

## Law Commission – Disabled Children’s Social Care Consultation Paper

Cerebra’s response  
29 January 2025

### **Consultation Question 1 (Paragraph 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.***

The impact assessment would be improved by considering savings that could be made by the effective use of Disabled Facilities Grants. The Cerebra report: [Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants: a Small Scale Pilot Study](#) (Clements, McCormack, 2017) found that significant savings can be made by local authorities by funding home adaptations rather than allowing families to reach crisis point, resulting in children and young people being placed into care. The pilot study suggested in the case of 3 of the families interviewed, that a total of 14 years of ‘looked after child’ funding had been avoided by the adaptations, saving almost £1.5 million, if the cost of looking after a child was assumed to be £2,000 per week (and almost £2.2 million if the assumption was £3,000 per week). The cost of the adaptations was under £300,000. A case study – [Disabled Facilities Grants – One Family’s Story](#) (Clements, 2021) provides further evidence of savings to a local authority, in this case over £1.1 million as a result of providing a Disabled Facilities Grant of £165,000. See also [Disabled Facilities Grant and other adaptations: external review](#) (Sheila Mackintosh et al, 2018) and [Disabled facilities grants \(DFGs\) for home adaptations](#) (HoC Library, April 2023).

We believe that the impact assessment could also consider the losses incurred by families who have to plug gaps in support with their own resources. According to Contact’s [Counting the Costs Online Survey](#) (2024), caring responsibilities mean the majority (62%) of parents/partners had to give up a paid job or reduce hours. On average these parents have lost £21,174 of income per year.

The impact assessment could also refer to the huge resources spent on child protection referrals and the potential savings to be made from reducing the number of inappropriate referrals by tackling the ‘parent blame’ culture within local authorities. For reference, see Prof Andy Bilson’s research (for example, see [this overview](#)) on the human and financial costs of inappropriate child protection proceedings. A significant proportion of money spent on inappropriate safeguarding proceedings could be put towards funding more effective assessment and provision for disabled children and their families.

### **Consultation Question 2 (Paragraph 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?***

The proposals if enacted will result in advantages for disabled children in general and neurodivergent children in particular, provided there are suitable accountability mechanisms put in place alongside reforms. Specifically, we consider the proposals will likely improve the issues addressed in the following Cerebra research:

- [Unlawful restrictions on the rights of disabled children with autism to social care needs assessments](#) (Bahri, Clements et al, 2020);
- [Institutionalising parent carer blame](#) (Clements and Aiello, 2021);
- [Challenging Parent Carer Blame: Interim research report 1: Disability and human rights training and guidance for disabled children’s assessors](#) (Clements and Aiello, 2022);

- [An impact snapshot on the unlawful restrictions on the rights of disabled children with autism to social care needs assessments](#) (Bahri, Clements and Aiello, 2022);
- [The prevalence and impact of allegations of Fabricated or Induced Illness](#) (Clements and Aiello, 2023).

**Consultation Question 3 (Paragraph 3.62)**

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

***Do consultees agree?***

Yes.

**Consultation Question 4 (Paragraph 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?***

We favour either (1) or (2), or a combination of both. The other options are inappropriate, setting a bar that is higher than in adult social care which requires assessment where "...it appears to a local authority that an adult may have needs for care and support..." (s9(1) Care Act 2014). Alternatives (3) & (4) are circular, as it would be impossible to know whether a child is eligible for support unless some form of assessment is undertaken. There is a risk that these thresholds would have the effect of screening out children by pre-empting the results of any assessment. We consider there should be a presumption (as in Wales) that all disabled children need care and support in addition to that provided by their families.

We understand the legal test set out in the Care Act 2014 works well. We expect that local authorities will seek as high a threshold as possible, for resource reasons, but would urge the Commission to keep the threshold low. We would refer the Commission to the threshold for carrying out EHC needs assessments, which is a low threshold but is still higher than our preferred option for disabled children's social care. It is still regularly disregarded by local authorities who unlawfully refuse to carry out assessments. According to Special Needs Jungle ([source](#), 2023), it is likely that parents appeal around 14 percent (one in every seven) of local authorities' refusals to assess decisions and the vast majority of these decisions are either conceded by local authorities prior to a hearing or are overturned by the SEND Tribunal. As such, we believe that the threshold for disabled children's social care assessments should be kept low, as the evidence relating to EHC assessments suggests that local authorities will interpret any threshold very narrowly - so that in effect the threshold in practice is likely to be higher than that set out in legislation.

