prefer other means of communication, as well as provision for children for whom English is not their first language.
>
> Every area supports children and young people to share their wishes and feelings freely and independently from the views of parents, carers, or other adults in their lives.[63]

21.43 The *Special Educational Needs and Disability Code of Practice* goes into considerably greater detail than the other two documents discussed above about participation, with a particular focus on what to do as children get older.[64]

The case for reform

21.44 As we noted above at paragraph 21.10, our work preparing for this consultation has led us to agree with the independent review of children's social care that the aim of strengthening the voice of the child in decision-making in this area has not been achieved. This is particularly so where the child has either communication difficulties or cognitive disabilities. We are told that children are not always involved or consulted in decision making in these instances. Stakeholders gave different reasons for why this might be the case, including lack of expertise on the part of assessors, and also (in some cases) a misconception that a child who was not verbal could not have relevant wishes and feelings.

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[61] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 161.

[62] Department for Education, *Children's Social Care National Framework* (December 2023) p 14.

[63] Department for Education, *Children's Social Care National Framework* (December 2023) p 30.

[64] Department for Education and Department of Health, *Special Educational Needs and Disability Code of Practice: 0-25 years* (January 2015) pp 20-21 and chapter 8.

Options for reform

21.45 The main options are whether to model the approach to participation on that contained in the Children Act 1989 or the Children and Families Act 2014. We provisionally favour the latter because it is clearer and simpler. Further, the approach in the Children Act 1989 frames the issue as one of ascertaining the child's wishes and feelings; the approach in the Children and Families Act 2014 goes further, requiring the taking of active steps to support the child to participate fully. This would seem to be of particular importance in the context of children who may require greater assistance to be able to make their wishes and feelings known.

Our provisional proposals

21.46 We do not make specific provisional proposals here, but rather refer consultees to paragraph 20.33, where we outline how the approach set out in the Children and Families Act 2014 would feature in our provisional checklist for decision-makers. The accompanying statutory guidance could, in turn, identify practical steps that can be taken to ensure that professionals maximise the child's ability to express their wishes and feelings, especially where additional and creative steps are to be taken.

The relationship between our proposals and the process of assessment under the Children and Families Act 2014

21.47 For completeness, and to assist consultees in their consideration of the questions set out above, we set out here the relationship between our provisional proposals for children's participation and the approach to participation in the Children and Families Act 2014.

(1) The position would be materially identical as regards the ability of a 16- or 17-year old to make a request for assessment, to make representations in the course of assessment, and about the content of any plan developed as a result of the assessment, and to exercise a right to pursue remedies.

(2) Children under 16 (with the requisite ability, see further paragraphs 21.23 to 23.32) would be able to make requests for assessments, and representations in the course of those assessments and exercise rights to pursue remedies in a way that the Children and Families Act 2014 does not provide for.

(3) The position would be different as regards the ability of a 16- or 17- year to refuse an assessment (subject to safeguarding concerns) for social care needs, as such a 16- or 17- year old does not have the ability to opt-out of an assessment under the Children and Families Act 2014. Consultees may wish to note in this regard that Welsh legislation, which allows for an opt-out in relation to social care assessment, does not allow for an opt-out in relation to additional learning needs assessments.

(4) The position would be different as regards advocacy, a matter we address further in Chapter 22.

PARTICIPATION OF OTHERS FOR THE CHILD'S BENEFIT

The current law

21.48 In general, the Children Act 1989 does not contain any express requirement to take into account the views of parents and carers when making decisions about disabled children. Nor – as a consequence – does it require any particular weight to be given to those views. The exceptions are in relation to direct payments, where the parent must consent,[65] and (more tenuously) in relation to the design of short breaks services.[66]

21.49 In contrast, the Children and Families Act 2014 makes express reference to the importance of the child's parent participating as fully as possible in relevant decisions.[67] This means that, indirectly, the child's parents will be included in some social care decisions where they are being considered as part of the education, health and care plan development process.

21.50 The Children and Families Act 2014 also emphasises the importance of the child's parents being provided with the information and support necessary to enable participation.[68] We note in this regard that the nature of such support will vary, not least if the parent or carer is themselves disabled.

Statutory guidance

21.51 The new *Working Together* guidance has a section on principles for working with parents and carers. However, nowhere in the section is there an express recognition that such parents and carers will – in very many cases – have expertise to bring to bear as regards the needs of their child. In similar vein, the *Children's Social Care National Framework* places the centre of expertise with the professionals, requiring that "practitioners are confident to identify the needs of disabled children and support families to meet their needs".[69] As we have discussed in Chapter 4, practitioner expertise is important, but so, too, is the expertise of parents and carers.

21.52 Building on this, the statutory *Special Educational Needs and Disability Code of Practice* emphasises that:

> Local authorities, early years providers and schools should enable parents to share their knowledge about their child and give them confidence that their views and contributions are valued and will be acted upon.[70]

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[65] Children Act 1989, s 17A(2), unless the direct payments are being made on the basis of the consent of a disabled child aged 16 or 17 (see the table following para 21.6 above).

[66] Children Act 1989, sch 2, para 6(1)(c) and the Breaks for Carers of Disabled Children Regulations 2011, SI No 707, reg 3(1).

[67] Children and Families Act 2014, s 19(1)(b).

[68] Children and Families Act 2014, s 19(1)(c).

[69] Department for Education, *Children's Social Care National Framework* (December 2023) p 33.

[70] *Special Educational Needs and Disability Code of Practice: 0-25 years* para 1.7.

The case for reform

21.53 As we explain at paragraph 21.45 above, we provisionally consider that the approach to the participation of the child in the Children and Families Act 2014 is better than approach in the Children Act 1989, as it requires more active steps to be taken to support participation. We think the same is also true when it comes to the participation of the child's parents and carers. We have been reinforced in this view in the work that we have done preparing for this consultation. Many parents and carers we have heard from feel that they are not listened to and that their knowledge of their own child and the expertise they have developed in their child's condition and how best to meet their needs are often overlooked. This can mean that important information about the child is missed. It also adds to the stress that parents experience.

21.54 In this context, it is perhaps of note that the *Working Together* guidance does not appear to recognise the expertise of such parents and carers. Rather, it appears to place some parents and carers of disabled children in the category of those whom services find difficult to engage:

> Practitioners need to be particularly skilled in engaging and working with parents and carers whom services have found difficult to engage. Some examples may be parents and carers of disabled children, parents, and carers whose children are at risk of, or experiencing, harm from outside the home, fathers, and male carers, and those who are neurodivergent.[71]

21.55 We should be very clear that we recognise – as we do elsewhere in this consultation paper – that not all parents and carers are able or willing to participate in assessments in the interests of their children. However, our provisional view is that the starting point should be that parents and carers have expertise regarding their children which may be different to, but is not necessarily of lesser weight than, that of the professionals conducting the assessments. For these reasons we think that the law needs to change as regards the participation of parents and carers in the assessment of the needs of disabled children.

Options for reform

21.56 We have considered whether it would be possible simply to address the problem we have identified by way of guidance. However, as we will come on to discuss further in Chapter 23, we have real reservations about reliance upon guidance. This is particularly so in relation to such an important issue as securing the proper participation of parents and carers in the assessment of the needs of disabled children.

21.57 The other option would be to introduce legislative change. The obvious model to draw upon would be that contained in the Children and Families Act 2014. However, that approach requires modification to enable consideration of the role of those other than parents who are caring for the disabled child.

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[71] HM Government, *Working Together to Safeguard Children 2023* (December 2023) para 18.

Our provisional proposals

21.58 We do not make specific provisional proposals here. Rather, we refer consultees to paragraph 20.33, where we outline how an approach drawing on the Children and Families Act 2014 (but modified to provide for carers as well as parents) would feature in our provisional checklist for decision-makers.

PARTICIPATION OF OTHERS IN THEIR OWN ASSESSMENTS

21.59 We do not address this issue in detail here but refer consultees to Chapters 5 and 6, where we discuss parents’ and carers’ (including young carers) assessments. For present purposes, we highlight that there will need to be consideration of when the parent, carer or young carer is able to advocate for their own needs, and when they require assistance to do so. That inevitably leads to the questions of when and why advocacy should be available, which we address in Chapter 22.

Chapter 22: Advocacy

INTRODUCTION

22.1 There has long been recognition by disability groups, professionals, service providers and service users of the importance of advocacy and the valuable role it can play. Advocacy in social care refers to a particular role, distinct from advocacy in legal proceedings as understood by lawyers. The role of the advocate is to assist disabled people to speak up for themselves, or if the disabled person is unable to do so, to communicate and represent the disabled person’s needs and wishes. Advocacy is, therefore, seen as a vital component of achieving independent living and full citizenship for disabled people. It is just as important, if not even more important, for children as it is for adults.

22.2 Advocacy can take a number of forms. It can be statutory or non-statutory. It can be informal, or it can be paid. It can also be instructed (directed by the person themselves) or non-instructed (the advocate seeks to identify the person’s preferences).[1] Supporting children to speak up for themselves can be seen as supporting self-advocacy. For present purposes, we focus on the legal requirements to secure advocacy assistance for children and their parents and carers.

22.3 This chapter should be read together with Chapter 23, in which we discuss our provisional proposals for a new framework for social care for disabled children. As discussed below and in that chapter, we think that it would be very difficult to make the changes that we consider in this chapter without a new legal framework.

ADVOCACY FOR CHILDREN

The current law

22.4 There is a range of statutory entitlements to advocacy for children. They are complicated and spread across a number of legislative provisions. The most relevant entitlement for present purposes is to be found in section 26A of the Children Act 1989, which provides that:

> (1) Every local authority shall make arrangements for the provision of assistance to —
>
> …
>
> (b) children who make or intend to make representations under section 26.

