Law
Commission
Reforming the law

Disabled children's social care

Summary of the Consultation Paper

About this paper

This is a summary of our consultation paper on disabled children's social care. The purpose of this paper is to give you, in summary form, the information that you need to participate in the consultation and answer the consultation questions.

There are 84 consultation questions in the consultation paper. We refer to these questions throughout this summary. Some questions set out provisional proposals for law reform and ask whether or not you agree with them. Others are open questions in which we ask for your views or experiences. We will only reach our final conclusions and make recommendations for reform once we have considered all of the responses we receive.

The full consultation paper and the consultation questions are available on our website at https://lawcom.gov.uk/project/disabled-childrens-social-care/.

We have not reproduced every detail or reference from the consultation paper or every consultation question in this summary. Instead, we have tried to focus on the most important information and the key questions. But if you want to know more about the law, or how and why we think it needs to change, we encourage you to look at the relevant section of the consultation paper too.

If you need this summary to be made available in a different format please email dcsc@lawcommission.gov.uk.

Responding to our consultation

Who are we?	We are the Law Commission of England and Wales. The Law Commission is an independent body established by statute to make recommendations to Government to reform the law in England and Wales.
What is it about?	We have been asked to review disabled children's social care law in England. The purpose of the review is to make recommendations aimed at simplifying, clarifying, and modernising the law, and making sure it sufficiently meets the needs of disabled children and their families.

Why are we consulting?	We are seeking your views on whether and, if so, how the law needs to be reformed. Consultation is a crucial pillar of our work. We want any recommendations we ultimately make to have as strong an evidence base as possible.
Who do we want to hear from?	Anyone who has an interest in, or experience of, disabled children's social care. This includes: children and young people; parents and carers; social workers, managers and directors at local authorities; charities; health and education professionals; lawyers and judges; and academics.
When is the deadline?	The deadline for responses is 20 January 2025.

How to respond

If you can, please respond to the consultation using the online form at https://lawcom.gov.uk/project/disabled-childrens-social-care/.

We will also accept responses in other formats. If you would like a response form in word format, email us at dcsc@lawcommission.gov.uk to request one. Please send your response:

- by email to dcsc@lawcommission.gov.uk; or
- by post to Disabled Children's Social Care Team, Law Commission, 1st Floor, Tower, 52 Queen Anne's Gate, London, SW1H 9AG.

What happens next?

After analysing all of the responses, we will make recommendations for reform which we will publish in a report. It will be for the Government to decide whether to implement our recommendations.

For further information about how we conduct consultations, and our policy on the confidentiality and anonymity of consultees' responses, please see the full consultation paper.

Introduction

See chapter 1.

In this review, we have been asked to look at disabled children's social care law in England and think about whether it sufficiently meets the needs of disabled children and their families. When we talk about "disabled children's social care law" we mean the legal rules covering:

- whether a disabled child can get help from social services to meet their needs;
- what help they can get; and
- how they get it.

This help could be personal care provided to a child in their home. It could be a short break, to give a child the chance to participate in activities in the community while their parent or carer has some time away from their caring responsibilities. It could be an adaptation to a child's home to make it accessible for a wheelchair. Alternatively, it could be "direct payments" (money) so that the family can arrange these services for themselves. A range of other services could also be provided.

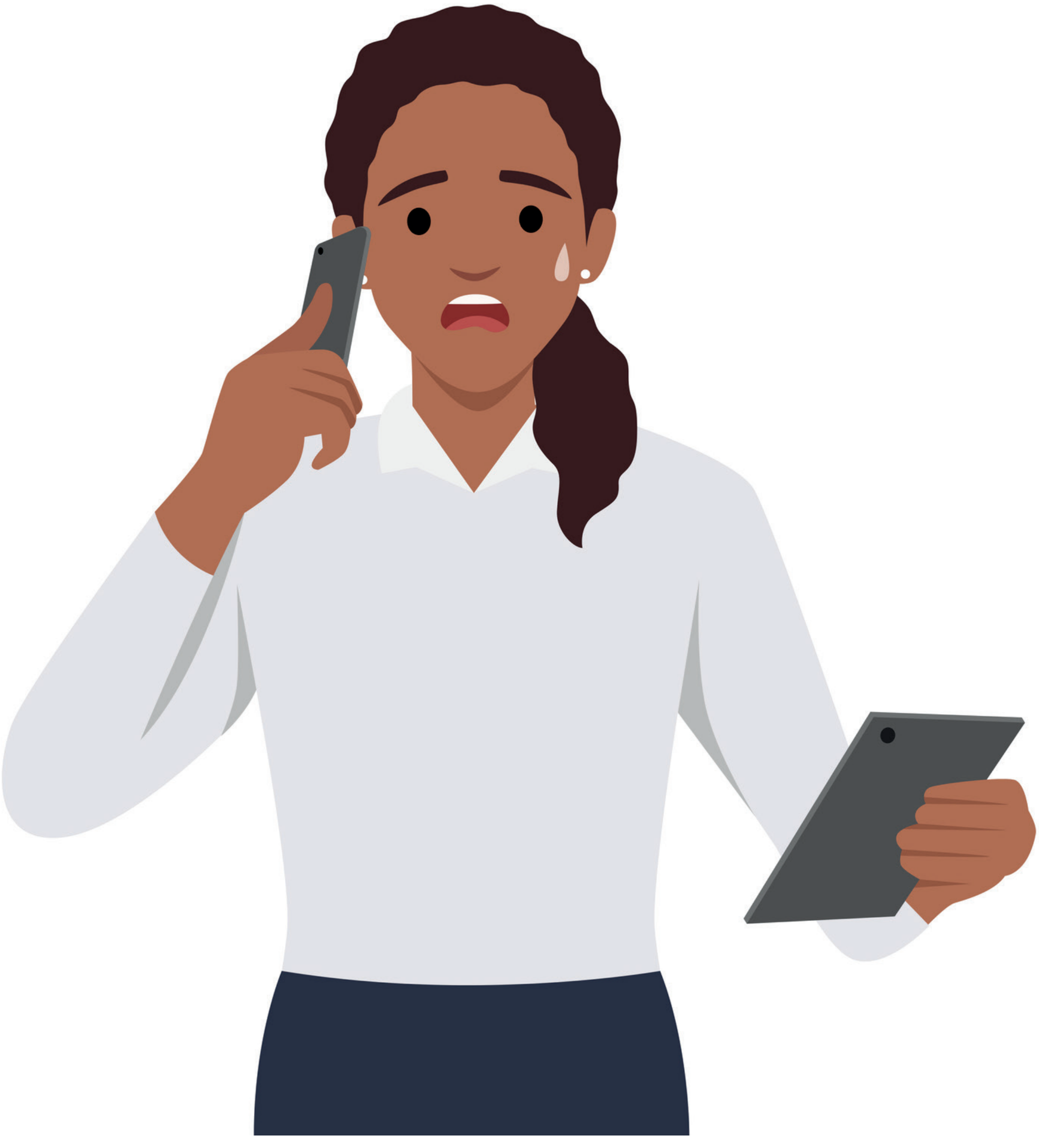
The most important parts of disabled children's social care law are section 2 of the Chronically Sick and Disabled Persons Act 1970 and section 17 of the Children

Act 1989. Both of these legal provisions were groundbreaking. The Chronically Sick and Disabled Persons Act 1970 was one of the first ever pieces of legislation to focus on helping disabled people. It did so by creating, for the first time, a duty to meet the needs of disabled children and adults. 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". Section 17 of the Children Act 1989 was meant to bring together lots of different bits of law 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. In the words of Baroness Hale, one of the architects of the Act, "the hope was that all would be seen simply as children in need of help".

However, society has changed a lot since the foundations of disabled children's social care law were laid in the 1970s and it is questionable whether the law is up to the job of meeting the needs of disabled children and their families. Disabled children who need help from social services often have serious and complex needs. The person asking for the help will usually be the child's parent or carer – in practice this is often their mother – who may be exhausted from juggling their caring responsibilities around work and looking after the child's siblings. The person deciding whether to provide help and, if so, what kind of help to provide, will often be a busy social worker with a large case load to manage. In these circumstances, for the law to be useful, it should be up to date, easy to find and understand, and fair. Arguably, it is none of these things.

The law is out of date. Under section 17 of the Children Act 1989, a disabled child is a 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". This definition is from the 1940s. It comes from legislation that was intended to help injured soldiers find jobs after the Second World War. The language used to describe disability at that time is offensive now and doesn't capture the nuances of neurodiversity.

The law is inaccessible. In fact, it is not one law at all. It is a complicated set of rules, instructions and advice contained in numerous Acts of Parliament, regulations, court decisions, Government guidance and local authority policies. 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". We think that is a fair description.



The law is also – potentially – unfair. It allows local authorities to draw up their own local eligibility criteria, to determine which disabled children qualify for services and which do not. This means that disabled children with the same needs get treated differently depending on where they live in the country. That was not the intention of the legislation.