Further, the Local Government Association recently suggested the Tribunal Procedure Committee consider removing a parent carer's right to appeal against a local authority's decision to refuse to assess in order to tackle the backlog of appeals ([source](#)). This would be a major departure from public law principles and provides a worrying insight into local authorities' attitude to the rights and entitlements of disabled children and their families. It must be noted that the backlog is, in almost every case, caused by unlawful local authority decision-making in the first instance. The success rate for local authorities defending appeals has always been extremely poor. In 2013-14, 83%<sup>1</sup> of appeals were decided in

<sup>1</sup><https://assets.publishing.service.gov.uk/media/5a7ef650ed915d74e33f3864/tribunal-grc-statistics-quarterly-jul-sep-2014.pdf> (page 23)

favour of parent carers and by 2023-24 this had increased to 99%.<sup>2</sup> The Law Commission may wish to consider a precautionary approach to its recommendation given the above.

With reference to para 3.59 of the consultation paper, we are concerned by the suggestion that a single duty to assess would not resolve the lack of clarity surrounding Early Help assessments, which could presumably still apply to disabled children. We worry that some local authorities will try to circumvent any single duty to assess by continuing to refer families for 'Early Help' assessments, causing confusion and delay to families. Our research paper, [Institutionalising parent carer blame](#) (p17) explains why we believe that the use of Early Help assessments is inappropriate in the case of disabled children. The Commission has suggested that the interaction between Early Help and the single duty to assess could be clarified in guidance but we would welcome the Commission's further views and/or recommendations on how this interaction would work.

#### **Consultation Question 5 (Paragraph 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 preferable.***

Option (3)(a) or (c). It is generally advantageous to combine assessments; for practical reasons, to avoid repetition, but also to prevent separate assessments driving a wedge between the family and child - the child is part of a family and the contextual information gathered by combining assessments can help keep this in the mind of the assessor. Assessments should be face to face.

However, we would draw a distinction between the information gathering phase of an assessment and the subsequent decision-making and care planning stages. While combining assessments at the information gathering stage can be beneficial for the above reasons, we believe that any combined written record of the assessments should still contain separate analysis and decisions in respect of (for example) a parent carer's needs. We also believe that any resulting care plans should not be combined - each person eligible for a plan should have an individual plan. Exceptionally, if a child with capacity requests a separate assessment this should be agreed to.

We have some concerns about how a local authority's power to combine assessments can work in practice. For example, local authorities currently have the power (under section

<sup>2</sup><https://www.gov.uk/government/statistics/tribunals-statistics-quarterly-july-to-september-2024/tribunal-statistics-quarterly-july-to-september-2024#annual-special-educational-needs-and-disability-send-statistics>

17ZE of the Children Act 1989) to combine a parent carer's needs assessment with a child in need assessment, without the consent of the parent (or child who has capacity). In combining assessments, they must still have regard to the parent carer's needs and well-being (including the need to work), as specified in section 17ZD, ss (9) and (10). However, in our experience, some local authorities refuse to undertake separate PCNAs (asserting their right to combine assessments) but simultaneously fail to properly specify or analyse a parent carer's circumstances in the child in need assessment. See [Institutionalising parent carer blame](#), para 5.18. As such, we believe that guidance should make it very clear that where assessments are combined, local authorities must still meet any requirements specific to each assessment. We would also ask the Commission to consider whether or not local authorities should seek parent carers' consent before combining assessments.

**Consultation Question 6 (Paragraph 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.***

No response.

**Consultation Question 7 (Paragraph 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.***

Through case work we see child in need assessments, parent carer's needs assessments and combined assessments from many different local authorities. Almost all are deficient. Sometimes documents don't identify what type of assessment is being undertaken. Assessments very often have an inappropriate child protection agenda. The Commission has already noted our work on parent carer blame and unlawful assessments and has set out these issues in detail in the consultation. Another consequence of adopting a safeguarding approach is that, as well as ascribing a child's behaviour and needs to parental failings in some cases, local authorities assume in other cases that well-resourced families (i.e. whose children have access to toys, books, outdoor space) have no unmet needs at all.