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[1] For further detail of the differences, see the proposed new national standards for advocacy consulted upon by the Department for Education in the autumn of 2023: Department for Education, *National Standards for the Provision of Children and Young People’s Advocacy Services* (September 2023) pp 15 to 17. We recognise that some stakeholders do not like the term “non-instructed” advocacy as, in effect, it appears to be a licence to exclude the participation of the child. We address this issue below at para 22.39.

> (2) The assistance provided under the arrangements shall include assistance by way of representation.

22.5 Section 26 provides in material part that:

> (3) Every local authority shall establish a procedure for considering any representations (including any complaint) made to them by—
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> > (a) any child who is being looked after by them or who is not being looked after by them but is in need;
> >
> > (b) a parent of his;
> >
> > (c) any person who is not a parent of his but who has parental responsibility for him;
> >
> > (d) any local authority foster parent;
> >
> > (e) such other person as the authority consider has a sufficient interest in the child's welfare to warrant his representations being considered by them,
>
> about the discharge by the authority of any of their qualifying functions in relation to the child.

22.6 These provisions are amplified by the Advocacy Services and Representations Procedure (Children) (Amendment) Regulations.[2] These include, in particular, a duty to provide information about advocacy services and to offer help in finding an advocate to a child or young person who is making representations or, when they become of aware of the fact, who is intending to make representations.[3] "Qualifying functions" in section 26 include the local authority's functions under Part 3 of the Children Act 1989, including those under section 17.[4]

22.7 These provisions can be read as securing the right of a child in need by way of disability to call upon assistance to make representations in relation to the assessment of their needs under section 17 of the Children Act 1989.[5] However, as we return to below, the relevant statutory guidance appears to point in a different direction.

22.8 Where a local authority considers that it is required to arrange an advocate, it is not necessarily the case that the advocate will be provided by way of an externally commissioned agency. Advocacy support under the Children Act 1989 can be provided by people employed directly by local authorities. In a December 2023 report, the Children's Commissioner for England found that 14% of local authorities in England provided advocacy solely through in-house employees, and a further 28%

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[2] SI 2004 No 719.

[3] Advocacy Services and Representations Procedure (Children) (Amendment) Regulations 2004, SI No 719, reg 4.

[4] Children Act, s 26(3A)(a).

[5] Reading Children Act, s 26A(1)(b) together with s 26(3)(a).

provided advocacy through a combination of in-house and externally commissioned services.[6]

22.9 By contrast, duties to provide access to independent[7] advocacy arise in respect of the following categories.

(1) Children who may need continuing care and support in adulthood, under sections 58 and 67 of the Care Act 2014. By contrast to the position under the Children Act 1989, the duty to arrange an independent advocate under section 67 of the Care Act 2014 is not engaged where the child wishes to make representations about the discharge of assessment functions. Rather, and subject to an important caveat, the duty is engaged automatically to support the child's involvement in the process of assessment, if the local authority considers that:

> were an independent advocate not to be available, the individual would experience substantial difficulty in doing one or more of the following—
>
> (a) understanding relevant information;
>
> (b) retaining that information;
>
> (c) using or weighing that information as part of the process of being involved;
>
> (d) communicating the individual's views, wishes or feelings (whether by talking, using sign language or any other means).[8]

The caveat is that the duty to appoint does not arise if the local authority is satisfied that there is an appropriate person who can support the child's involvement in the assessment. That person must also not be providing care or treatment for the child in a professional capacity or for remuneration.[9]

(2) Carers[10] for children who are likely to need support in adulthood, under sections 61 and 67 of the Care Act 2014.

(3) Young carers for adults who may themselves need support in adulthood, under sections 63 and 67 of the Care Act 2014. The same approach applies as in relation to advocacy support in respect of transitional assessments.

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[6] Children's Commissioner for England, *The state of children and young people's advocacy services in England* (December 2023) p 38.

[7] With statutory provisions guaranteeing independence: see, for instance, Care and Support (Independent Advocacy Support) (No. 2) Regulations 2014, SI No 2889, reg 2(3)(b), which provides that a Care Act 2014 advocate cannot be employed by, or otherwise working for, the local authority.

[8] Care Act 2014, s 67(4).

[9] Care Act 2014, s 67(5).

[10] "Carer" being defined as an adult (including one who is a parent of the child) who provides or intends to provide care for the child, but not on a contractual basis or as voluntary work: Care Act 2014, s 61(8) read together with s 60(7).

(4) Those under-18 detained under the relevant provisions of the Mental Health Act 1983, and therefore entitled to advocacy support from an Independent Mental Health Advocate under the provisions of section 130A of the Mental Health Act 1983.

(5) Those aged 16 or 17 lacking the material decision-making capacity and entitled to advocacy support from an Independent Mental Capacity Advocate in relation:

(a) to the provision of accommodation in a hospital or care home by an NHS body; or

(b) accommodation by a local authority under section 117 of the Mental Health Act 1983.[11]

22.10 Other duties that are more properly identified as securing access to advocacy (rather than placing a direct duty to commission advocacy) arise in respect of looked after children whose care and progress is being reviewed,[12] and children and young people living in children's homes.[13]

22.11 Further, the Department for Education considers[14] that entitlement to advocacy also arises in respect of two further categories of children.

(1) Children and young people in residential special schools who qualify for advice and assistance. The Department for Education considers that such entitlement arises in consequence of two interlocking requirements. The first is the obligation imposed by section 19 of the Children and Families Act 2014 on local authorities to have regard to the views, wishes and feelings of children and young people when exercising relevant functions. The second is paragraph 2.15 of the *Special Educational Needs and Disability Code of Practice*, which provides that "advocacy should be provided where necessary".[15] The *Code of Practice* does not specify the powers under which advocacy can be provided in this respect, other than in respect of young people undergoing transition assessments. As paragraph 2.15 notes, this is a mandatory requirement where the conditions set out in section 67 of the Care Act 2014 are met. Otherwise, it is not clear to us that there is any standalone power under section 19 of the Children and Families Act 2014 to provide advocacy support in the context of residential special schools (a point we develop in the next paragraph).

(2) Children in secure settings who qualify for advice and assistance. Rule 44 of the Secure Training Centre Rules 1998[16] provides that children in custody

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[11] Mental Capacity Act 2005, s 39(1) and (2) (in both cases, the accommodation must be provided for a period of time exceeding a statutory minimum).

[12] Care Planning, Placement and Case Review (England) Regulations 2010, SI No 959, reg 45(1).

[13] Children's Homes (England) Regulations 2015, SI No 541, reg 7.

[14] Department for Education, *National Standards for the Provision of Children and Young People's Advocacy Services* (September 2023) p 37 in an annex entitled "advocacy entitlements".

[15] Department for Education and Department of Health and Social Care, *Special Educational Needs and Disability Code of Practice: 0-25 years* (January 2015) para 2.15.

[16] SI 1998 No 472.

should be able to make representations to “independent persons”. As the Department for Education explains, “independent persons” has been interpreted as meaning “advocates” by the Youth Justice Board.

22.12 The Children and Families Act 2014 does not contain provision for advocacy in the same way as either the Children Act 1989 or the Care Act 2014. The Children and Families Act 2014 contains a power[17] to make regulations providing for advocacy and other support services, but only in the context of mediation about disputes involving special educational needs (see further Chapter 13). The regulations made under that power[18] do not include provisions relating to advocacy. There is a right to “support” under the Special Educational Needs and Disability Regulations 2014,[19] but it is unclear on the face of the regulations whether this includes advocacy[20]. Even if it does, it is a right which only extends to the child’s parents or, in the case of a young person,[21] the young person; it does not extend to a younger child.

22.13 We are aware that Special Educational Needs and Disabilities Information Advice and Support Services[22] commissioned by local authorities do provide support and, on occasion, advocacy services. It may be that in all the situations not covered by the express duty to commission advocacy under section 67 of the Care Act 2014, local authorities are in fact commissioning such services under section 1 of the Localism Act 2011. However, even if this is the case, there are no statutory criteria to identify when a child should be entitled to support from an independent advocate in such situations.

22.14 We have not been able to identify any specific reasons advanced at the time of the introduction of what became the Children and Families Act 2014 to explain the difference in approach to advocacy in that Act to that set out in the Children Act 1989.[23]

Statutory guidance

22.15 As noted at paragraph 22.7 above, reading the relevant statutory provisions together could lead to a situation in which a disabled child is supported by an independent advocate during an assessment under section 17 of the Children Act 1989. That does

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[17] Children and Families Act 2014, s 56(1)(f).

[18] Special Educational Needs and Disability Regulations 2014, SI No 1530.

[19] SI 2014 No 1530, reg 9.

[20] Special Educational Needs and Disability Regulations 2014, SI No 1530, reg 9 uses the word “support”. In contrast, Children and Families Act 2014, s 56(1)(f) (discussed in the paragraph below) uses the word “advocacy”. This suggests that, in the context of special educational needs and disability law, support and advocacy may be distinct services.

[21] In other words, a child over compulsory school age. See para 1.16 above.

[22] Required under sections 30 to 33 of the Children and Families Act 2014 and Part 4 of and Schedule 2 to The Special Educational Needs and Disability Regulations 2014, SI No 1530.