On top of these problems, parents and carers we heard from in the lead up to this consultation have told us that the law is applied in a way which makes it difficult for their children to access the services they need. The things that we have heard most often are that:

- There is too much focus on safeguarding disabled children from harm at the expense of meeting their needs. They are often viewed as children in need of *protection*, rather than children in need of *help*.
- Those assessing the needs of disabled children do not always have expertise in disability.
- The eligibility criteria for accessing services are often too high.
- The needs of parents, carers and siblings are often forgotten.
- The different teams, departments, and organisations responsible for a child operate in silos and do not always talk to each other.

These concerns bring 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 you to help us answer them.

In answering them, we need to keep in mind that we – at the Law Commission – are not elected politicians. We are lawyers who have been given legal responsibility for making proposals to reform the law, and we do so within limits agreed with the Government. The limits of this project are set out in our terms of reference. Law reform involves simplifying and modernising the law and weeding out anomalies. But decisions about how much money should be spent on social care, or which children should or shouldn't get help, are not for us to make.

This review started in September 2023. Since then, we have met with a range of individuals and groups with lived or professional experience of disabled children's social care. This has included disabled children and young people, parents and carers, social workers, managers and directors at local authorities, health and education professionals, charities, academics, lawyers and judges. We are really grateful to all those who have given up their time to meet with us. It has helped a lot in developing our understanding of the current problems with the law and the possible solutions.

We haven't met with everyone who is affected by this review, and those we have met don't necessarily represent the views and experiences of those we haven't. But the work we have done so far has helped us form an initial impression of what is and isn't working with the current system and what could be done to fix it. This has helped us to get to a position where we can consult more widely on an informed basis.

In this paper, building on the work we have done so far, we make a number of provisional proposals for law reform. These culminate in a provisional proposal that there should be an entirely new legal framework for disabled children's social care. We think this may be necessary to make the law simple and accessible, to make sure that the focus is on meeting children's needs, and to make our other proposals effective. But we emphasise that all of this is provisional. It is our initial view about how we think the law should be reformed. The purpose of the consultation paper is to seek your views on this. Do we need to change our proposals? Are they bad ideas which we should just abandon altogether? What have we missed? We will be undertaking a wide consultation in order to gather as many different views and as much information as possible. We welcome responses from any person or group interested in, or affected by, this review. All of our provisional proposals and consultation questions can be found at https://lawcom.gov.uk/project/disabled-childrens-social-care/. The purpose of this summary is to give you the information you need to answer those questions. But if you want more detail on the law or the thinking behind our proposals, or references for documents and quotations, you'll find it in the relevant chapter of the consultation paper.

The consultation period will run from 8 October 2024 to 20 January 2025. During this time, 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.

After the consultation period, we will analyse all the responses we receive and, based on this, reach 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 2025. The Government will then consider the report and decide whether to implement our proposals.

The impact of this review

See chapter 2.

Economic impacts

This review is focused on the law. But we still need to keep the financial context in mind. The overwhelming majority of people we've 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. But lots of them are worried that their local authority can't afford to pay for it. The financial situation for many local authorities in England is very difficult. The Local Government Association estimates that authorities will face a £4 billion funding gap over the next two years. 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 to answer. But that doesn't mean 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's important for us to provide a realistic idea of how much they will cost.

We will publish a draft impact assessment alongside this consultation paper. That impact assessment will set out our best estimate of the cost of implementing our provisional proposals. We want your views on this, so that we can refine our estimate and make it more accurate. **See consultation question 1**. But don't let the financial context put you off from engaging with the substance of our proposals. Whether our proposals will work and how much they will cost are both important questions. But they're different questions and we need to answer them both.

Equality impacts

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

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. For example:

- There are higher proportions of disabled children in the most deprived areas of the country.

- Around 60% of unpaid carers in England and Wales are women. Both male and female parents and carers have told us that women are not always listened to or given a level of respect appropriate to their experience, expertise and knowledge of their own child, when they seek support from social services. In addition, if female carers 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.
- 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. But the exclusion rate among older children in these groups is lower in cases where the child has been referred for or received support from social services.
- Research suggests that families from Black and Asian ethnic backgrounds face significant additional barriers in accessing social care support.
- Moderate and severe learning difficulties are more common among children from Gypsy, Roma and Traveller communities and members of the Gypsy, Roma and Traveller communities who struggle with literacy skills can face particular barriers accessing public services.

- More unpaid carers in England are disabled, compared with non-carers. This can present particular problems for disabled parents and carers trying to access social care for their disabled children. For example, research shows that autistic parents struggling to access and navigate the system may be characterised as themselves being difficult rather than finding the process difficult.
- Research has identified "astonishing levels of discrimination based on the triad of minority statuses: being young, being LGBT+ and being disabled".

It is important for us to be aware of 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 proposals. **See consultation question 2**.

Assessments

Assessing the needs of children

See chapters 3 and 4.

Services for disabled children are generally provided under section 17 of the Children Act 1989 and section 2 of the Chronically Sick and Disabled Persons Act 1970.

Section 17 of the Children Act 1989 applies to children who are "in need". A child is in need if:

- they are unlikely to have a reasonable standard of health or development without help from social services;
- their health or development is likely to be significantly impaired without help from social services; or
- they are disabled.

Under section 17, social services have a power to help children in their area who are in need. That power can be used to provide a wide range of services.

Section 2 of the Chronically Sick and Disabled Persons Act 1970 applies to disabled children only. Under section 2, social services have a duty to provide the services they think are necessary to meet the needs of disabled children. But, unlike under section 17 of the Children Act 1989, this does not allow social services to provide whatever help they think is appropriate. There is a list of services they can provide which includes things like "the provision of practical assistance for the child in the child's home" and the provision of "wireless, television, library or similar recreational facilities". We discuss these services more on pages 39 to 43.

In order to decide whether and how to provide services to a disabled child, social services need to carry out an assessment of the child's needs. At the moment, under section 17 of the Children Act 1989, social services are required to assess the needs of any child in the area who appears to be a child in need. As disabled children are one category of a child in need, this means that there is a duty to assess the needs of any child in the area who appears to be disabled. This duty is not written down in the legislation. But the courts have decided that there must be a duty in order to make the legislation work.

In practice, we have found that not everyone knows this is the case and that assessments are not always carried out when they should be. We have heard that this is a particular problem in the Special Educational Needs and Disability (SEND) context. The overlap between disabled children's social care and SEND does not always work effectively. Specifically, during an Education, Health and Care (EHC) needs assessment for a disabled child, the education team should seek advice from social services about the child's social care needs. The information in that request about the child should normally be enough to trigger an assessment under section 17. But we have heard that responses to referrals, and the relevant sections of the EHC needs assessment will often record that the child is "not known to social care".

When assessments are carried out, we have heard (to quote the Chief Social Worker for Children and Families) that there is 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". The Independent Review of Children's Social Care drew attention to this issue as well, noting that families of disabled children felt "that they are navigating a system that is set up for child protection, not support". This is something that we have also heard from the parents and carers who have spoken to us in the lead up to this consultation. The most common examples of this are assessors interviewing the child without their parent or carer present or inspecting the child's bedroom. We have been told that this often happens in instances where there is no evidence of risk to the child. So that we can get a comprehensive picture, we are interested in hearing more about experiences – both positive and negative – of the assessment process. **See consultation question 7**.

We have also heard that disabled children are not always asked or able to participate in their assessments, and that the views and expertise of their parents or carers are not always taken into account. We discuss this on pages 63 to 74.

On top of this, the legal routes to obtaining an assessment are very complex. For example, a child who has been detained in hospital under the Mental Health Act 1983 who is being assessed to see whether they need "aftercare", after discharge, is entitled to have their social care needs assessed. But to know that this is the law, you would have to look at five different bits of legislation and one court decision.

There is another layer of complexity which arises because there are a lot of different types of assessment that may need to look at the social care needs of a disabled child. For example, child in need assessments, EHC needs assessments, assessments of the needs of “looked after” and “eligible children”, short break and Early Help assessments. Some of these are assessments required by law. Others are assessments that local authorities choose to carry out or are just names that are given to assessments carried out in particular circumstances. The legal basis for these different types of assessment, and the relationship between them, isn’t always clear. Parents and carers also tell us that they sometimes need to tell their child’s story repeatedly when going through the different assessment processes. Also, the different people, teams and departments responsible for carrying out the assessments don’t always work together or communicate with each other.

Our provisional proposal is that there should be a single duty to assess the social care needs of a disabled child that is set out clearly in legislation. After the assessment is carried out, the family should be entitled to a written copy.

This single assessment duty would be the gateway to all the various social care services available to disabled children that we discuss on pages 39 to 43. This would make the law clearer which, in turn, should make it more likely that assessments are done when they should be. **See consultation questions 3 and 10**.