In addition to parent blame, another common theme during the assessment process is the failure of local authorities to recognise that parenting a disabled child is qualitatively different from raising a typically developing child. Assessors fail to understand and appreciate the additional demands of caring for a disabled child. Assessments reflect outdated individualist assumptions that families must bear sole responsibility for meeting their child's disability-related needs. For example, a local authority may recognise a parent's need for rest due to chronic sleep disturbance, but claim that this can be met by sleeping while the child is at school, with no regard for the parent's work or family commitments. Local authorities advise families that they do not provide 'childcare', a 'baby-sitting service' or support 'to allow parents to work'. Parents are expected to have to give up work in order to meet their child's needs.

The following casework example is from a recent child in need assessment which concerned a family with two disabled children of primary school age, one of whom is non-verbal, has behavioural issues and attends a special school:

*“However, it is the parent’s responsibility to ensure they balance work, study and family life so they can care for their children and provide for their basic care needs...[The local authority] can support parents through charities and voluntary organisations to meet the needs of children where parents are struggling. However, it is the parents’ responsibility to provide their children with basic care needs...One of the main issues that parents have consistently raised has been about their ability to care for the children and also fulfil work and study commitments. There has been repeated advice given to parents about managing the children’s care and work commitments in relation to discussions with their employers or making decisions about work that they wish to undertake which fits in with their family life. They have also been advised to consider services like childminding.”*

The local authority assessed the family as having no statutory social care needs. A number of the non-statutory services the local authority identified as being available to meet the family’s needs were not able to do so. The family was not eligible for some services due to the age of the assessed child; another had a waiting list of six months and provided only time-limited support. Another service provided coffee mornings and a discount card which did not address the family’s needs. Parent carer’s needs assessments were undertaken, but similarly no provision resulted.

While we find that (generally) a child’s needs are identified reasonably well, these have a tendency to be framed inappropriately as risks, reflecting the tenor of the Working Together to Safeguard Children guidance. Assessments almost always fail to set out how all the identified needs are going to be met, no matter whether the local authority is going to meet none, some or all of those needs, either through non-statutory or statutory provision. Consequently, analysis sections lack detail and logic, and fail to set out a realistic plan of action (R (on the application of MM) (by his Mother and Litigation Friend, TM) v London Borough of Hounslow at paragraph 8).

Assessments often contain unsubstantiated opinions and simplistic conclusions. For example, a child who displays challenging behaviour was deemed able to ‘manage their emotions’ because there was no aggressive behaviour at school – disregarding the possibility of ‘masking’, the additional support available in school and the views of qualified behavioural specialists. We have also come across assessments which contain worryingly prejudicial attitudes to disabled children themselves, for example by dismissing a child’s anxiety-driven attempts to pull out her PEG tube as attention-seeking ‘learned behaviour’.

The written style of some assessments pays lip service to inclusivity but fails to demonstrate any meaningful understanding of the barriers faced by families. For example, we have seen assessments which purport to be accessible (to children with extremely limited understanding) merely by addressing the child by name at the beginning of each paragraph throughout the assessment, notwithstanding the complex and technical information which follows.

It is extremely rare to see eligibility criteria applied in a transparent way. Eligibility criteria are often incomprehensible, irrational and difficult to find. As noted in *Disabled Children: a legal handbook* (Broach and Clements, LAG (2021)) at para 3.59, there is already a requirement for eligibility criteria to be rational and transparent. A solution may be to require local authorities to state the eligibility criteria and demonstrate how they have been applied when communicating the decision to the parent carer as part of a national assessment template (See Q8 for further details).

#### **Consultation Question 8 (Paragraph 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?***

Yes. However, there must be a presumption that assessments are face to face unless parent carers or children who have capacity request an alternative. Parent carers should decide the extent and format of assessment jointly with the local authority so as to exert a meaningful level of control over the process. Some parents may not wish to have full-blown assessments.

We consider that there need to be national templates for assessments and plans to improve the consistency and quality across local authorities, similar to those being trialled in the Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan.<sup>3</sup>

In the case of assessments, we consider there should be a standard form prescribed by regulations and expanded upon in statutory guidance which, minimally:

- Identifies the type of assessment being undertaken;
- Identifies under which law and guidance the assessment is being carried out;
- Requires each need to be identified;
- Requires provision to be identified for each need including those needs that the local authority decides not to meet (thereby setting out a realistic plan of action);
- Sets out and applies the eligibility criteria in an understandable, rational way.