[23] A Hansard search, for instance, does not show any reference to the word “advocacy” during the passage of the Bill, nor was there any reference to advocacy outside the context of mediation in the Explanatory Notes provided with the Bill. The detailed command paper produced in response to pre-legislative scrutiny of the Bill, similarly, made no mention of advocacy for children: Children and Families Bill 2013: Contextual Information and Responses to Pre-Legislative Scrutiny (2013) Cm 8540.

undoubtedly happen on occasion.[24] However, the statutory guidance points away from this in two ways:

(1) The current version of the statutory guidance on advocacy does not address assessment under section 17 of the Children Act 1989. Rather, it focuses on the situation where a child or young person wishes to make a complaint after the event. See, for instance, this passage:

> Children and young people can be especially vulnerable at times when they have a problem or want to make a complaint. The emphasis in this guidance is on early detection and early resolution, so that concerns and problems are put right quickly and effectively. Complaints procedures should be devised and operated in the wider context of encouraging children to speak out and encouraging decision-makers to hear their views.[25]

There is also no reference to the provision of advocacy during the conduct of assessments and care planning under section 17 in the proposed revised *National Standards for the Provision of Children and Young People's Advocacy Services* issued for consultation in September 2023.[26]

(2) The statutory guidance on advocacy, accurately reflecting the fact that there is no right to independent advocacy, also points away from it in outlining the choices available to children and young people:

> There will be times when children and young people will wish to choose their own advocate, for example, a relative, teacher, carer, friend or family member. Children and young people may select anyone of their choice as an advocate although there may be reasons why the person chosen by the child should not agree to take on the role, for example, there might be a conflict of interest. Children and young people should be helped by the complaints officer, children's rights officer or equivalent officer to understand the choices open to them and the differences between the options. For example, the child should be helped to understand the differences in the kind of support available and be helped to make an informed choice between "informal" advocacy provided by a relative or friend and a professional advocate provided under the arrangements made by the local authority.[27]

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[24] Research by the Children's Commissioner for England, *The state of children and young people's advocacy services in England* (December 2023) identifies at a number of points in the report (in particular p 21) that some local authorities make referrals for advocacy in respect of children being assessed by children's social care. Logically, we would anticipate that these assessments were being carried out under section 17 of the Children Act 1989, although the research does not expressly state this.

[25] Department for Education and Skills, *Providing Effective Advocacy Services for Children and Young People Making a Complaint under the Children Act 1989* (2004) para 2.1.

[26] Department for Education, *National Standards for the Provision of Children and Young People's Advocacy Services* (September 2023).

[27] Department for Education and Skills, *Providing Effective Advocacy Services for Children and Young People Making a Complaint under the Children Act 1989* (2004) para 2.13.

The case for reform

22.16 In December 2023, the Children's Commissioner for England published a report on the state of children and young people's advocacy services in England.[28] The report both makes clear the benefits of advocacy and the problems with accessing high-quality advocacy. As the Children's Commissioner found, even when children get a referral to an advocate (and most children do not), many referrals do not result in children getting direct support from an advocate.[29] The Children's Commissioner also noted that there:

> are also inconsistencies in how advocates are trained and the qualifications they are required to have to advise children on their rights and entitlements. Fundamental to an advocate's ability to stand up for a child is that they both are, and are seen to be, genuinely independent. But this report shows that there are real question marks about how [many] independent advocates are from the local authority that commission them.[30]

22.17 The findings reported in the Children's Commissioner's research chime with the views expressed to us by many stakeholders in the lead up to this consultation, including by children and young people themselves. Taken together, we consider that there is a case for reconsidering the approach to advocacy in the context of disabled children.

22.18 We are aware that there have been a number of initiatives under way in relation to advocacy. Between September and December 2023, the Department for Education consulted on a revised version of the *National Standards for the Provision of Children Advocacy Services 2002*.[31] The title of the proposed revised version is extended expressly to cover young people's advocacy services.[32] Both the current and proposed versions emphasise the benefits of advocacy and set out clear ways in which to secure those benefits.

22.19 At the same time as consulting on a revised version of the *National Standards*, the Department for Education consulted on a revised version of the 2004 guidance relating to complaints and representations under the Children Act 1989.[33] The proposed revised version, *Effective Advocacy for Looked-After Children, Children in*

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[28] Children's Commissioner for England, *The state of children and young people's advocacy services in England* (December 2023).

[29] Children's Commissioner for England, *The state of children and young people's advocacy services in England* (December 2023) p 4.

[30] Children's Commissioner for England, *The state of children and young people's advocacy services in England* (December 2023) pp 4 and 5.

[31] Department of Health, *National Standards for the Provision of Children's Advocacy Services* (November 2002).

[32] Department for Education, *National Standards for the Provision of Children and Young People's Advocacy Services* (September 2023).

[33] Department for Education and Skills, *Providing Effective Advocacy Services for Children and Young People Making a Complaint under the Children Act 1989* (April 2004).

Need and Care Leavers,[34] is broader in focus than the 2004 guidance. The proposed revised version recognises that:

> advocacy is an option available to children and young people whenever they want advocacy support in asking them to represent them in meetings and not just when they want to make a formal complaint.[35]

22.20 It also makes clear that:

> A child or young person can request an advocate at any time. There are, however, key points in their lives when, due to a significant or unexpected change, or an identifiably high level of need, having an advocate will ensure that their views, wishes and feelings are listened to and taken into account.[36]

22.21 However, we note that none of the examples where commissioning organisations should be actively offering advocacy assistance are ones where the local authority is assessing whether the child is a child in need for the purposes of section 17 of the Children Act 1989.

22.22 The independent review of children's social care recommended that "independent, opt-out, high quality advocacy for children in care and in proceedings should replace the existing Independent Reviewing Officer and Regulation 44 Visitor roles".[37] The review also recommended that the Children's Commissioner for England should oversee these advocacy services, with powers to refer children's complaints and concerns to the court. The Government supported the need for an independent, opt-out advocacy service, but did not accept the recommendation to remove the role of independent reviewing officer and Regulation 44 visitors.[38] We understand that, before the 2024 general election, the Department for Education had been working with the sector on options to implement an opt-out model of independent advocacy.

22.23 In April 2023, the Child Safeguarding Practice Review Panel made a limited recommendation in relation to advocacy. That was that all children with disabilities and complex health needs in residential settings should have access to independently commissioned, non-instructed advocacy from advocates with specialist training to actively safeguard the children and respond to their communication and other

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[34] Department for Education, *Effective Advocacy for Looked-After Children, Children in Need and Care Leavers: Statutory guidance for local authorities* (September 2023).

[35] Department for Education, *Effective Advocacy for Looked-After Children, Children in Need and Care Leavers: Statutory guidance for local authorities* (September 2023) p 5.

[36] Department for Education, *Effective Advocacy for Looked-After Children, Children in Need and Care Leavers: Statutory guidance for local authorities* (September 2023) p 20.

[37] J MacAlister, *The independent review of children's social care – Final Report* (May 2022) p 183. "Opt-out" advocacy means that an advocate must be provided unless the child declines the provision of such advocacy. As to the independent reviewing officer see para 8.20 above. Regulation 44 Visitors are those appointed under the Children's Homes Regulations 2015, SI No 541, reg 44.

[38] Department for Education, *Stable Homes, Built on Love: Implementation Strategy and Consultation* (February 2023) p 196.

needs.[39] In its response,[40] the Department for Education pointed to the consultation on revised *National Standards* for the provision of advocacy noted above. It also noted that a requirement has been added to the relevant minimum standards for boarding schools and residential special schools[41] to comply with the revised *National Standards*.

22.24 However, it is important to note that neither the independent review of children's social care nor the Child Safeguarding Practice Review Panel were considering the position of advocacy in the broader context of the assessment and meeting of needs under section 17 Children Act 1989. Nor do we understand that the Department for Education was considering implementing opt-out independent advocacy other than for children in care before the 2024 general election.

22.25 One other, distinct, theme that emerged in our engagement was the importance of culturally competent advocacy, recognising the specific needs of disabled children from different communities. This is a matter which has also been raised, most recently, in the context of the review of and proposed reforms to the Mental Health Act 1983.[42] In both the proposed *National Standards* for the provision of advocacy, and the proposed guidance on providing advocacy, the (relatively limited) coverage of this issue focuses on the recruitment of advocates from different backgrounds.[43] Based on the work that have conducted in the lead up to this consultation, our provisional view is that this is likely to be part of the solution, but not the whole of it.

22.26 Finally, we note that in December 2023 the Children's Commissioner for England recommended that the following steps be taken.

(1) The opt-out model of advocacy provision should be explicitly extended to all children who have a statutory entitlement to advocacy, including for example young carers and children with special educational needs and disabilities.

(2) A new independent, national advocacy service should ensure local authorities have access to a sufficient number of advocates who can provide independent and high-quality advocacy for children and young people. The Children's Commissioner recommended that the Department for Education should fund this organisation to act as a broker between local authorities and external advocacy providers to ensure the needs of children and young people are met across local authorities and independence is maintained. The Children's

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[39] Child Safeguarding Practice Review Panel, *Safeguarding children with disabilities and complex health needs in residential settings: Phase 2 report* (April 2023) recommendation 1.

[40] Department for Education, *Safeguarding children with disabilities and complex health needs in residential settings: government response* (December 2023) pp 17 and 18.

[41] Both published by the Secretary of State for Education under Children Act 1989, s 87C(1).

[42] See the *Final Report of the Independent Review of the Mental Health Act 1983* (December 2018) pp 90 to 95; Draft Mental Health Bill, Report of the Joint Committee on the Draft Mental Health Bill (2022-23) HC 696, HL Paper 128 pp 95 to 99 and Department of Health, *Government response to the Joint Committee on the draft Mental Health Bill* (2024) CP 1036 pp 29 and 30.

[43] Department for Education, *National Standards for the Provision of Children and Young People's Advocacy Services* (September 2023) p 23 and Department for Education, *Effective Advocacy for Looked-After Children, Children in Need and Care Leavers: Statutory guidance for local authorities* (September 2023) p 23 under "Advocates represent a range of backgrounds".

Commissioner proposed that, while a national service, the advocates would not operate nationally, but be allocated to individual local authorities, so they could build relationships and understanding of local systems.

(3) The Children's Commissioner's office should be formally established as an escalation point for all commissioned advocacy services in England through an amendment to the Advocacy Services and Representations Procedure Regulations 2004.[44] Where an advocate believed a child's rights had been breached and the formal complaints process was not sufficient or appropriate, the Children's Commissioner recommended that the Advocacy Services and Representations Procedure Regulations 2004 should specify that the advocate could escalate their concerns to the Children's Commissioner's independent advocacy service Help at Hand.[45]

Options for reform

22.27 It would be possible for the existing guidance to be revised. It would, for instance, be possible for the guidance to clarify the current ambiguity as to whether disabled children are entitled to support in making representations about assessments under section 17 of the Children Act 1989. However, no guidance could *require* that support to be by way of independent advocacy, as that is a matter for legislation. Our work preparing for this consultation has suggested that independent advocacy is of particular importance in the context of disabled children, especially for those whose disabilities mean that (for whatever reason) they have difficulty making their voice heard.