If we are pursuing this option, we need to work out what the threshold should be for carrying out the assessment. Currently an assessment should be done where it appears that a child has a disability. But some local authorities have suggested to us that this threshold is too low: it would be too much work for very little benefit to assess the needs of every child who might be disabled even if there is no real chance of them being eligible for help at the end of the assessment. On the other hand, if the threshold is set too high then social services might have to do quite a lot of work to decide whether a child qualifies for an assessment. A very high threshold, in effect, would require some kind of pre-assessment assessment, which would be self-defeating and might lead to mistakes. We seek your views on what the appropriate threshold would be. **See consultation question 4**.

Whatever the appropriate threshold is, we think it is important for the law to clarify that an assessment does not always have to be an onerous or time-consuming process.

Following the approach in adult social care law, we provisionally propose that there should be a statutory requirement that an assessment is proportionate and appropriate to the circumstances of the child and their family.

See consultation question 8. For example, a family of a disabled child that wants to be assessed for a short break (see pages 36 to 37) may be able to provide all the information social services require by simply filling out a form, and social services are then left with the simpler task of verifying that the information is correct. That is the approach some authorities already take to short breaks.

We would like to hear your views on how, if at all, the law should allow or compel the different assessments that a disabled child might need to be combined, to reduce unnecessary duplication and families having to tell their stories repeatedly. We are particularly interested to hear experiences of "equivalent assessments" under the Mental Capacity Act 2005. This is where the law permits a similar assessment, that has already been carried out in another context by an appropriate person, to be reused for a slightly different purpose. **See consultation questions 5 and 6**.

A duty to assess the social care needs of a disabled child would, by design, be focused on identifying the needs arising from the child's disability. This, we think, would reduce the potential for the assessment to be used to inappropriately "judge parenting capacity through a child protection lens rather than through a lens of social care need". However, in cases where there was genuine evidence of risk to the child the local authority would remain under a duty to investigate those concerns under section 47 of the Children Act 1989. Likewise, having a duty that is focused on social care needs arising from disability is not meant to stop social services from thinking about other needs, such as need arising from poverty. We think guidance should make this clear. **See consultation question 11**.

A lot of parents and carers tell us that assessments of disabled children aren't always carried out by people who know about disability, or who understand their child's particular disability. Requiring the assessor to have appropriate expertise and training would help change that.

We provisionally propose that there should be a statutory requirement that an assessment should be carried out by a person with appropriate expertise and training.

This is a requirement which applies in adult social care law and which we think could be equally helpful in disabled children's social care law. In the adult social care context, there are also specific expertise requirements for assessors of adults who are deafblind. We have not proposed an equivalent requirement. But we are interested in people's views on whether there should be additional expertise requirements for particular conditions. **See consultation question 9**.

The option of delegating the assessment to a trusted third party like a specialist charity may be one way of harnessing expertise in particular conditions. We are interested in hearing people's views on this. **See consultation question 12**.

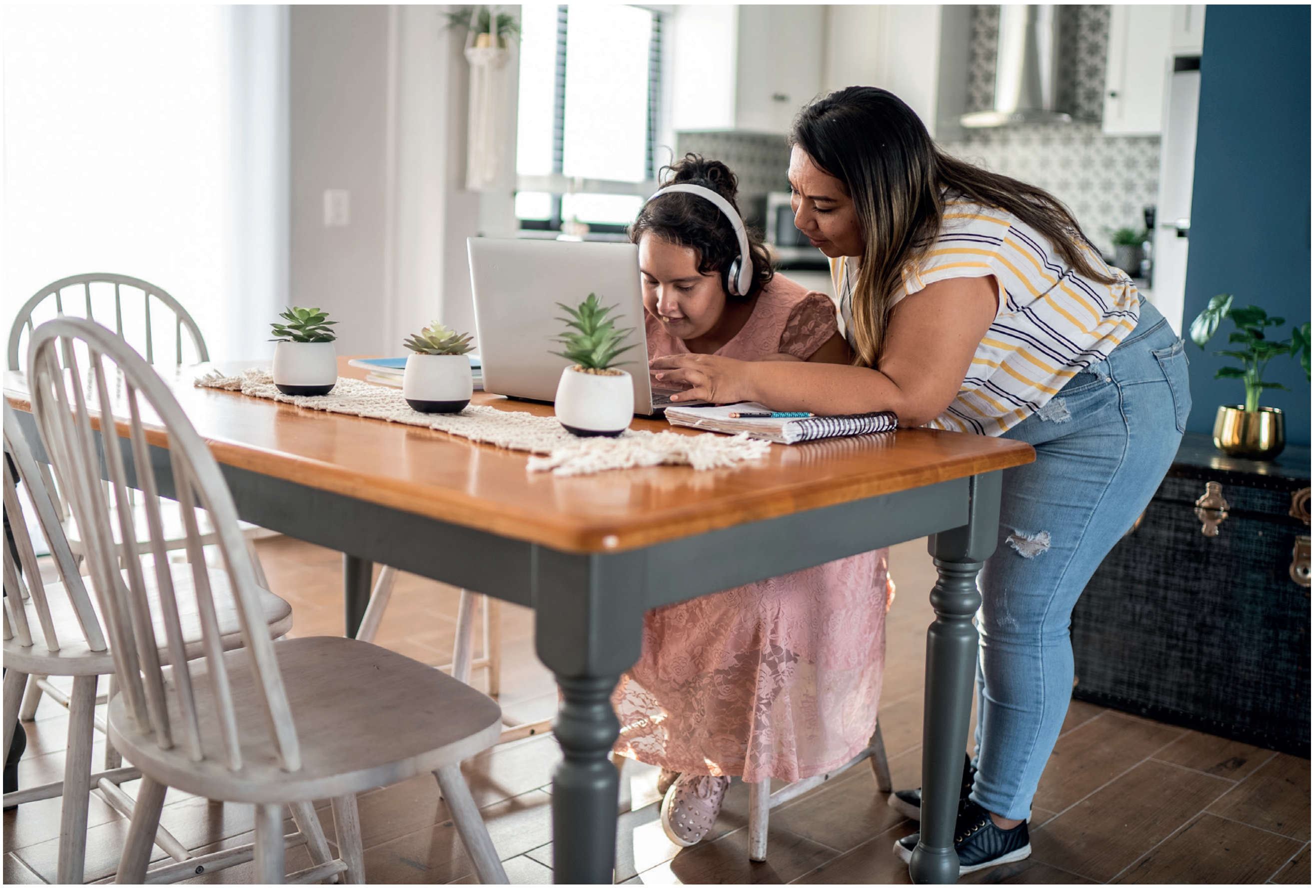
Assessing the needs of parents and carers

See chapter 5.

Unlike the position in relation to children, there are clear duties contained in the legislation requiring local authorities to assess the needs of parents and carers. However, the duties – which are in different bits of legislation – differ depending on whether or not the carer has parental responsibility. A carer who has parental responsibility is entitled to an assessment if they request one or if "it appears to the authority that the parent carer may have needs for support". The assessment must consider their well-being. The carer is then entitled to a copy of it afterwards. For carers who do not have parental responsibility – which includes some kinship carers – an assessment can only be requested if they provide or intend to provide a "substantial amount of care on a regular basis" for a disabled child.

The legislation does not say much about what the assessment should cover and the carer does not have a right to a copy of the assessment. The difference in the assessment rights for carers with and without parental responsibility does not appear to have been deliberate.

We have been told that assessments of parents and carers are not always offered or carried out, even when requested. We have also been told that, when they are carried out, they sometimes focus on the child's needs rather than what the parent or carer requires in order to carry on meeting those needs. So we can get a full picture, we are interested in hearing more about people's experiences of these assessments. **See consultation question 13**.



We provisionally propose that all carers should be entitled to an assessment, under one single assessment duty, either where they request one or if it appears to the authority that the parent or carer may have needs for support.

We think that is the appropriate threshold as it is focused on the question that really matters: whether the carer needs help. The assessment should consider the carer's wellbeing. That is a factor that is obviously relevant, as it impacts on whether they can continue to provide care. They should also have a right to a written copy of the assessment at the end of the process so they can understand the local authority's decision. As for children, we think the law should make clear that the assessment should be proportionate. **See consultation question 17**.

Assessing the needs of siblings

See chapter 6.

There are three situations where the sibling of a disabled child may require their needs to be assessed.

The first is where meeting the sibling's needs is necessary to meet the needs of a disabled child. We are interested in hearing peoples' experiences of this situation. **See consultation question 18**. But we think that it should be covered by our provisional proposal that there should be an express duty to assess the needs of a disabled child. The sibling's needs will have to be considered during this assessment, and that could be made clear in guidance. **See consultation question 20**.

The second is where the sibling is not disabled but is a child in need for some other reason. This falls outside of our terms of reference.