Any plan must properly quantify and specify statutory provision.

We believe that using a standard form will ensure consistency and thoroughness and help to embed a more positive and empathetic approach to assessments over the longer term, while still giving local authorities the flexibility to complete sections of the form as appropriate in individual cases.

Please see also the [draft guidance](#) “Assessing the Needs of Disabled Children and their Families” developed by independent Parent Carer Groups in conjunction with Prof Luke Clements for information on the overarching principles and practice that should inform assessments of disabled children and their families.

#### **Consultation Question 9 (Paragraphs 4.37 and 4.38)**

***We provisionally propose that assessors should be required to have appropriate expertise and training. Do consultees agree?***

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

Yes - to replicate the requirements in the Care and Support (Assessment) Regulations 2014 at reg 5. See also paras 7-9 of the [draft guidance](#) “Assessing the Needs of Disabled Children and their Families” for additional details. We agree with the Commission’s proposals to mirror the approach taken in the Care Act 2014.

<sup>3</sup>[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1139561/SEND\\_and\\_alternative\\_provision\\_improvement\\_plan.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1139561/SEND_and_alternative_provision_improvement_plan.pdf) (paras 49-53)

**Consultation Question 10 (Paragraph 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?***

Yes. There should be an additional requirement to provide detailed information on how the decision can be appealed and information on any other services or assessments that may be relevant to the family.

**Consultation Question 11 (Paragraph 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?***

Yes

**Consultation Question 12 (Paragraph 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.***

No, as third parties might prioritise their financial relationship with local authorities and avoid any actions which might jeopardise that relationship, to the detriment of families in need of support. We believe that local authorities should be responsible for carrying out assessments in order to ensure accountability and transparency within the system. Parent carers, if unhappy with the assessment, will find it harder to complain if there is an additional layer of bureaucracy involved. There is a risk that the market will dictate the cheapest provider and not prioritise quality.

**Consultation Question 13 (Paragraph 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.***

In our experience, parent carer's needs assessments are rarely carried out separately from a child in need assessment. Local authorities advise parents that there is no process or paperwork in place for parent carer assessments. In other cases, local authorities have sent a short form to parents by post, which they are expected to complete at home on their own, without any proper discussion or analysis of their needs by a social care professional. We have also come across local authorities whose 'carer's assessment' essentially comprises a small annual cash grant or voucher which parents can apply for. Local authorities frequently use a 'child and family assessment' form to carry out a s17 assessment and claim that the parents' needs are included, but the identification and analysis of those needs is often lacking.

As noted above, local authorities habitually fail to properly consider a parent's well-being, particularly a parent's need or desire to work. Councils fail to recognise the difference

between those caring responsibilities that are common to all parents and the additional responsibilities of caring for a disabled child. Unfortunately, many local authorities fundamentally misunderstand their legal duties towards families with disabled children and dismiss requests for support on the grounds that all working parents have to make childcare arrangements and that they have no obligation to 'subsidise' parents who want to work or to 'babysit' while they take a break. For example, we have supported families who have been told the following by local authorities:

- "we won't pay for childcare so that you can go to work"
- "your husband/wife/partner should reduce their working hours so that they can help more at home"
- "we don't offer a 'babysitting' service so that parents can go out together"
- "we don't have a duty to provide services to enable parents to access leisure activities"

We believe that clearer legislation and guidance is needed to ensure that local authorities have a better understanding of the needs of working parents and their duties to meet those needs.

**Consultation Question 14 (Paragraph 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?***

Yes. Local authorities should also be under a duty to inform carers of their right to an assessment when they become aware that a child may be disabled.

**Consultation Question 15 (Paragraph 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?***

Yes, and we believe that greater emphasis should be given in regulations and guidance to a parent's "*participation in work, education, training or recreation*", to address the common misconception among local authorities that parenting a disabled child is no different from parenting a typically developing child and that parent carers should simply expect to reduce or give up their work completely in order to meet their child's disability-related needs

**Consultation Question 16 (Paragraph 5.37)**

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

***Do consultees agree?***

Yes. There should be an additional requirement to provide detailed information on how the decision can be appealed and information on any other services or assessments that may be relevant to the family at the same time.