22.28 In terms of a legislative solution, it would be possible for the framework that we provisionally propose in Chapter 23 not to make any provision for advocacy, and for any provision to be made by a continuation (with any necessary technical amendments) of the provisions contained in the Children Act 1989 and the regulations outlined above. However, our provisional view is that this would be problematic for two reasons.

22.29 The first reason is that it would perpetuate the need to navigate between different pieces of legislation to identify when a child is eligible for advocacy support, and the basis of that support. That would be directly contrary to our task of simplifying the law.

22.30 The second, and perhaps more fundamental reason, is that we think that the model of advocacy contained in the Children Act 1989 does not go far enough to meet the needs of disabled children, in particular as regards securing the provision of independent advocacy.

Our provisional proposals

22.31 We therefore provisionally propose that the framework that we propose for assessing and meeting the needs of disabled children should include express provisions in relation to advocacy. We think that the model should draw upon that contained in the

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[44] SI 2004 No 719.

[45] Children's Commissioner for England, *The state of children and young people's advocacy services in England* (December 2023) pp 45 and 46.

Care Act 2014, rather than the "assistance with the right to make representations" model set out in the Children Act 1989. This would mean providing a right to independent advocacy for the child who would otherwise have difficulty participating unless there is an appropriate person who represents and supports that child. Our provisional view is that this would have the following advantages.

(1) It would provide a concrete way in which to secure the child's voice in the process. Importantly, this would include circumstances where the child's parents or carers may be finding it difficult to draw the child's voice out, or may – for whatever reason – be drowning out that voice. There could therefore be circumstances where an advocate is instructed because the parents require additional support to help their child through the process.

(2) It would help secure access to a person with appropriate skills to support the local authority social workers or others if they do not have the appropriate expertise (be that condition-related, culture-related, or otherwise).

(3) It would maximise the chances that the right decision is made at the outset, something which is of benefit to everyone – the child, their parents or carers, and the local authority.

22.32 There is a precedent for the use of this approach to advocacy in relation to those under-18 in the context of the duty imposed under sections 58 and 67 of the Care Act 2014 in respect of children who are likely to need support after they turn 18. We consider that we are doing no more than extending the logic of this approach to a younger cohort of children, who will in many cases have exactly the same needs and be in very similar familial or caring situations.

22.33 Where the advocacy duty is engaged, the local authority would be required to secure the services of an advocate. We recognise, however, that there are situations where a child may feel strongly that they do not want the involvement of an advocate. If that is the case and if they have the ability to do so, we think that the child should be able to decline such assistance.[46]

22.34 This means, in practice, that the model we are provisionally proposing would be an "opt-out" model of advocacy. This is an approach that the previous Government had accepted in its response to the independent review of children's social care (see paragraph 22.22 above) in the context of children involved in the care system.[47]

22.35 The approach that we are provisionally proposing would require the local authority to determine whether there is an appropriate person who can provide support to the child in question. Such an approach runs the risk of a local authority over-estimating the extent to which a parent or carer can act as the child's support. However, we consider that the risks in this approach can be mitigated by setting out (whether in legislation or guidance, or a combination of the two) what it means for an appropriate person to be available. Drawing on the approach under the Care Act 2014, for example, an

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[46] The test for whether the child is able to make such a decision is addressed in ch 21.

[47] A point noted by the Children's Commissioner for England: Children's Commissioner for England, *The state of children and young people's advocacy services in England* (December 2023) p 16.

appropriate person would be independent of those providing care to the child, be able to support and represent the child and facilitate their involvement in the process. They could also not be someone who the child did not want to be involved.[48]

22.36 The only other alternative would be to require independent advocacy to be provided in relation to every assessment. That would not only be impractical, but it would also in many cases give the entirely incorrect message that parents or carers are incapable of advocating for their children. We provisionally consider that the model set out above provides the right balance, but welcome views on this.

22.37 If the model of advocacy set out here were to be adopted, it would be in line with the approach in the Care Act 2014. It would, however, go further than the Children and Families Act 2014. As noted above, we have not been able to identify a specific reason why the latter Act contains different provision for advocacy. Our provisional view is that we should proceed by reference to what advocacy provision is the correct provision for the purposes it is needed in our framework. However, the potential for inconsistency is a matter that consultees need to be aware of when responding to this consultation paper.

Consultation Question 78.

22.38 We provisionally propose that a new legal framework for disabled children's social care should include a right to independent advocacy for any disabled child who would otherwise have difficulty in participating in the assessment and planning process around their social care needs. This right would apply unless:

(1) there is already an appropriate person who can represent and support that child; or

(2) a child with the ability to do so (as to which, see Chapter 21) does not want an advocate to be involved.

Do consultees agree?

22.39 We recognise that, the younger the child, the more likely it is that any advocacy support will be on a non-instructed basis. We also recognise the concerns that some stakeholders have that the term "non-instructed" advocacy, in effect gives licence to ignore the wishes of the child. We wonder, however, if this risk can be overstated. The statutory guidance accompanying the Care Act 2014, makes clear that:

> Where a person has been assisted and supported and nevertheless remains unable to make their own representations or their own decisions, the independent advocate must use what information they have collected and found, and make the representations on behalf of the person. They must 'advocate' on their behalf, to put their case, to scrutinise the options, to question the plans if they do not appear to

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[48] Department of Health and Social Care, *Care and Support Statutory Guidance* (March 2024) paras 7.32 to 7.36.

> meet all eligible needs or do not meet them in a way that fits with the person's wishes and feelings, or are not the least restrictive of the person's life, and to challenge local authority decisions where necessary. The ultimate goal of this representation is to secure a person's rights, promote the individual's well-being and ensure that their wishes are taken fully into account.[49]

22.40 We are conscious that the approach we provisionally propose would give rise to more circumstances in which independent advocates need to be instructed. However, the size of the gap will depend upon whether it is measured against what should be happening at present, or what is actually happening. The Children's Commissioner's report of December 2023[50] suggests that there is a significant gap between what should be happening and what is actually happening. We are very interested to understand more about this in this consultation.

Consultation Question 79.

22.41 We invite consultees to provide their experiences of situations where support by an independent advocate has been provided to a disabled child being assessed under section 17 of the Children Act 1989.

22.42 As regards cultural competence, as the previous Government noted in its response to the Joint Committee on the draft Mental Health Bill:

> When commissioning advocacy services, local authorities are already required under section 149 of the Equality Act 2010 to eliminate discrimination and advance equality of opportunity, including in respect of taking steps to meet specific needs based on race as well as religion or belief and other protected characteristics.[51]

22.43 Our provisional view is that it may not be necessary to do more by way of legislative provision in this regard, as opposed to making clear in guidance what such culturally competent advocacy requires. However, before we reach a final view, we want to hear about people's experiences both of culturally competent advocacy and of advocacy which failed to be culturally competent. We also want to hear about factors that support cultural competency, and factors which make it more difficult to achieve.

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[49] Department of Health and Social Care, *Care and Support Statutory Guidance* (March 2024) para 7.52.

[50] Children's Commissioner for England, *The state of children and young people's advocacy services in England* (December 2023).

[51] Department of Health and Social Care, *Government response to the Joint Committee on the draft Mental Health Bill* (2024) CP 1036 pp 29 and 30.

Consultation Question 80.

22.44 We invite consultees to provide us with experiences of culturally competent advocacy (both positive and negative).

ADVOCACY FOR PARENTS AND CARERS IN THE CONTEXT OF THE ASSESSMENT OF THE NEEDS OF THEIR CHILDREN

The current law

22.45 Parents and carers do not at present have any right to advocacy support when taking part in the assessment process for their children.

The case for reform

22.46 Some parents and carers we have heard from in the lead up to this consultation have described feeling exhausted, side-lined or intimidated by the process of assessment of their children. We have discussed further in Chapter 4 above how this can flow from an approach to assessing disabled children which is predicated upon a child protection model. On the face of it, this suggests parents and carers themselves might require their own advocates to assist them in the process.

Options for reform

22.47 We can see that there is a case for an "opt-out" model of advocacy support for parents and carers of disabled children being assessed. It would respond to a clear demand that we have heard from some parents in the lead up to this consultation, and would, again, potentially maximise the chances that decision-making is correct first time around. We are, however, mindful of the following issues.

(1) Under the model we have provisionally proposed above, an advocate for the child could be appointed because the parent or carer is not able, themselves, to carry the load of advocating for their child. That, in turn, may mean that the parent or carer is then able to find it easier to speak up for themselves.

(2) Unless absolutely necessary, we would not want to create the potential for situations where both the child and parents have an advocate appointed. Not only would this be costly, it would also give rise to the potential for extremely difficult problems resolving the "battle of the advocates".

(3) Our approach to disabled children's social care is predicated upon creating the conditions for such children to be viewed through the lens of their needs, rather than through a child protection lens. If steps were taken to rebalance the assessment process, as discussed in Chapter 4, we would anticipate that the problems that we have identified at paragraph 22.46 are lessened. This would, in turn, lessen the need for advocacy support, and hence the justification for any form of "opt-out" model of advocacy.

22.48 An alternative, "softer" approach would be to establish an "opt-in" model, where parents can request support from an advocate, and local authorities have the power to commission such advocacy support. Again, though, we have a concern that we may be proposing a legislative solution for a problem that may be (at least partially) resolved if the other measures we are provisionally proposing were to be implemented.