The third is where the sibling is a young carer to a disabled child. Again, we are interested in hearing about experiences of this situation. **See consultation question 19**. There is already an express statutory duty to assess the needs of young carers and we have heard no complaints about it so far. But, in the spirit of simplification, we provisionally propose that it is combined with the single duty to assess the needs of parents and carers that we discuss above. We think, for simplicity, there should just be one single duty to assess the needs of all carers irrespective of their age. **See consultation question 21**.

Eligibility

See chapters 7 and 8.

At the moment, eligibility for disabled children's social care is a postcode lottery. Whether a disabled child is eligible for help from social services depends on where they live in the country. This is because local authorities are allowed to draw up their own eligibility criteria. Of the eligibility criteria we've looked at in the lead up to this consultation, no two are the same. Some criteria make it particularly difficult for autistic children to access services, for example requiring them to have a learning disability as well in order to qualify for services. Some experts have expressed concerns that this kind of criteria may be discriminatory.

This wasn't the intention when section 2 of the Chronically Sick and Disabled Persons Act 1970 was introduced. The intention was to standardise provision across the country and place social services under a duty to provide services that previously had been discretionary. But a court case in 1997 decided that local authorities are entitled to take their resources into account in deciding whether the duty under section 2 has arisen. This allows authorities to design their own eligibility criteria, based on how much money they have available to spend on social care. That downgrades the duty into a power.

The problems with this were summed up by one of the judges in the 1997 case who disagreed with the decision:

> *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.*

The fact that local authorities are entitled to take into account their resources in deciding whether they owe a duty to meet the needs of a disabled child means that disabled children's social care law is out of step with other similar areas of law. In particular it is out of step with adult social care law, where local authorities are required to meet an adult's needs for care and support, if those needs meet national – rather than local – eligibility criteria. This means that there is no postcode lottery for adults.

This has not always been the case. Until 2015, the law for children and adults was very similar and local authorities were able to design their own eligibility criteria for adult social care (subject to some national guidance) taking into account their resources. But this all changed when the Care Act 2014 came into force, introducing standardised national criteria and meeting long-held concerns that local criteria gave rise to unfair variation across the country. We haven't been able to identify a good reason why the approach should be different for children.

We provisionally propose that disabled children's social care law is brought in line with adult social care law and that there should be a single duty to meet the needs of disabled children. That duty should be subject to national eligibility criteria.

Having a single duty with national eligibility criteria would get rid of the postcode lottery. The services provided under the duty could be provided to the child's family, and not solely to the child, where necessary to meet the child's needs. **See consultation questions 22 and 23**.

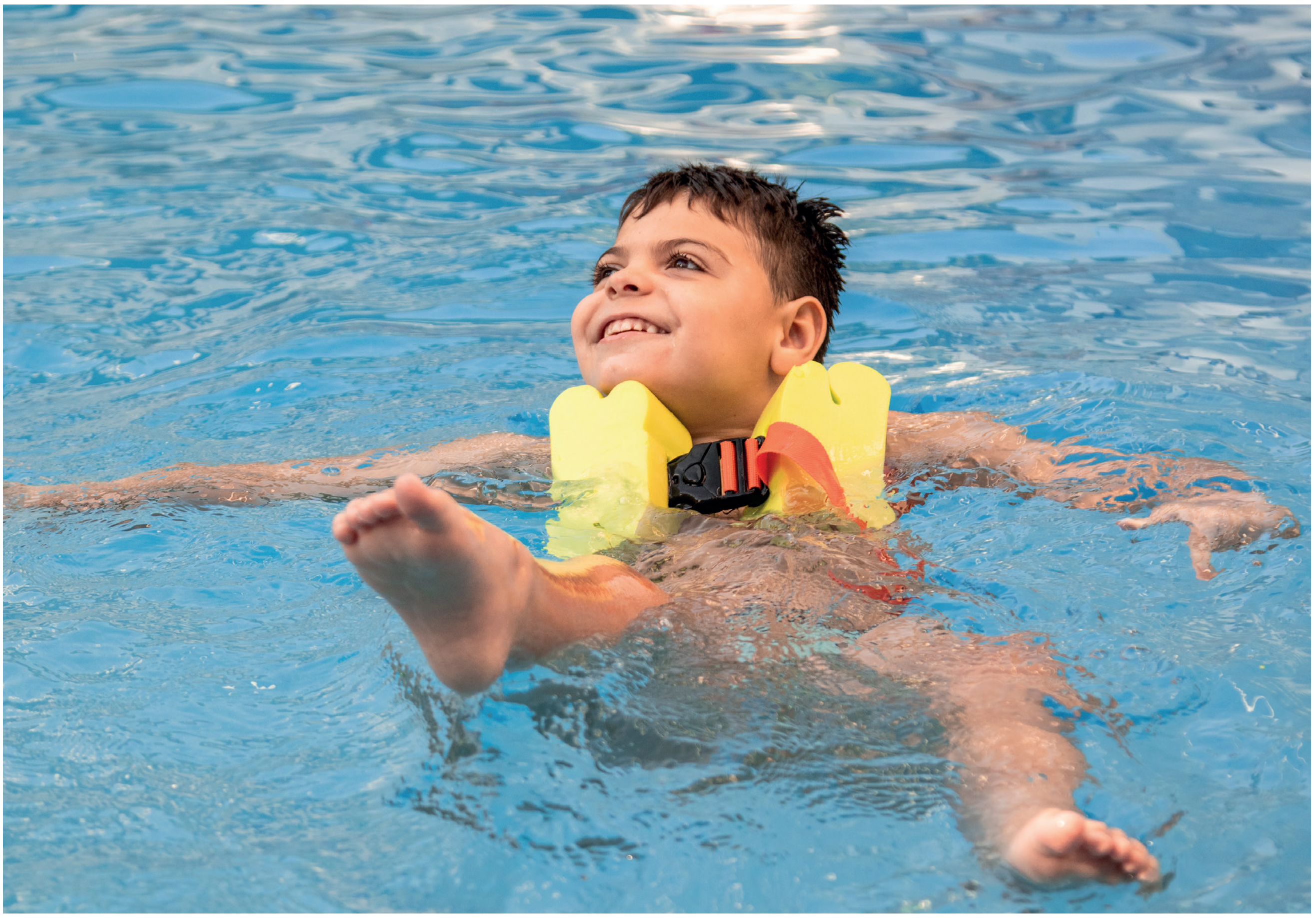
It is not for us to decide what the eligibility criteria should be: the criteria will need to be co-produced between central and local Government, taking into account the amount of central Government funding which is to be made available for disabled children's social care. But we invite views on what the essential features of any eligibility criteria should be if a single approach is adopted across England. **See consultation questions 24 and 25**.

At the moment the power to provide support to disabled children under section 17 of the Children Act 1989 applies to children who are physically present in the area of the local authority. In contrast the duty under section 2 of the Chronically Sick and Disabled Persons Act 1970 applies to children who are ordinarily resident. If we are to combine these legal provisions into a single duty to meet the social care needs of disabled children, we need to decide which of these residence requirements should apply. We seek views on this. **See consultation question 27**.

We provisionally propose that the single duty should cover all of the different types of services which can be provided to disabled children, including short breaks. Short breaks are services to:

- provide breaks for the benefit of disabled children; and/or
- 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.

They can include things like accommodation, the provision of care at home or elsewhere, and educational or leisure activities. **See consultation questions 31 to 35**.



At the moment, social services have the power to pay for adaptations to the homes of disabled children, and we think that should continue to be the case. But there is also a parallel scheme, run by local housing authorities, for grants for home adaptations for disabled people. These are called disabled facilities grants. We are interested in views on whether transferring responsibility and funding for disabled facilities grants for children from local housing authorities to social services would be viable. **See consultation question 28**.

Having a duty to meet the needs of disabled children which is subject to eligibility criteria would mean, by definition, that not every need of every disabled child would be met. If a child's needs do not meet the eligibility criteria, then a local authority would not be required to meet them. In those cases, our provisional proposal is that local authorities should still have a power to meet those needs if they thought it appropriate. So the eligibility criteria would set out the minimum which authorities should be required to do, but they would have the option to do more if they chose to. That same power could be used to provide support while a child's needs are being assessed and to meet the needs of parents, carers and siblings, if that would help promote the welfare of a disabled child. **See consultation questions 29 and 30**.