**Consultation Question 17 (Paragraph 5.39)**

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

***Do consultees agree?***

Yes. As with a child's assessment (see Q8 above), we believe that a parent carer's needs assessment must be recorded on a similar standard form, prescribed by regulations and expanded upon in statutory guidance which specifically:

- Requires consideration of whether it is appropriate for the parent carer to provide, or continue to provide, care for the disabled child in light of the parent carer's needs for support, other needs and wishes
- Requires consideration of parent carer wellbeing including each subsection as set out in s1(2) Care Act 2014;
- Requires an analysis of how the parent carer's wellbeing needs are going to be met either by the local authority or otherwise (including the wish to work or study);
- Identifies specific provisions that are available to meet the wellbeing needs of the parent carer thereby setting out a realistic plan of action.

Any plan must properly quantify and specify statutory provision. See Q8 for further details.

**Consultation Question 18 (Paragraph 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.***

We do not generally see separate assessments for siblings of disabled children. The extent to which siblings' needs are considered as part of a child in need assessment varies. While some assessments may identify a sibling's needs, e.g. for one-to-one time with a parent, we rarely see provision being made to meet those needs. .

**Consultation Question 19 (Paragraph 6.20)**

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

No response.

**Consultation Question 20 (Paragraph 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?***

Yes - in fact we would go further and suggest that the guidance should simply direct local authorities to consider the needs of any siblings, as in our experience they are almost always impacted to a greater or lesser extent, so local authorities should be required to consider their needs in all cases.

**Consultation Question 21 (Paragraph 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?***

Yes

**Consultation Question 22 (Paragraph 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?***

Yes

**Consultation Question 23 (Paragraph 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?***

Yes

**Consultation Question 24 (Paragraph 7.52)**

***We invite consultees' views on what the essential features of any national eligibility criteria should be.***

These should be short and easily comprehensible - of the order of one page. One effect of having short and easily comprehensible criteria would be that local authorities would be more easily held to account for a failure to implement the criteria properly - i.e. they should be considered part of an accountability framework. We currently see many local authority eligibility criteria that are irrationally high, incomprehensible, or circular, rendering eligibility determinations impossible to fully understand. In many instances there is a failure to refer to eligibility criteria entirely when a decision not to provide services is communicated to families. It is essential that when determining eligibility, local authorities are required to set out the criteria and clearly explain how the decision is made with reference to the criteria. They should be written into a nationally mandated assessment form or eligibility determination decision letter.

**Consultation Question 25 (Paragraph 7.53)**

***We invite local authority consultees to provide us with copies of any eligibility criteria they apply to disabled children's social care.***

N/A.

**Consultation Question 26**

***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?***

Yes, we agree that the single statutory duty must trump any other duty or power which could potentially be engaged to provide any identified services. We would add the proviso that any such duty must be a non-resource dependent duty owed to the individual child to ensure that recognised eligible needs must be met.

**Consultation Question 27 (Paragraph 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.***

We have no direct experience of disputes concerning residence requirements and would therefore endorse Professor Luke Clements' submission, which he has kindly shared with us.

**Consultation Question 28**

***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.***

We strongly agree with this proposal.

The current situation poses significant difficulties for disabled children and their families. The current maximum for a DFG grant is £30,000 which is frequently sufficient in the case of disabled adults who generally need adaptations such as ramps, stair lifts and accessible showers. However, the adaptations required to meet children's needs are frequently much larger and more complex involving loft conversions or extensions (sometimes two-storey). These typically cost significantly more than the £30,000 maximum DFG.

It is true that the Regulatory Reform (Housing Assistance) (England and Wales) Order 2002 (RRO) provides general powers for local housing authorities to provide assistance for housing renewal, including home adaptations providing they have adopted a Housing Assistance Policy (HAP). And the HAP may include the possibility of discretionary grants and/or loans to potentially top up any deficit between the maximum DFG grant and the actual costs of the works. However, the awarding of these discretionary grants and/or loans is usually dependent on available funds and even when granted there often remains a substantial shortfall in the funds required. For example, we are supporting one family who have applied for DFGs for a number of disabled siblings and even with maximum DFGs for each child and the maximum discretionary grant under the HAP there is still an estimated shortfall of £180,000 (This includes a 10% contingency fund but not the cost of an estimated 8 weeks' worth of temporary accommodation during which the family have been told they will have to move out if the works go ahead).