Our provisional proposals

22.49 At this stage, and for the reasons set out above, we are not making any provisional proposals for any form of advocacy support for parents or carers during the assessment of the disabled child's social care needs. We will reach a final view on this in light of the consultation responses that we receive to our other provisional proposals, especially those as to the process of assessment set out in Chapter 4.

ADVOCACY FOR PARENTS AND CARERS IN THE CONTEXT OF THE ASSESSMENT OF THEIR OWN NEEDS

The current law

22.50 Carers (including parents)[52] of children who are likely to have needs extending after the age of 18 have an entitlement to advocacy support under sections 61 and 67 of the Care Act 2014 when the carers' own needs are being assessed. Parents and carers of younger children do not have any such right to advocacy support.

The case for reform

22.51 We find it difficult to see why parents or carers of younger children should not have an entitlement to support when their own needs are being assessed if, without it, they will have significant difficulty in participating. The needs of such parents in respect of such children are likely to be just as great as (if not in many cases greater than) those of the parents of older adolescents. We therefore cannot see any principled reason why parents and carers of disabled children (of any age) who are having their own needs for care assessed should not be entitled to advocacy support where required.

Our provisional proposals

22.52 Where parents and carers of disabled children are having their own needs assessed, we provisionally propose that they should be entitled to advocacy support on the same basis as would apply to other such assessments under the Care Act 2014. This would mean providing a right to independent advocacy for the parent or carer if they would otherwise have difficulty participating (unless there is an appropriate person who represents and supports them).[53] We are conscious that this argument applies equally to parents and carers of children in need for reasons other than disability, but we cannot make a blanket provisional proposal in relation to amending the relevant provisions of the Children Act 1989. This might be thought to be another factor in favour of the establishment of a separate framework relating to disabled children, so that the advocacy entitlements for parents and carers can be appropriately tailored.

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[52] Care Act 2014, s 60(7).

[53] The parent or carer must consent to being supported by the appropriate person if they have capacity to do so; if they do not, the local authority must be satisfied that it is in their best interests to be represented and supported by them: Care Act 2014, s 67(6).

Consultation Question 81.

22.53 We provisionally propose that a new legal framework for disabled children's social care should provide an entitlement for parents and carers of disabled children to have advocacy support in respect of the assessment of their own needs where, without such support, they would have difficulty participating in the assessment (and where there is no appropriate person who can represent and support them).

Do consultees agree?

PART 6 – A NEW LEGAL FRAMEWORK

Chapter 23: A new legal framework?

INTRODUCTION

23.1 In this chapter, we take a step back from the detail of the preceding parts to assess the scale of the legal change that is required. We ask whether it would be possible to make the changes that we provisionally propose within section 17 of the Children Act 1989 and section 2 of the Chronically Sick and Disabled Persons Act 1970, or whether a new framework is required.

OPTIONS FOR REFORM

23.2 We have set out in Parts 1 to 5 above a series of problems with the law as it stands. There are three ways in which these problems could potentially be solved.

(1) Through the use of statutory guidance alone, rather than statutory change (although, as we note below, this solution could not work in each case).

(2) The existing framework could be amended.

(3) A new statutory framework could be created for assessing and meeting the social care needs of disabled children.

Guidance alone

23.3 In respect of the first option, we have identified a number of places in different chapters where we provisionally propose that the problem is one that could be best addressed by guidance.[1] However, we have in other places identified why we presently think that guidance alone would be insufficient.[2] In addition to the specific reasons that might relate to each example, there are some more fundamental reasons why we provisionally consider that reliance on guidance is problematic.

23.4 Reliance by successive Governments on guidance is understandable. It is easier to change guidance than it is to amend legislation. It can also provide clear instructions to professionals about the contents of the law, of particular importance for staff exercising their judgement drawing upon their own expertise. Further, where professionals:

> all have to exercise the same discretionary powers in a stream of individual cases which come before them, a policy may provide them with guidance so that they apply the powers in similar ways and the risk of arbitrary or capricious differences of outcomes is reduced. If placed in the public domain, policies can help individuals to understand how discretionary powers are likely to be exercised in their situations and can provide standards against which public authorities can be held to account.

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[1] For instance, in relation to the need to take into account the potential for siblings' needs to be assessed when assessing the disabled child (see ch 6) and in relation to culturally competent advocacy (see ch 22).

[2] For instance, in relation to the duty to assess (see ch 3); eligibility criteria (see chs 7 and 8); participation (see ch 21) and advocacy (see ch 22).

In all these ways, policies can be an important tool in promoting good administration.[3]

23.5 However, all of this presupposes that the guidance both accurately sets out[4] and does not go beyond what the law requires. This latter point is particularly important given that the Supreme Court has confirmed that statutory guidance cannot create legal obligations: in other words, it can reflect, but not make the law.[5] We have noted in a number of places above where statutory guidance either does not accurately reflect the current law or goes beyond what the law requires.[6] A further example is the opening of the *Working Together* guidance published in 2023. This states at paragraph 6 that "this document should be complied with unless exceptional circumstances arise".[7] A decision-maker could well be forgiven for thinking that they are legally required to apply it unless the circumstances are truly exceptional. However, that it is not the case. The courts have made clear that the test for when statutory guidance should be departed from is not one of exceptionality, but whether the decision-maker has cogent reasons to depart from the statutory guidance.[8] There may well be situations in which decision-makers exercising their discretion in the difficult situations covered by the *Working Together* guidance could have cogent reasons for not following it, but could not properly say that the circumstances were "exceptional". In such a case, the law would require the decision-maker to exercise their discretion; following the *Working Together* guidance would lead them in the wrong direction.

23.6 There are also two further problems regarding guidance.

(1) The sheer volume of guidance that has to be read to understand Government policy or understanding of good practice. The most recent version of the *Working Together* guidance (itself 168 pages long) refers to 29 guidance documents published by the Department for Education, 42 published by other government departments or agencies, and 28 published by external organisations. Taken together, those documents run to several thousand pages.

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[3] *R (A) v Secretary of State for the Home Department* [2021] UKSC 37, [2021] 1 WLR 3931 at [2] by Lord Sales and Lord Burnett.

[4] *R (A) v Secretary of State for the Home Department* [2021] UKSC 37, [2021] 1 WLR 3931 and *R (BF (Eritrea) v Secretary of State for the Home Department* [2021] UKSC 38, [2021] 1 WLR 3967 address the consequences of the position where guidance documents do not properly reflect the law.

[5] The Supreme Court confirmed in *An NHS Trust v Y* [2018] UKSC 46, [2019] AC 978 at [97] that statutory guidance (in that case, a statutory Code of Practice accompanying the Mental Capacity Act 2005) cannot create a legal obligation.

[6] See, for instance, the statement made about Early Help in the *Working Together* guidance discussed at para 3.19, the statement about the welfare of the child being paramount in the *Children's Social Care National Framework* (Department for Education, *Children's Social Care National Framework* (December 2023)) discussed at para 20.9 and the statement about advocacy in the guidance accompanying the Children and Families Act 2014 discussed at para 22.11 above.

[7] HM Government, *Working Together to Safeguard Children 2023* (December 2023).

[8] *R (Munjaz) v Mersey Care NHS Trust* [2005] UKHL 58, [2006] 2 AC 148 at [21] by Lord Bingham.

(2) That the guidance it, itself, fragmented. Professionals working in different parts of the same local authority, considering different statutes, may find themselves having to apply multiple pieces of guidance when it comes to considering the same person.

23.7 In this context, it is striking that there is no single piece of guidance which sets out how local authorities are to consider the needs of disabled children. "Practice Guidance" on safeguarding disabled children can be found on the Department for Education's website.[9] It dates from 2009 and is not referred to in *Working Together*. Its current status is unclear. In any event, it focuses on only one aspect of meeting the needs of disabled children.

23.8 In the circumstances, it is perhaps not surprising, but is problematic, that there is no single source of guidance for parents or carers of disabled children to be able to identity what they can seek from local authorities or other statutory bodies. It is also problematic that there is no one source of guidance that can be used by local authorities or other statutory bodies to determine which services they must or may provide to disabled children and their parents or carers. Whilst charities and other organisations do sterling work in helping parents and other carers navigate the maze, that is never going to be a fully adequate substitute for clear statutory provisions amplified by clear guidance.

23.9 Providing one single guidance document addressing the needs of disabled children, their parents and carers would undoubtedly help. But ultimately, it cannot create legal obligations to act in the same way as can legislation enacted by Parliament. It will therefore always carry less weight in the final analysis than statute in securing that disabled children, their parents and carers are provided with the services that they require.

Amending the existing framework

23.10 The second option we have identified above would be to amend the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970 to respond to each of the issues that we have addressed. Our provisional view, however, is that this option is problematic for three reasons.

23.11 The first reason is that, even in respect of those provisional proposals which could be introduced by way of amendments, it would not simplify but instead would add further complexity to the law. In our earlier work on adult social care, we specifically identified the complexity of the legal structure in relation to meeting the needs of children.[10] The Court of Appeal has described it as "a maze of interacting statutory provisions, which have been subject to frequent amendment".[11] The independent review of children's social care also identified – in recommending that we undertake this project – that:

> At present there is a patchwork of duties that sit between the Children Act 1989, the Chronically Sick and Disabled Persons Act 1970, and the Children and Families Act

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[9] Department for Education, *Safeguarding Disabled Children: Practice Guidance* (2009).

[10] Adult Social Care (2010) Law Commission Consultation Paper No 192 para 11.2.

[11] *R (Spink) v Wandsworth London Borough Council* [2005] 1 WLR 2884, [2005] 1 WLR 2884 at [1] by Lord Phillips MR.

2014; outdated definitions that exist in some legislation; and poor alignment with the Care Act 2014. All of this works together to make it hard for families and professionals to understand what support they should receive.[12]

23.12 The problems go even deeper than that. It is often not enough to follow the cross-references from one piece of legislation to another. It is then necessary to work out whether what appears to be the same thing said in two places is in fact the same thing. To take one example, is an assessment of a carer[13] the same as an assessment of a parent carer[14] or a young carer?[15] The answer, as we discussed in Chapters 5 and 6, is no.