Service provision

The range of services that should be available

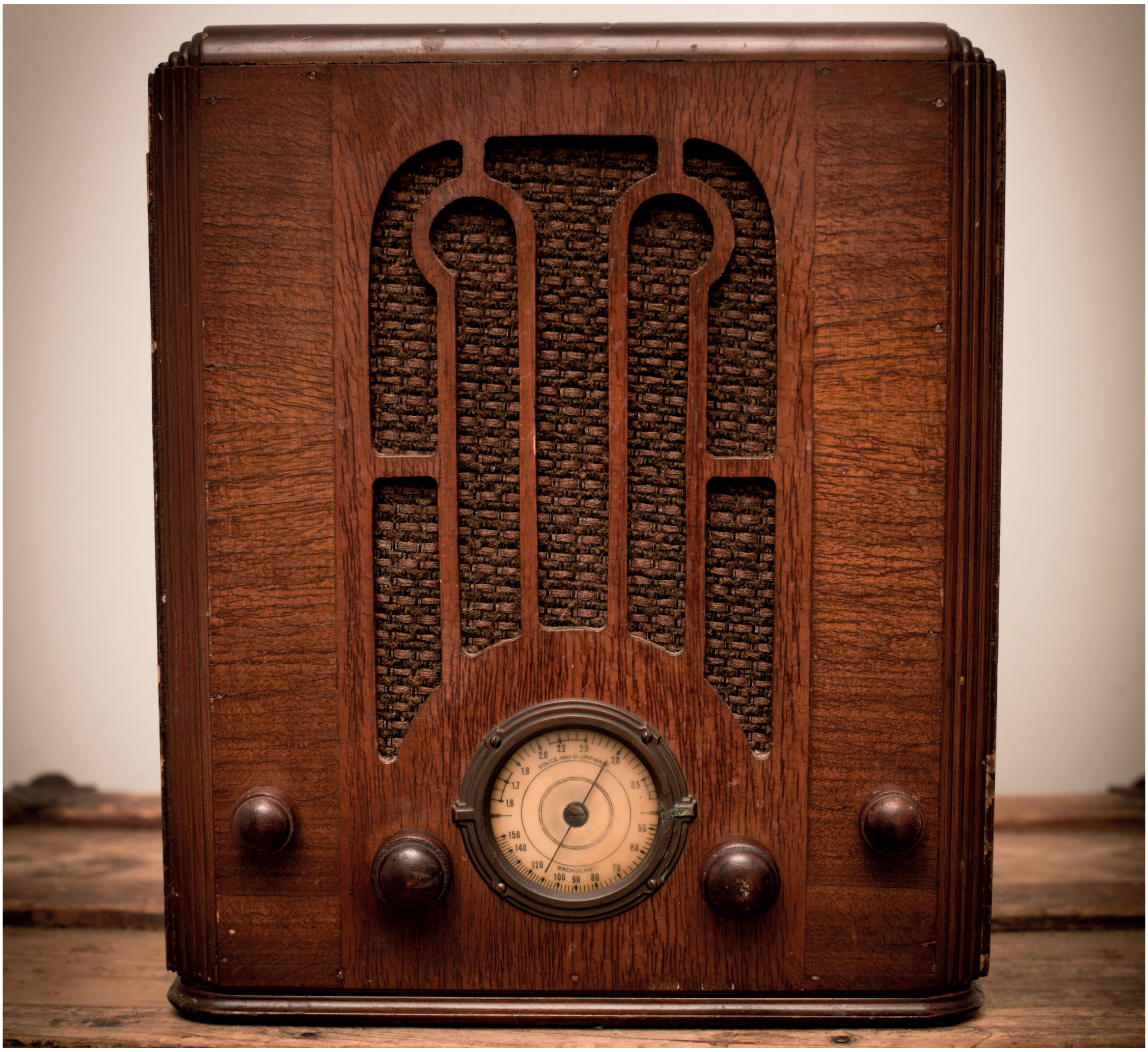
See chapter 9.

Under section 17 of the Children Act 1989 local authorities can provide a broad selection of services to safeguard and promote the welfare of disabled children. Section 17 does not contain an exhaustive list of things that can and cannot be provided. But it gives examples of things that can be provided including accommodation, assistance in kind (which means goods and services other than money) and cash. Under section 17 there is no real limit to what can be provided, as long as it promotes or safeguards the child's welfare and doesn't cross the line into health care. See pages 52 to 54.

Section 2 of the Chronically Sick and Disabled Persons Act 1970 is different. Under section 2 there is an exhaustive list of things that local authorities can provide to meet the needs of disabled children. The list includes providing "wireless, television, library or similar recreational facilities", practical assistance for the child in their home and assistance in arranging adaptations to the home. If a child needs something that is not on the list, it can't be provided under section 2.

Because we are provisionally proposing that there should be a single duty to meet the needs of disabled children, subject to national eligibility criteria, we also need to think about what the legislation should say about the range of services that can be provided under that duty. To help us answer this question we would like to hear your views on what the main services that disabled children require are, and what services are currently available. **See consultations question 37 and 38**.

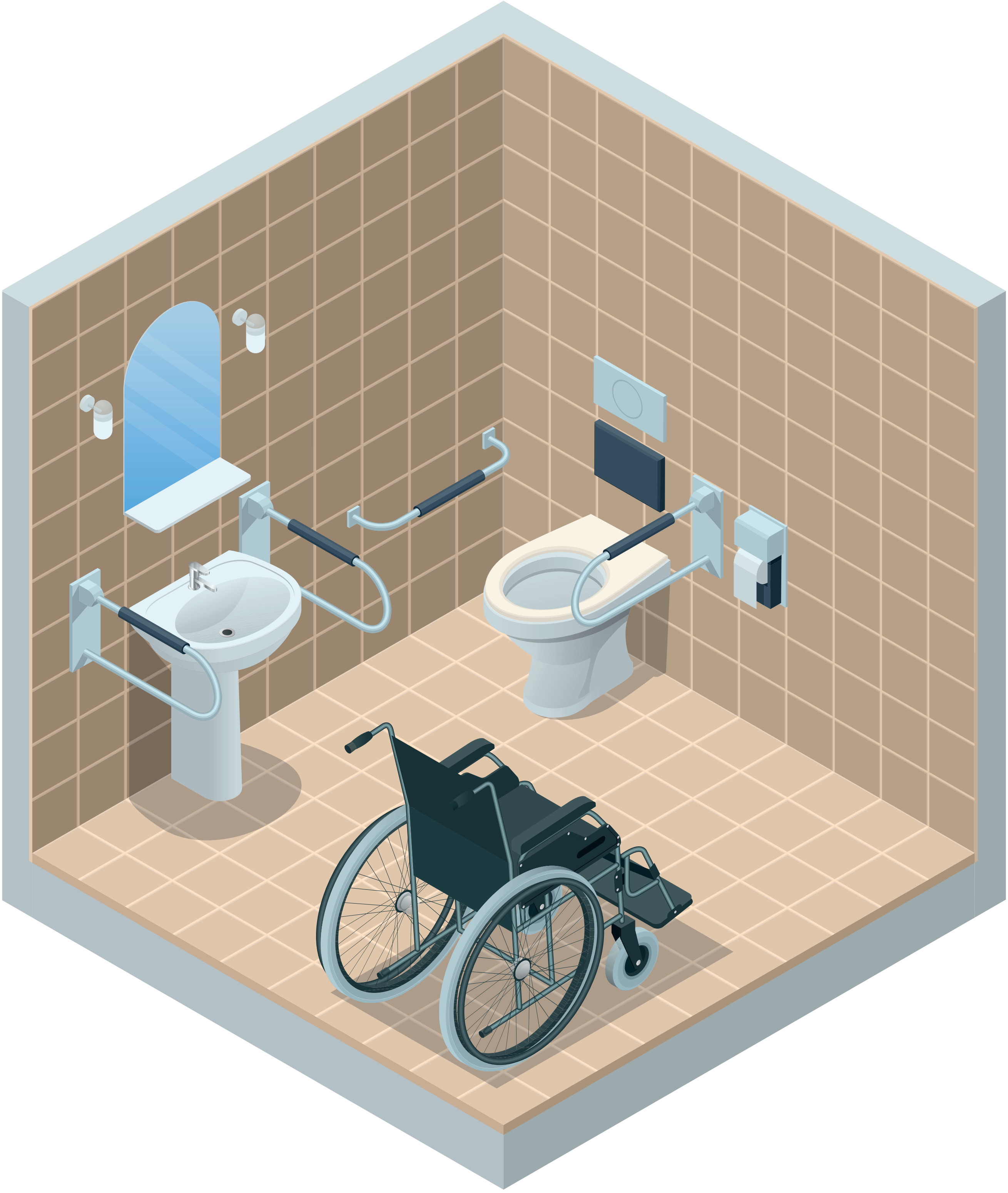
In the meantime, our initial view is that having a non-exhaustive list of services is the best option. The problem with having an exhaustive list of services is that it will go out of date as technology develops and society changes. The reference in section 2 to a "wireless" is a good example of this. Many people think this is a reference to wireless internet and not a wireless radio (pictured).



An exhaustive list might also limit the flexibility of social workers to adapt to different situations. But we think a non-exhaustive list is better than no list at all, as it makes clear that certain things can be provided and avoids legal disputes about whether that is the case. For example, there have been quite a few court cases over the years about whether social services can provide accommodation. If the legislation says expressly that they can, that avoids expensive court cases.