23.13 It is then, further, necessary also to be aware that the legislation has, itself, been interpreted by the courts. For instance, as we identified in Chapter 4, it was only in the decision in *R (G) v Barnet London Borough Council*[16] that it became clear that there was a duty to assess children to determine whether they are in need for the purposes of section 17 of the Children Act 1989.

23.14 Importantly, it is not just parents and other carers seeking to navigate the system on behalf of disabled children who find the law inaccessible and complicated. It is also professionals who find it difficult to work out what legal framework they may be applying at any one time. To give one example, and as we discussed in Chapter 7, we repeatedly heard of local authorities delivering "non-statutory" help when providing Early Help[17] to families, by contrast to the statutory support required where the child is a "child in need" for purposes of section 17 of the Children Act 1989. A local authority is a creature of statute, and any help that is being provided – no matter what it is called – must have a statutory basis.[18] This means that there is no such thing as "non-statutory" help, although such help may be being provided under another power than that contained in section 17.[19] This is not just a question of language. If local authorities are not clear as to the basis upon which they are providing services, then not only does this give rise to the risk that different local authorities apply the law inconsistently, but it also places those who are or should be receiving services in a precarious position. The position is precarious for them in two ways. It means those receiving services cannot know with precision what they are entitled to and why. It also puts them at risk of having to account for help received if it emerges, in fact, that there was no statutory basis upon which the service was provided.

23.15 The second reason why we provisionally consider that seeking to amend the existing framework is problematic is that it would not do anything to solve the fact that, as we

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[12] J MacAlister, *The independent review of children's social care – Final Report* (May 2022), p 86.

[13] Under the Carers (Recognition and Services) Act 1995, s 1(2).

[14] Under the Children Act 1989, s 17ZD(1) to (4) and (9) to (13).

[15] Under the Children Act 1989, s 17ZA(1)(a) and (b).

[16] *R (G) v Barnet London Borough Council* [2003] UKHL 57, [2004] 2 AC 208, relying on the combination of Children Act 1989, s 17 and sch 2, para 3.

[17] As to Early Help, see further, paras 3.18 to 3.21.

[18] *R (Ncube) v Brighton and Hove City Council* [2021] EWHC 578 (Admin), [2021] 1 WLR 4762 at [43] by Freedman J.

[19] For example, the Localism Act 2011. This issue is discussed further at paras 3.18 to 3.21.

have addressed in Chapter 3, disabled children, their parents and carers are all too often looked at through the lens of child protection. As we discuss below at paragraph 23.20, there are undoubtedly situations in which disabled children do need to be looked at as children in need of protection. However, our provisional view is that, at present, the balance between social care and child protection is not being struck correctly.

23.16 The third reason is that a new framework is fundamental to the achievement of our provisional reform proposals. We think that limiting change to amending existing legislation would make it impossible or unduly complicated to implement some of our proposals.

23.17 We think that it would be impossible to introduce the approach set out in Chapter 20 providing for a statutory principle, a checklist of considerations, and a 'least restrictive alternative' test. We think that it would not be possible to introduce such an approach so as to apply to some, but not all of the children governed by section 17 of the Children Act 1989. We also think that it would not be possible to simplify the charging framework, because the framework does not just apply to disabled children: see Chapter 21.

23.18 We also think that it would be very difficult to implement the provisional proposals relating to participation and advocacy that we set out in Chapters 21 and 22. Our view at this stage is that introducing amendments to existing legislation (applicable to all children) which provide for changes to participation and advocacy solely for disabled children would be so complicated as to risk making the legislation itself all but unworkable.

A new framework

23.19 It seems to us that the third option, a new framework, would have three key benefits.

(1) It would minimise the chances that disabled children are seen purely through the child protection or safeguarding lens. It would also minimise the chances that they are seen through the lens of the Children and Families Act 2014, in which (unsurprisingly, given its focus) the special educational needs aspect dominates to the exclusion of both broader social care needs and health needs.

(2) It would meet the clear demand for a framework which is simple for families and practitioners, by setting out in one place the duties and powers to assess and meet needs.

(3) It would allow a focus on disabled children who require services to address their specific needs as disabled children. It would also recognise and reinforce the importance of such services. It would also establish clear and enforceable powers for and duties upon local authorities. They could then be accompanied by guidance amplifying those powers and duties in practical terms, making it easier for local authorities and other public bodies to provide these services.

23.20 Conversely, we can identify the following potential risks in moving to a new framework.

(1) It could be said to go against the ethos of the Children Act 1989, which was intended to be a comprehensive piece of legislation addressing the needs of children. In a similar vein, section 17 of the Children Act 1989 was intended to be the vehicle to help all children in need, irrespective of the basis of that need. However, and as discussed further in Chapter 1, we consider that the reality is that this intention has been inadvertently undermined by developments since the Children Act 1989 came into force. There is the risk that, by creating a broad category of children in need, disabled children, as a discrete group, find that their needs are no longer fully met.

(2) A focus on social care needs could potentially come at the expense of a focus on child protection. Some disabled children are abused and neglected, including by their parents and carers. The evidence base as to the scale of such abuse and neglect is inadequate.[20] A particular issue for us is that much of the research has been conducted in different countries.[21] Much of it also does not clearly differentiate between abuse and neglect outside the home or in institutional settings on the one hand, and abuse and neglect in the familial setting on the other. However, and notwithstanding the problems with the evidence base, it is clear that abuse and neglect does occur in some cases. In this regard, we are very mindful of the recent report of the Child Safeguarding Practice Review Panel, which identified that:

> several reviews have highlighted the risk of missing abuse and neglect when the primary focus has been on a child's health condition, for example, learning disabilities, asthma or diabetes. Children with health conditions will necessarily have been seen by different health, education and care services. This can result in fragmented understanding about what is happening in a child's life and the ability of parents to meet their needs.[22]

Whilst we are acutely aware of the potential for increasing the risk of missing abuse and neglect, on balance our provisional view is that this is a risk which can be mitigated. Most importantly, the standalone legal framework we are proposing (and the guidance accompanying it) will sit alongside and does not replace the child protection framework contained in the Children Act 1989. If assessment for social care needs gives rise to a legitimate concern about child protection, it is then for the relevant professionals to investigate that concern. The new legal framework we propose is not intended to stop them from doing so and will not prevent these important investigations from taking place. We discussed how to make sure that this happens at paragraph 4.41.

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[20] A situation which has been regularly highlighted: see L Jones and others, "Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies" (2012) 380 The Lancet 899, and the follow up by Z Fang and others, "Global estimates of violence against children with disabilities: an updated systematic review and meta-analysis" (2022) 6(5) The Lancet Child & Adolescent Health 313.

[21] The commonly cited statistic that disabled children are three to four times more likely than non-disabled children to be abused or neglected is based upon a study carried out in the United States in 2000: P Sullivan, and J Knutson, "Maltreatment and Disabilities: A Population Based Epidemiological Study" (2000) 24 Child Abuse and Neglect 1257.

[22] The Child Safeguarding Practice Review Panel, *Annual Report 2022/2023* (January 2024) para 6.71.

(3) It would create a further framework for professionals and families to navigate, and the potential for a child to fall between frameworks. However, to minimise the risk of a child falling between different frameworks, the legislation can make it clear that the local authority considering a child who is (say) both disabled and suffering socio-economic deprivation would need to consider both aspects, and those assessments could be combined (see paragraphs 3.64 to 3.66). Similarly, the legislation would need to make clear that any assessment from a disability perspective must take into account assessments relevant to other statutory provisions designed to meet wider needs, for instance under section 17 of the Children Act 1989.

(4) Finally, not all parents and carers wish the child they care for to be identified as disabled, and not all disabled children wish to be identified as such. Singling out children on the basis of a separate piece of legislation might enable the meeting of needs, but at the cost of creating or reinforcing either externally or internally imposed negative views. This problem already exists. It is also a problem to which there is no purely legal solution. Importantly, we would not be proposing that section 17 of the Children Act 1989 be repealed in its entirety. This means that, in the situation where (for whatever reason) a child is not identified as disabled, the local authority would still have to consider whether the child nonetheless met the criteria of being a child in need.

23.21 We have identified what we see as the key benefits and risks above, but welcome views as to whether there are others that we might have missed.

OUR PROVISIONAL PROPOSALS

23.22 Of the three options set out above, we provisionally favour the third option: the creation of a new framework for assessing and meeting the social care needs of disabled children. We think that statutory guidance alone is insufficient to resolve the problems that we have identified. This means statutory change would be required. That change would, in some cases, be very difficult, and other cases impossible, to bring about within an existing legal framework which is already very complicated. And while the creation of a new legal framework would carry the risks that we set out at paragraph 23.20; we think those risks would be outweighed by the benefits we identify at paragraph 23.19.

Consultation Question 82.

23.23 We provisionally propose that disabled children should be taken out of the scope of section 17 of the Children Act 1989 and that there should be a new simplified and unified legal framework for addressing their social care needs.

Do consultees agree?

23.24 We further provisionally propose that any new framework should be accompanied by two sets of guidance: one for professionals applying the law, and the other for parents and carers who need (in particular) to understand their rights under the law. Whilst we have set out our reservations in relation to the overuse of guidance above, those reservations arise in particular where guidance is used as a substitute for statutory law. The guidance that we have in mind would accompany the statutory framework and help the two audiences to apply the framework to the situations they may encounter.

Consultation Question 83.

23.25 We provisionally propose that any new framework should be accompanied by two sets of guidance, one for professionals applying the law, and the other for parents and carers who need to understand their rights under the law.

Do consultees agree?

Chapter 24: Consultation Questions

Consultation Question 1.

24.1 We invite consultees' views on the provisional analysis of the costs set out in the draft impact assessment. In particular, please highlight any assumptions we have made that you consider may be incorrect and explain why.

Paragraph 2.7

Consultation Question 2.

24.2 We invite consultees' views and/or evidence as to whether our provisional proposals could result in advantages or disadvantages to particular groups or to individuals with particular characteristics?

Paragraph 2.12

Consultation Question 3.

24.3 We provisionally propose that that there be a single express duty to assess the social care needs of disabled children.

Do consultees agree?

Paragraph 3.62

Consultation Question 4.

24.4 We invite consultees' views on the appropriate threshold for carrying out an assessment. Should an assessment be carried out where:

(1) the child appears to be disabled;

(2) it appears the child may have needs for care and support;

(3) it appears the child may be eligible for care and support;

(4) the child is likely to be eligible for care and support; or

(5) it appears that a child may need care and support in addition to or instead of that provided by their family?

Paragraph 3.63

Consultation Question 5.

24.5 We invite consultees' views on the extent to which, if at all, the law should facilitate the combining of assessments undertaken for other purposes? There are three main options.

(1) The legislation could make clear that the assessment for a disabled child should be separate and additional to other assessments.

(2) The legislation could remain silent and allow local authorities freedom to choose whether the assessments can or should be combined.

(3) The legislation could encourage or compel the assessments to be combined. This could be done in three different ways:

  (a) by giving a power to combine assessments;

  (b) by imposing a duty to combine assessments; or

  (c) by a presumption of combining the assessments which can be rebutted with a good reason.

We invite consultees to indicate, if applicable, which sub-option within option (3) would be preferrable.

Paragraph 3.65

Consultation Question 6.

24.6 We invite consultees to provide their:

(1) experiences of the use of equivalent assessments under the Mental Capacity Act 2005; and

(2) views on whether this approach would be appropriate in the context of disabled children's social care.

Paragraph 3.67

Consultation Question 7.

24.7 We invite consultees to tell us about their experiences, both positive and negative, of the current process of assessing the social care needs of disabled children.

Paragraph 4.26

Consultation Question 8.

24.8 We provisionally propose a requirement that assessments are proportionate and appropriate to the circumstances of the child and their family.

Do consultees agree?

Paragraph 4.34

Consultation Question 9.

24.9 We provisionally propose that assessors should be required to have appropriate expertise and training.

Do consultees agree?

24.10 We invite consultees' views on whether assessors should be required to have expertise in specific conditions.

Paragraphs 4.37 and 4.38

Consultation Question 10.

24.11 We provisionally propose that local authorities should be required to provide disabled children and their families with a copy of their assessment.

Do consultees agree?

Paragraph 4.40

Consultation Question 11.

24.12 We provisionally propose that guidance should emphasise that assessors need to consider whether any other relevant statutory assessment duty is engaged when assessing the social care needs of a disabled child.

Do consultees agree?

Paragraph 4.42

Consultation Question 12.

24.13 We invite consultees' views on whether it is necessary and appropriate to give local authorities the power to delegate the assessment of the social care needs of disabled children to trusted third parties, retaining ultimate responsibility for the standard of the assessment.

Paragraph 4.45

Consultation Question 13.

24.14 We invite consultees to tell us about their experiences, both positive and negative, of parent carers' needs assessments, or assessments for carers without parental responsibility.

Paragraph 5.25

Consultation Question 14.

24.15 We provisionally propose that there should be a single duty to assess the needs of a carer for a disabled child, which should arise upon (a) request by the carer or (b) it appearing to the local authority that the carer may have needs for support.

Do consultees agree?

Paragraph 5.34

Consultation Question 15.

24.16 We provisionally propose that, in assessing the needs of a carer for a disabled child, the local authority should be required to have regard to the well-being of the carer.

Do consultees agree?

Paragraph 5.36

Consultation Question 16.

24.17 We provisionally propose that all carers should have a right to a copy of their assessment.

Do consultees agree?

Paragraph 5.37

Consultation Question 17.

24.18 We provisionally propose a requirement that carers' assessments are proportionate and appropriate to the circumstances of the carer.

Do consultees agree?

Paragraph 5.39

Consultation Question 18.

24.19 We invite consultees to provide their experiences of the extent to which siblings' needs are considered during the assessment of a disabled child.

Paragraph 6.18

Consultation Question 19.

24.20 We invite consultees to provide their experiences of the conduct of young carers' needs assessments.

Paragraph 6.20

Consultation Question 20.

24.21 We provisionally propose that statutory guidance should direct local authorities to consider whether the needs of any siblings need to be taken into account as part of the assessment of the needs of a disabled child.

Do consultees agree?

Paragraph 6.25

Consultation Question 21.

24.22 We provisionally propose that there should be a single duty to assess the needs of all carers, whatever their age.

Do consultees agree?

Paragraph 6.27

Consultation Question 22.

24.23 We provisionally propose that there should be a single statutory duty to meet the social care needs of disabled children.

Do consultees agree?

Paragraph 7.44

Consultation Question 23.

24.24 We provisionally propose that the single statutory duty to meet the social care needs of disabled children should be subject to national eligibility criteria.

Do consultees agree?

Paragraph 7.51

Consultation Question 24.

24.25 We invite consultees' views on what the essential features of any national eligibility criteria should be.

Paragraph 7.52

Consultation Question 25.

24.26 We invite local authority consultees to provide us with copies of any eligibility criteria they apply to disabled children's social care.

Paragraph 7.53

Consultation Question 26.

24.27 We provisionally propose that the single statutory duty to meet the social care needs of disabled children should take precedence over any other powers and duties which could be used to provide the services.

Do consultees agree?

Paragraph 7.55

Consultation Question 27.

24.28 We invite consultees’ views on the residence requirements that should apply to the single statutory duty to meet the social care needs of disabled children.

Paragraph 7.57

Consultation Question 28.

24.29 We invite consultees’ views on whether disabled facilities grants should be provided under the single statutory duty to meet the social care needs of disabled children.

Paragraph 7.59

Consultation Question 29.

24.30 We provisionally propose that there should be powers to meet needs:

(1) that do not satisfy the national eligibility criteria; and

(2) pending an assessment of needs.

Do consultees agree?

Paragraph 7.62

Consultation Question 30.

24.31 We provisionally propose that there should continue to be a power to meet the needs of parents and carers.

Do consultees agree?

Paragraph 7.69

Consultation Question 31.

24.32 We invite parent and carer consultees to provide their experiences of accessing short breaks.

Paragraph 8.32

Consultation Question 32.

24.33 We invite local authority consultees to tell us about the short break services available in their area and any criteria which must be met to access those services.

Paragraph 8.33

Consultation Question 33.

24.34 We provisionally propose to define short breaks as:

Services to:

(a) provide breaks for the benefit of disabled children; and/or

(b) assist individuals who provide care for disabled children to continue to do so, or to do so more effectively, by giving them breaks from caring.

Including:

(a) accommodation;

(b) the provision of care at home or elsewhere;

(c) educational or leisure activities; and

(d) services to assist parents and carers in the evenings, at weekends and during the school holidays.

Do consultees agree?

Paragraph 8.40

Consultation Question 34.

24.35 We provisionally propose that short breaks should be made available under a single statutory duty to meet the social care needs of disabled children.

Do consultees agree?

Paragraph 8.46

Consultation Question 35.

24.36 We provisionally propose that eligibility for a short break should be subject to national eligibility criteria.

Do consultees agree?

Paragraph 8.49

Consultation Question 36.

24.37 We provisionally propose that children who are provided with a short break in the form of accommodation away from the family home should have the same benefits and safeguards as currently apply to children provided with a short break under section 20 of the Children Act 1989.

Do consultees agree?

Paragraph 8.51

Consultation Question 37.

24.38 We invite consultees to tell us what, in their experience, are the main social services that disabled children require.

Paragraph 9.22

Consultation Question 38.

24.39 We invite consultees to tell us about the main social services for disabled children that are available in their area.

Paragraph 9.23

Consultation Question 39.

24.40 We provisionally propose that legislation should provide a non-exhaustive list of the social services that can be provided to disabled children.

Do consultees agree?

Paragraph 9.24

Consultation Question 40.

24.41 We invite consultees' views on the services that should be included in the list referred to in Consultation Question 39.

Paragraph 9.25

Consultation Question 41.

24.42 We provisionally propose that local authorities should be able to provide services:

(1) directly;

(2) indirectly through third parties; and

(3) by means of direct payments.

Do consultees agree?

Paragraph 10.27

Consultation Question 42.

24.43 We provisionally propose that parents, carers and children aged 16 and over should have a right to a personal budget.

Do consultees agree?

Paragraph 10.28

Consultation Question 43.

24.44 We provisionally propose that the regime for direct payments should be adapted so that:

(1) the amount of the payment is the amount sufficient to secure the provision needed, as opposed to an amount that is estimated to be reasonable; and

(2) payments should be kept under review, so that their sufficiency can be monitored and alternative arrangements made if necessary.

Do consultees agree?

Paragraph 10.29

Consultation Question 44.

24.45 We provisionally propose that disabled children who are eligible to have their needs met by social services should have a statutory entitlement to a plan setting out what services they are to receive, and where, when and how those services will be provided.

Do consultees agree?

Paragraph 11.26

Consultation Question 45.

24.46 We provisionally propose that the content of the plan to meet the needs of a disabled child should be dealt with in guidance.

Do consultees agree?

Paragraph 11.29

Consultation Question 46.

24.47 We provisionally propose that the plan to meet the needs of a disabled child should be combined, where appropriate, with other plans for the child such as their EHCP, care plan or pathway plan.

Do consultees agree?

Paragraph 11.31

Consultation Question 47.

24.48 We invite consultees to provide examples of local authority charging practices.

Paragraph 12.25

Consultation Question 48.

24.49 We invite consultees' views on whether local authority charging practices would be likely to change if any of the provisional proposals in this consultation paper were implemented. In particular, is it likely that local authorities would need to charge more, or more often?