Our provisional view is that the non-exhaustive list of things that social services can provide to meet the needs of disabled children could include:

- accommodation;
- the provision of care at home or elsewhere;
- educational or leisure activities;
- services to assist parents and carers in the evenings, at weekends and during the school holidays;
- adaptations to the home;
- counselling and other types of social work;
- goods and facilities;
- information, advice and advocacy.



We would like to know what services you think should be included in any list. **See consultation questions 39 and 40**.

How to provide services

See chapter 10.

There are three ways in which local authorities can secure the provision of services for a disabled child or their family:

- By providing those services directly, for example in the form of support from a local authority social worker.
- 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.
- 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".

We think that all of these options should continue to be available. But we have heard in the lead up to this consultation that direct payments don't always work very well. They are not always enough to pay for carers, and services aren't always available in the local area to spend them on. **See consultation questions 41 and 43**.

To deal with that we provisionally propose that direct payments for disabled children's social care should be brought closer in line with direct payments under the SEND system. Specifically, we think that:

- direct payments should be set at an amount that is sufficient to secure the provision needed, as opposed to an amount that is estimated to be reasonable; and
- direct payments should be kept under review, so that their sufficiency can be monitored, and alternative arrangements made if they are not working.

Under both the SEND system and the adult social care system, there is also a right to a "personal budget". That is an amount of money identified by the local authority to deliver provision set out in the plan to meet the child's needs, where the parent or child (if they are old enough) is involved in securing that provision. That could involve direct payments. Or it could involve an arrangement where the local authority or a third party holds and manages the funds. Personal budgets represent a more modern and flexible approach to service provision, and we think that there should also be a right to a personal budget under disabled children's social care law. **See consultation question 42**.

Care planning

See chapter 11.

A care plan is a document which sets out what services are to be provided, where, when and by whom. The legislation does not say expressly that disabled children who receive social care are entitled to a care plan. However, Government guidance and the courts have said that disabled children (and other children in need) are entitled to a plan.

We provisionally propose that this right to a care plan should be set out in legislation. This would make the law clearer.

We do not think it's appropriate for us, or for legislation, to dictate what should go in the plan over and above the core requirements of "what, where, when and who". In some instances, a short and simple plan may suffice. For example, a child who uses a wheelchair who is seeking swimming lessons to help them develop their motor skills may need little more than a letter setting out when, where and with whom the lesson is to take place. On the other hand, a child whose needs are so complex that they can only be met in long-term residential accommodation with the support of multiple carers will need a far more detailed document, including the identities of the carers, a timetable for the provision of care and a contingency plan. The different requirements of the plans that would be needed in these cases are, we think, better left to guidance which is more flexible than legislation. **See consultation questions 44 and 45**.

In proposing a statutory right to a care plan for disabled children, we want to avoid making families have to repeat their stories unnecessarily and local authorities having to duplicate their work.

For that reason, we provisionally propose that where the care plan for a disabled child could appropriately be combined with another plan for the child, such as an Education, Health and Care Plan (EHCP), then it should be.

See consultation question 46.

Means testing and charging

See chapter 12.

Currently, there are various charging regimes for the different services that local authorities can provide for disabled children under the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970. They are all, however, based on the same core principles which are that:

- Charging is discretionary. Local authorities can charge if they want to, but they don't have to.
- A person should not be charged more than is "reasonably practicable" for them to pay.
- The charge can't exceed the amount the local authority considers "reasonable" for the provision of the service.
- Those in receipt of the main means tested welfare benefits (such as universal credit) should not be liable to pay charges.

The funding of disabled children's social care is a matter for elected officials rather than law reform. It wouldn't be appropriate for us to propose changes to these principles. If a new legal framework is adopted for disabled children's social care – something we discuss on page 32 – we think the various charging regimes should be replaced with one unified regime based on the existing principles which we have set out above.

Otherwise, we are not proposing any change to charging. But we would like to know more about local authority charging practices and whether authorities might need to charge more, or more often, if our provisional proposals were implemented. **See consultation questions 47 and 48**.

Systemic issues

The intersection between disabled children's social care and SEND law

See chapter 13.

In this review we are focusing on the reform of disabled children's social care law, important parts of which date back to the 1970s and 80s. We are not looking at reforming SEND law (found in the Children and Families Act 2014). That was comprehensively updated more recently and was the subject of a House of Commons inquiry in 2019.

However, SEND law is still relevant to our review because:

- SEND law and disabled children's social care law overlap. In particular, social care provision is part of the support which children with special educational needs are entitled to receive under an EHCP.
- We have been asked to think about the alignment between SEND law and disabled children's social care law.
- One of the concerns we've heard from parents and carers 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.

- There is an overlap between children who need support at school to meet their special educational needs and the children who need social care support at home because they are disabled.

Focusing on the last point, we are not sure exactly how much overlap there is. There are no statistics on this. The experts we've spoken to think the overlap is significant. But most agree that it's not a 100% overlap. Some children who need special educational needs (SEN) support at school may not need social care support at home to meet their disability related needs. And not all disabled children who need social care support at home will need SEN support at school. For example:

- A dyslexic child may need support to meet their special educational needs at school, but not need any social care support at home.
- A child who uses a wheelchair may need social care provision outside of school, in the form of a grant to make adaptations to their home. However, they might not need any additional support at school because mainstream educational settings should already be wheelchair accessible.

On top of this, the legal tests that have to be applied to work out whether a child can get SEN support are quite different from the sort of tests that have to be applied to work out whether a disabled child should get social care support. For example, whether a child gets an EHC needs assessment or an EHCP will depend on whether the support they need is the kind of thing that is normally available to children of their age in mainstream schools. That sort of test wouldn't work for disabled children's social care law, where the goal is to work out (among other things) whether the child needs extra support at home or in the community.

For those reasons, we don't think that it would be possible – without completely rewriting the law on SEND – to have one single law dealing with SEND and disabled children's social care. But we do think that SEND law and disabled children's social care law could be brought closer together, and some of the provisional proposals in our consultation paper are meant to do that. For example, we think that social care assessments and plans and EHC assessments and plans should be combined where possible for disabled children. Also, the statutory principles we discuss below on pages 63 to 65 are based on the principles that apply in SEND, to try and make sure that everyone working with disabled children is pulling in the same direction. **See consultation question 49**.

The intersection between disabled children’s social care and health care

See chapter 14.

The social care needs of disabled children are met by social services. The health care needs of disabled children are met through the NHS. Local authorities can charge for social care. Health care, on the other hand, is usually free. This means that deciding whether the needs of a disabled child are social care or health care needs is really important: it dictates who meets the needs and who pays for it. But this is not always straightforward, particularly for children with complex needs. In this context we've been told that disputes between local authorities, the NHS and integrated care boards can be quite common. Part of this comes down to the fact that the boundary between health and social care isn’t always fixed. For example, whether nursing care provided to a disabled child in their home is classed as health or social care will depend on the nature and extent of the care.

There is a limit to what we can do about this. We can’t redraw the boundary between health and social care. However, we can at least try and make the boundary clearer. At the moment the boundary isn’t written down in the disabled children’s social care legislation. It is written down in the adult social care context, in section 22 of the Care Act 2014 which says that:

> *A local authority may not meet needs… by providing or arranging for the provision of a service or facility that is required to be provided under the National Health Service Act 2006 unless—*
>
> - *doing so would be merely incidental or ancillary to doing something else to meet needs under those sections, and*
> - *the service or facility in question would be of a nature that the local authority could be expected to provide.*

This is the same as the boundary that the courts have said applies to disabled children's social care law, and we think the boundary for disabled children should also be set out in legislation.

We provisionally propose that the boundary between health care and disabled children's social care is set out in legislation.

The legislation could contain a power to change the boundary, to cater for the possibility that national policy changes in future. The legislation could also be accompanied by guidance on the intersection between health care and social care. **See consultation question 50 and 52**.

Separately to all of this, there is also a specific point in the law where health and social care intersect.

This is found in section 117 of the Mental Health Act 1983, which deals with “aftercare” services for people who’ve been discharged into the community after having been detained in hospital. Aftercare is arranged jointly by the NHS and social services. There is a complicated legal route which means that a disabled child who is being assessed for aftercare services should also have their social care needs assessed. We think this should be simplified. **See consultation question 51**.

The transition to adult social care

See chapter 15.

Many parents, carers, social workers and others we’ve spoken to in the lead up to this consultation have talked about the “cliff-edge” disabled children face when they turn 18. This is where the services that a child was getting either stop or change significantly when they reach adulthood, and they are left feeling unsupported and unprepared. Similarly, the most pressing concern identified by the disabled children and young people we’ve heard from is that they haven’t had the support they needed to make the transition to adulthood and (in some cases) independent living.