Paragraph 12.26

Consultation Question 49.

24.50 We invite consultees' views on the extent to which disabled children's social care law can and should be aligned with SEND law.

Paragraph 13.29

Consultation Question 50.

24.51 We provisionally propose that the current dividing line between social care and health care in respect of children, based upon the scale and type of the care being provided, should be placed on a statutory footing, with a regulation-making power to enable that line to be changed in future.

Do consultees agree?

Paragraph 14.51

Consultation Question 51.

24.52 We provisionally propose that there should be a single provision setting out when a local authority with responsibilities under section 117 of the Mental Health Act 1983 is required to assess a disabled child's social care needs.

Do consultees agree?

Paragraph 14.53

Consultation Question 52.

24.53 We provisionally propose that guidance include a specific section – co-produced between local authority and NHS representatives – on the intersection between health care and social care. This should make the following clear.

(1) How children with health care needs are to be identified (see further in this regard our provisional proposals regarding referral for assessment at paragraph 4.41).

(2) Local authority responsibilities to meet the health care needs of disabled children.

(3) NHS responsibilities to meet the health care needs of disabled children.

(4) Expectations for joint working and joint accountability where local authority and NHS responsibilities overlap in the meeting of such needs.

(5) Mechanisms for dispute resolution, including an expectation that "internal" disputes as between local authority and NHS organisations should not affect the meeting of the needs of the child in the interim.

Do consultees agree?

Paragraph 14.55

Consultation Question 53.

24.54 We invite consultees' views on the cause of the problems faced by disabled children receiving social care in making the transition to adult social care.

Paragraph 15.19

Consultation Question 54.

24.55 We provisionally propose that the Care Act 2014 be amended to provide a statutory age at which transition planning should be started in relation to disabled children.

Do consultees agree?

Paragraph 15.33

Consultation Question 55.

24.56 If the Care Act 2014 were to be amended to provide a statutory age at which transition planning should be started in relation to disabled children, we invite consultees' views as to the age at which this should start.

Paragraph 15.34

Consultation Question 56.

24.57 We invite local authority consultees to tell us the methods they use to:

(1) identify the nature and extent of social care provision required by disabled children in their area;

(2) ensure that sufficient services are made available to meet those needs; and

(3) keep the sufficiency of service provision under review.

Paragraph 16.24

Consultation Question 57.

24.58 We invite consultees' views on, and experiences of, the sufficiency of disabled children's social care provision in the local area.

Paragraph 16.25

Consultation Question 58.

24.59 We invite consultees' views on whether it should be mandatory for local authorities to have a designated social care officer.

Paragraph 17.21

Consultation Question 59.

24.60 We invite consultees to tell us about their experiences of co-operation and joint working in the social care context, or between social care, education and health.

Paragraph 17.24

Consultation Question 60.

24.61 We invite consultees' views on the factors that help and hinder effective co-operation and joint working.

Paragraph 17.25

Consultation Question 61.

24.62 We invite consultees' views of the statutory complaints procedure (either through making or handling a complaint).

Paragraph 18.79

Consultation Question 62.

24.63 We invite consultees to tell us about experiences of complaints to the Local Government and Social Care Ombudsman. Do consultees consider that the current system enables timely and appropriate resolution of such complaints?

Paragraph 18.84

Consultation Question 63.

24.64 We invite consultees' views on whether the Children's Commissioner should be given an express power to initiate legal proceedings in respect of the social care needs of disabled children.

Paragraph 18.90

Consultation Question 64.

24.65 We invite consultees' views on the changes necessary in order for families to have an effective and independent mechanism to challenge and rectify decisions about disabled children's social care.

Paragraph 18.100

Consultation Question 65.

24.66 We invite consultees' views on extending the powers and jurisdiction of the SEND Tribunal as a potential option to challenge and rectify decisions about disabled children's social care.

Paragraph 18.101

Consultation Question 66.

24.67 We provisionally propose that the Special Educational Needs and Disability (First-tier Tribunal Recommendations Power) Regulations are amended. This amendment should make clear that the SEND Tribunal has the power on an "extended" appeal to recommend that a local authority carries out a social care assessment where one has not been carried out.

Do consultees agree?

Paragraph 18.103

Consultation Question 67.

24.68 We provisionally propose that a child should be regarded as disabled for the purposes of disabled children's social care law if:

(1) they have a physical or mental impairment; and

(2) the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

Do consultees agree?

Paragraph 19.28

Consultation Question 68.

24.69 We provisionally propose that the statutory definition of disability should clarify that social care services should not be denied to a child purely on the basis that their impairment gives rise to:

(1) addiction;

(2) a tendency to set fires;

(3) a tendency to steal;

(4) a tendency to physical or sexual abuse of other persons;

(5) exhibitionism; and

(6) voyeurism.

Do consultees agree?

Paragraph 19.29

Consultation Question 69.

24.70 We invite consultees' views on whether the definition of "substantial and long term" requires adaptation for younger children in the context of disabled children's social care law.

Paragraph 19.31

Consultation Question 70.

24.71 We provisionally propose that decision-making as to the assessment and meeting of the social care needs of disabled children should be:

(1) an overarching principle that the best interests of the child be the primary consideration for decision-makers;

(2) a set of considerations to which decision-makers must have regard in applying that principle; and

(3) a final check that decision-makers must apply as to whether the purpose being served by the proposed decision or action can be as effectively achieved in a way which is less restrictive of the child's rights and freedom of action.

Do consultees agree?

Paragraph 20.39

Consultation Question 71.

24.72 We are provisionally proposing the following list of considerations to which decision-makers should have regard:

(1) the importance of promoting the upbringing of the child by the child's family, in so far as doing so is consistent with promoting the best interests of the child;

(2) the importance of the child participating as fully as possible in decisions relating to the exercise of the function concerned;

(3) the importance of the child being provided with the information and support necessary to enable participation in those decisions, having regard to their particular needs;

(4) the views, wishes and feelings of the child;

(5) the views, wishes and feelings of the child’s parents and carers and their knowledge of their child’s condition and needs;

(6) the need to support the child and their parent carers in order to facilitate the development of the child and to help them achieve the best possible outcomes at each stage of their life;

(7) the importance of preventing or delaying the development of the needs for care and support;

(8) the need to prepare the child for adulthood and independent living; and

(9) the characteristics, culture and beliefs of the child (including, for example, language).

Do consultees agree?

Paragraph 20.40

Consultation Question 72.

24.73 We invite consultees’ views on the operation and practical effect of the list in section 1(3) of the Care Act 2014.

Paragraph 20.41

Consultation Question 73.

24.74 If the approach that we have set out in this chapter to participation were to be adopted, we invite consultees' views as to whether and how it should vary according to the age of the child.

Paragraph 20.43

Consultation Question 74.

24.75 We provisionally propose that legislation should provide that children (of any age) who have the ability to do so, can:

(1) request an assessment of social care needs (see further Chapter 3);

(2) make representations in the course of the assessment of those needs (see further Chapter 4);

(3) make representations about the content of any plan developed to meet those needs (see further Chapter 11);

(4) opt-out of advocacy support where a duty to provide such advocacy is engaged (see further Chapter 22);

(5) request that services are provided by way of direct payments (see further Chapter 10); and

(6) make use of the relevant remedies that are available where a local authority has failed to assess or meet their needs appropriately (see further Chapter 18).

Do consultees agree?

Paragraph 21.19

Consultation Question 75.

24.76 We provisionally propose that the test for whether a child aged 16 or 17 is able to make the decisions set out in the question above should be the test contained in the Mental Capacity Act 2005.

Do consultees agree?

Paragraph 21.22

Consultation Question 76.

24.77 We invite consultees' views as to whether legislation should provide that the test for whether a child aged under 16 is able to make the decisions set out in the question above is:

(1) competence (and not provide any further definition of the term); or

(2) the child's ability to understand, retain, use and weigh the relevant information, and to communicate their decision.

Paragraph 21.32

Consultation Question 77.

24.78 We provisionally propose that the law should provide that a local authority must carry out an assessment of the social care needs of a disabled child where the child is seeking to opt out of such an assessment if the child is experiencing, or is at risk of, abuse or neglect.

Do consultees agree?

Paragraph 21.35

Consultation Question 78.

24.79 We provisionally propose that a new legal framework for disabled children's social care should include a right to independent advocacy for any disabled child who would otherwise have difficulty in participating in the assessment and planning process around their social care needs. This right would apply unless:

(1) there is already an appropriate person who can represent and support that child; or

(2) a child with the ability to do so (as to which, see Chapter 21) does not want an advocate to be involved.

Do consultees agree?

Paragraph 22.38

Consultation Question 79.

24.80 We invite consultees to provide their experiences of situations where support by an independent advocate has been provided to a disabled child being assessed under section 17 of the Children Act 1989.

Paragraph 22.41

Consultation Question 80.

24.81 We invite consultees to provide us with experiences of culturally competent advocacy (both positive and negative).

Paragraph 22.44

Consultation Question 81.

24.82 We provisionally propose that a new legal framework for disabled children's social care should provide an entitlement for parents and carers of disabled children to have advocacy support in respect of the assessment of their own needs where, without such support, they would have difficulty participating in the assessment (and where there is no appropriate person who can represent and support them).

Do consultees agree?

Paragraph 22.53

Consultation Question 82.

24.83 We provisionally propose that disabled children should be taken out of the scope of section 17 of the Children Act 1989 and that there should be a new simplified and unified legal framework for addressing their social care needs.

Do consultees agree?

Paragraph 23.23

Consultation Question 83.

24.84 We provisionally propose that any new framework should be accompanied by two sets of guidance, one for professionals applying the law, and the other for parents and carers who need to understand their rights under the law.

Do consultees agree?

Paragraph 23.25

Consultation Question 84.

24.85 We invite consultees' views on whether any of the proposals in this consultation paper require adaptation in order to meet the needs of disabled children who are not in family-based care (for example, children in custody).