We would like to hear your views and experiences of this “cliff-edge” and why it exists. **See consultation question 53**. We think that one of the factors underpinning it is that, in contrast to the SEND system, there is no set age when social services have to start preparing disabled children to make the transition to the adult social care system under the Care Act 2014. We think that there should be a set age and would like to hear views on whether that is right and, if so, what that age should be. **See consultation questions 54 and 55**.

Identifying need in the local area and securing sufficient services to meet that need

See chapter 16.

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. However, in the lead up to this consultation we've heard that services aren't always available in the local area to meet the needs of disabled children and their families.

The Children Act 1989 does not require local authorities to identify the needs of disabled children in the local area, or to make sure that sufficient services are provided in the local area so that those needs can be met. But the SEND legislation does. For example, the SEND legislation requires local authorities to:

- exercise their functions with a view to identifying all of the children in the area who have a disability;

- work together with other bodies to commission the social care provision reasonably required by disabled children in the area;
- keep the social care provision for disabled children in the area under review; and
- consider, in consultation with disabled children and their parents, whether the social care provision in the area is sufficient.

We think that these legal duties, on paper, are enough to ensure that the right services are available for disabled children. We also think that, if in practice, the system is not currently working, that may mean that the duties need to be regulated more closely. But we don’t think the duties themselves need to change. However, we’d like to hear about people’s experiences of the availability of services in their local area, and what local authorities are doing to identify local need so we can consider this further. **See consultation questions 56 and 57**.

Co-operation and joint working

See chapter 17.

There are lots of different statutory duties requiring the different teams and public bodies responsible for disabled children's social care, health care and SEND to co-operate. But in practice we've heard that this does not always happen, and they often work in silos and don't communicate or work well with each other. We are interested in hearing your experiences of joint working, and the things that can help or hinder it. At the moment we don't think more onerous legal duties are the answer. **See consultation questions 59 and 60**.

One way to promote co-operation is to have a designated person who is responsible for promoting joint working and who is senior enough to make that happen. With that in mind, and to improve joint working between social care services and the SEND system, 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… 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.*

Some authorities have told us that the DSCO can promote joint working. We would like to hear your views on the DSCO role and whether requiring all local authorities to have one would be an effective change. **See consultation question 58**.

Remedies

See chapter 18.

There are various remedies which a disabled child or their parent or carer might try to pursue if they're unhappy with a decision that has been made about them or the way that they have been treated. These include internal complaints, complaints to the Local Government and Social Care Ombudsman, appeals to the SEND Tribunal and judicial review.

The parents and carers we've spoken to in the lead up to this consultation have given us the impression that complaints systems (whether internal or to the Ombudsman) don't always work for them. Judicial review is complicated, expensive (if you don't have legal aid) and only meant to be used as a last resort. The SEND Tribunal is more accessible but it's not always an option: it can only deal with disputes about disabled children's social care where there is also a dispute about SEN. It only has limited powers to deal with social care disputes. Parents, carers and local authorities have also expressed mixed views to us about their experiences at the Tribunal, and many have been negative. The Tribunal also has a very large workload meaning that appeals can take a long time. We'd like to hear about your experiences of these remedies. **See consultation questions 61 and 62**.

We would also like to hear your views on what an effective and independent system to challenge and change decisions about disabled children's social care could look like. **See consultation question 64**. Expanding the jurisdiction of the SEND Tribunal to deal with all disabled children's social care disputes and strengthening its powers in those cases (including giving it a power to order a social care assessment) is one option. But we're not sure it's the right one or whether it would be practically achievable. Giving the Children's Commissioner a greater role could be another option, but we recognise that could come at the expense of other important priorities she has. We seek your views on these options. **See consultation questions 63, 65 and 66**.

Wider issues

The definition of disability

See chapter 19.

We set out the definition of disability in the Children Act 1989 on page 10. The language is out of date and needs to be modernised. But what do we replace it with? The most obvious option is the definition under the Equality Act 2010. This says that a person has a disability if:

- they have a physical or mental impairment, and
- the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

This definition is not perfect. The word “impairment” is offensive to some people. It doesn’t fit well with the social model of disability: the idea 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. However, the Equality Act definition is more modern than the definition we are currently using for disabled children’s social care and it is used across Government and in the SEND system. We think it could cause problems if we used a completely different definition.

We provisionally propose to adopt a definition of disability based on the Equality Act definition. But we think that some adaptations may be needed to make sure the definition works for disabled children's social care. **See consultation question 67.**

Under the Equality Act definition, for children aged six and over, the effect of an impairment is long-term if it has lasted for at least 12-months, is likely to last for at least 12-months, or is likely to last for the rest of the person's life. The effect is substantial if it is more than minor or trivial. But for children under six, whether the effect of a condition is long-term and substantial is decided by considering the effect that their condition would have on an older child. We seek views on whether this dual approach for children under and over six is appropriate for disabled children's social care. **See consultation question 69**.

The definition of disability under the Equality Act 2010 excludes conditions that arise from addiction. Is also excludes certain behaviours including a tendency to set fires or be physically abusive. Our provisional view is that these exclusions should not apply to disabled children's social care.

- Currently, in disabled children's social care law, conditions that arise from addiction are not excluded from the definition of disability. Children whose conditions arise from addiction can still get help. We don't propose to exclude them. That would be a political decision which is not for us to make: whether children, particularly younger children, should be held responsible for addiction is a difficult moral question on which people hold differing views.
- Currently, disabled children's social care law does not exclude behaviours such as a tendency to set fires or be physically abusive from giving rise to a disability. Children whose disabilities give rise to challenging behaviour can still get help. Again, we don't propose to exclude them. That would be a political decision and excluding challenging behaviour could well mean that disabled children with some of the highest needs don't get the support they require.

However, if these exclusions are not applied, then we will still be in a position where the definition of disability in disabled children's social care law is (slightly) different to the definition in the SEND legislation. We would like your views on this. **See consultation question 68**.

Statutory principles

See chapter 20.

Statutory principles are legal propositions which guide the application of the law. For example, in child care law, when a court has to make a decision about a child’s upbringing section 1(1) of the Children Act 1989 says that “the child’s welfare shall be the court’s paramount consideration”. In applying a principle, legislation will sometimes require particular things to be taken into account. For example, in adult social care law, in applying what is sometimes referred to as the “well-being principle”, social services must have regard to the adult’s views, wishes, feelings and beliefs.

We think principles like this are a good idea and could help solve some of the problems we have heard about during the review so far. For example, one of the main concerns we’ve heard from parents and carers is that the knowledge they have of their child’s condition(s) and the expertise they have developed isn’t always taken into account. Requiring social services to take this knowledge and expertise into account might help ensure that important information isn’t overlooked. Similarly, one of the main concerns we’ve heard from disabled children and young people is that the support they received didn’t prepare them for independent living. Requiring social services to keep in mind the need to prepare children for adulthood and (where appropriate) independent living may help ensure that services are planned and provided in a way which eases the transition to adulthood.

With this in mind, our provisional proposal is that when working with disabled children and their families, local authorities should treat the best interests of the child as the primary consideration.

In applying this principle we think that local authorities should 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 best interests of the child;
- the importance of the child participating as fully as possible in decisions;
- 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;
- the views, wishes and feelings of the child;
- the views, wishes and feelings of the child’s parents or carers and their knowledge of their child’s condition(s) and needs;

- the need to support the child and their parents or 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;
- the importance of preventing or delaying the development of the needs for care and support;
- the need to prepare disabled children for adulthood and independent living; and
- the characteristics, culture and beliefs of the child.

Having taken these considerations into account we think that decision makers should apply a final check and ask themselves whether the aim they are trying to achieve could be as effectively achieved in a way which is less restrictive of the child's rights and freedom of action.

These proposals are a mixture of: requirements under other related legislation (like the SEND legislation) which we would like disabled children's social care to align with; things that should be considered when working with disabled children but are sometimes overlooked; and duties under international treaties like the United Nations Conventions on the Rights of the Child and the Rights of Persons with Disabilities. **See consultation questions 70 and 71**.

Participation

See chapter 21.

Participation is important. Children should be involved in decisions that are made about them. That doesn't change just because they are disabled. In fact, that may make it more important for them to be involved. Even if the law doesn't allow a child to make a decision for themselves, their voice should still be heard. This is important for its own sake. But it also helps social services make better decisions, by ensuring they have the information they need. The same applies to the involvement of parents and carers.

There are three ways in which disabled children's social care law allows for participation:

- by allowing the child to make a decision for themselves;
- by taking into account the views of the child when making a decision about them;
- by taking into account the views of the parent or carer when making decisions about the child.

We will deal with each of these ways in turn. The first is the most complicated.

Children making their own decisions

At the moment, disabled children's social care law only allows children to make some decisions for themselves. For example, older children can decide whether they want direct payments or accommodation under section 20 of the Children Act 1989. There is no particular logic behind which decisions children are allowed to make for themselves and which they aren't. And the legal tests which have to be applied to work out whether a child can make a decision – because not all children will have the level of understanding they need to make a decision even if they are allowed to do so – aren't always clear or consistent.

In contrast, we think that the approach taken under the Children and Families Act 2014 in relation to SEND is clearer, more consistent and involves children in decision making to a greater extent. For example, a child over compulsory school age who has "capacity" to make decisions within the meaning of the Mental Capacity Act 2005 (which we discuss further below) is able to request an assessment for an EHCP, make representations about the EHCP, ask for a personal budget to implement it, and appeal to the SEND Tribunal about it.

We provisionally propose that disabled children's social care law should be brought closer into line with SEND law. Following the SEND approach, but expanding it to those under 16, we think all children should – in principle and when they can – be able to decide for themselves to:

- request an assessment of social care needs;
- make representations during the assessment of their needs;
- make representations about the plan to meet their needs;
- turn down an offer of advocacy support;
- ask for direct payments; and
- make use of the relevant remedies that are available where a local authority has failed to assess or meet their needs appropriately.

See consultation question 74.

We say “in principle” because not all children will be able to make these decisions for themselves. For example, a two-year old is not going to have the level of understanding needed to request an assessment. Some children with learning disabilities may also struggle, even with assistance, to understand the decision that needs made. Because of that, we need to decide what legal test to apply to work out whether a child can make decisions for themselves. In other areas of law (if there is a test at all) the most widely used legal tests are:

- The test from the Mental Capacity Act 2005, applied in a number of contexts to those aged 16 and above. This test looks at a person’s ability to understand, retain, use and weigh the information relevant to a decision at a specific point in time, and to communicate their decision. If a person cannot do one of these things because of an “impairment of, or a disturbance in the functioning of, the mind or brain” then the law says that they lack the “capacity” to make the decision.
- Whether the child is “competent”. This test has been developed by the courts and applies to children under the age of 16. A child that has sufficient understanding, maturity and intelligence to make a decision is judged to be competent to make it. The courts have not been entirely consistent in how they have applied this test.

For children aged 16 and 17 our provisional proposal is that, in deciding whether the child is able to decide for themselves, local authorities should consider whether the child has capacity using the test from the Mental Capacity Act 2005.

See consultation question 75.

For children under 16, one option would be for the legislation to say that the child has to be competent, and to let that test continue to be developed by the courts. Another option would be for the legislation to set out a new test, based on the test for capacity, which asks whether the child is able to understand, retain, use and weigh the information relevant to a decision at a specific point in time, and to communicate their decision. We seek your views on this.

See consultation question 76.

Taking the views of the child into account

Disabled children's social care is administered by local authorities. That means that there are many decisions which, ultimately, are for the local authority to make and not the child or their parent or carer. But even where the child does not have a right to make a decision themselves, they should be involved in it and social care law recognises this already. However, in practical terms, the child may need help or information to make that possible. SEND law recognises that and requires local authorities exercising their SEND functions to have particular regard to:

- the importance of the child participating as fully as possible in decisions relating to the exercise of the function concerned;
- the importance of the child being provided with the information and support to enable them to participate;
- the child's views, wishes and feelings.

We provisionally propose that the same approach should apply in disabled children's social care law, and we've included these factors in our proposals on pages 63 to 65 relating to statutory principles.

Taking the views of parents and carers into account

There is no general requirement for local authorities to take into account the views of parents and carers when making decisions about disabled children's social care. We have been told that this can be a problem as it can mean that the views and expertise of parents and carers can be overlooked. This can be contrasted with the approach under the SEND legislation, where there is a requirement to have regard to the views, wishes and feelings of the parent and facilitate their participation. Building on that approach, we provisionally propose that social services should have regard to the views, wishes and feelings of the child's parents and carers and their knowledge of their child's condition(s) and needs. We have included them in our proposals on pages 63 to 65 relating to statutory principles.

Advocacy

See chapter 22.

An advocate is someone who assists a disabled person to speak up for themselves, or if the disabled person is unable to do so, to communicate and represent their needs and wishes. Advocacy is one of the ways in which a child or their parent can be helped to participate in decision making.

Under the current legal framework in the Children Act 1989, disabled children (among others) are entitled to advocacy to help them to make representations about the way the local authority is carrying out its social care responsibilities. It is not clear whether this includes advocacy while the needs of a disabled child or their parent or carer are being assessed. That lack of clarity is a problem. **See consultation question 79.** On top of that, there is no requirement for the advocate to be independent. That can be a problem as the role of the advocate is to represent the child's interests even if they conflict with the interests of the authority, and that may be difficult if the advocate is not independent.

This is quite different to the adult social care system. Under the Care Act 2014, adults who need care and support – as well as children who might need care and support in adulthood – have a right to representation and support for the purposes of facilitating their involvement in the process of assessing and planning to meet needs. This is available automatically where, without an advocate, they would have difficulty in understanding, retaining and weighing up information, or communicating their views. The exception to this is that the local authority doesn't have to appoint an advocate if they are satisfied there is already an appropriate person who can support the individual's involvement.

Our provisional proposal is that this same approach should apply to disabled children's social care: there should be 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:

- there is already an appropriate person who can represent and support that child; or
- a child with the ability to do so (see pages 67 to 70 above) refuses an advocate.

We think this is a better way to achieve the purpose of advocacy - to support the involvement of those who would otherwise struggle to participate - than the current framework. Adopting this approach, we think, would give effect to the proposals we make on participation and help make sure that local authorities have the information they need to make the right decision first time. For the same reasons we provisionally propose that advocacy should be available on the same terms for parents and carers who are having their own needs assessed and planned for. **See consultation questions 78 and 81**.

A new legal framework

See chapter 23.

An important question we have needed to keep in mind throughout this review is whether the law actually needs to change. The definition of disability set out in the legislation definitely needs to be updated. But could the other problems that we have heard about, and which we have explained above, be dealt with by new and better guidance without the need for law reform? If not, what sort of legal changes are required?

As will already have become clear, our provisional view is that the law does need to change. Publishing new guidance will not do anything to solve the problem that the law is far too complicated, and the fact that the legal rules that parents, carers and social workers need to know about are spread across numerous statutes, regulations and court decisions. Added to that, guidance doesn't always have to be followed. Also, where guidance conflicts with the law, courts require local authorities to follow the law, not guidance. So, we don't think guidance would be enough to solve all the problems we've heard about.

We think that legal change is needed and that the simplest, most accessible system that we could have would be a new legal framework focused solely on meeting the social care needs of disabled children. We think this would help ensure that disabled children are viewed as children who may need extra help and not always children who need protection. It would also make it possible to implement some of the other proposals we make above relating to statutory principles, participation, advocacy and simplification of the charging regime. Without a new framework, we think it would be too difficult to fit these proposals into the current law.

Our provisional proposal is that there should be a new legal framework for disabled children's social care. This would mean taking disabled children out of the scope of section 17 of the Children Act 1989.

That would be a big decision. It would undo one of the important things which section 17 was meant to achieve: bringing all children in need of help together under one statute. Whether this is the right thing to do requires careful consideration of some difficult issues. If we take disabled children out of the scope of section 17, would we make it harder for local authorities to identify children who are at risk of harm? Similarly, would we make it harder for social workers to identify and meet other needs that the child has in addition to needs arising from their disability, such as needs arising from poverty? We think the answer to these questions is no. Any new legal framework should make it clear that these are still things that local authorities can and should look out for and that the different types of assessment and investigations that cover these different issues can be combined. But these are difficult issues, and you'll need to keep them in mind when answering the consultation questions. **See consultation questions 82 and 83**.

Glossary

Assessment: the process of identifying a person's needs by collecting information and evidence.

Child: any person under the age of 18.

Child in need: a child –

- who is unlikely to achieve or maintain, or to have the opportunity to achieve or maintain, a reasonable standard of health or development without support from their local authority;
- whose health or development is likely to be significantly impaired, or further impaired, without support; or
- who is disabled.

Children Act 1989 & Chronically Sick and Disabled Persons Act 1970: the main pieces of legislation covering disabled children's social care law. Most social services for disabled children are provided under section 17 of the Children Act 1989 (which covers all children in need) or section 2 of the Chronically Sick and Disabled Persons Act 1970 (which covers disabled children only).

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

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 setting out a child's special educational needs, together with related social care and health care needs.

Judicial review: the process where someone makes an application to the High Court arguing that a public body has made a legal error.

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 needs.

Safeguarding: measures taken to protect a child and keep them safe from harm.

Short breaks: services to provide breaks for the benefit of disabled children and their parents or carers.

Special educational needs (SEN): a child has special educational needs if they have a learning difficulty or disability which means that they need help with their education or training, over and above the help that is generally available to children of that age in mainstream educational settings.

SEND: special educational needs and disability.

Social services: the part of a local authority that deals with social care for disabled children. This is separate to the part of the authority that deals with education. But both parts fall within children's services.