If families are unable to make up any shortfall from their own resources for any reason then there is a real danger that the adaptations will not go ahead and the identified eligible needs of the disabled children will not be met, with a potentially significant negative impact on the child(ren), siblings and parents.

Section 2 of the Chronically Sick and Disabled Persons Act 1970 (CSDPA) places a duty on the social services authority to assist with home adaptations if it considers it 'necessary'. And this is reflected in the Government's guidance - [Disabled Facilities Grant \(DFG\) delivery: Guidance for Local Authorities in England](#) (paragraphs 2.24 - 2.26).

However, this doesn't seem to be well known by the front line officers liaising with families and even when it is brought to their attention it is difficult to ensure that there is the correct communication between the housing authority and the social services authority (in both one-tier and two-tier local authorities). When enquiring about the possible use of the CSDPA to top-up a shortfall, one family was told by their social worker that it was "above their pay grade" but they failed to take it to higher management. And we are aware of two local authorities who sought clarification on their duties under the CSDPA from external legal sources (as it seems their in-house legal services were unable to give definitive advice), one of which claimed that the CSDPA was not relevant to top up funding.

In our experience, even when the appropriate level of management in the social services authority is engaged in the process, there does not seem to be a written policy on how to decide whether it is 'necessary' to support the delivery of the home adaptation required. For example, a family we are supporting was told more than 4 years after the initial request for a DFG that it was 'policy' to expect the family to approach charities in first instance before a request for top-up funding would be considered: however, when the family requested sight of the written 'policy' the local authority was unable to provide one. And this makes it very difficult for the family to hold the authority to account.

We strongly believe that providing DFGs under the single statutory duty to meet the social care needs of disabled children would eliminate these issues. The social care authority would inevitably be aware of a request for a DFG from day one and would have ownership of the process, enabling it to foresee any potential funding issues well in advance and to make contingency plans to ensure that the identified eligible needs of the child are met.

**Consultation Question 29 (Paragraph 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?***

Yes

**Consultation Question 30 (Paragraph 7.69)**

***We provisionally propose that there should continue to be a power to meet the needs of parents and carers.***

***Do consultees agree?***

Agreed. However, we understand (see Luke Clements '[Parent Carer Needs Assessments](#)' and Steve Broach's '[What's the point of a parent carer's needs assessment?](#)') that the current legislative position leads local authorities to wrongly assume that a parent carer's needs assessment can never give rise to a duty to provide support identified as necessary during the assessment. As such, we believe that guidance should clarify the position.

**Consultation Question 31 (Paragraph 8.32)**

***We invite parent and carer consultees to provide their experiences of accessing short breaks.***

No response.

**Consultation Question 32 (Paragraph 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.***

N/A.

**Consultation Question 33 (Paragraph 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?***

Yes, we agree.

**Consultation Question 34 (Paragraph 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?***

Yes.

**Consultation Question 35 (Paragraph 8.49)**

***We provisionally propose that eligibility for a short break should be subject to national eligibility criteria.***

***Do consultees agree?***

Agreed, but we believe that all services, including short breaks, should be subject to a single set of eligibility criteria. We aren't clear as to why the Commission is proposing a separate set of criteria for short breaks and would welcome further clarification.

**Consultation Question 36 (Paragraph 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?***

We do not have the expertise to respond to this question.

**Consultation Question 37 (Paragraph 9.22)**

***We invite consultees to tell us what, in their experience, are the main social services that disabled children require.***

We trust that parent carers with direct experience of services will respond to this question in detail, but in our (general) experience, families most often require personal assistants to help their children engage in community activities and develop independence from their parents outside of the family home, as well as to provide support within the home.

**Consultation Question 38 (Paragraph 9.23)**

***We invite consultees to tell us about the main social services for disabled children that are available in their area.***

We do not have the requisite knowledge to respond to this question.

**Consultation Question 39 (Paragraph 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?***

Yes

**Consultation Question 40 (Paragraph 9.25)**

***We invite consultees' views on the services that should be included in the list referred to in Consultation Question 39.***

We welcome the non-exhaustive list set out in para 9.20, but we would add that families may require “care **and support** at home or elsewhere” (for example in terms of support to help a disabled child socialise or engage with community activities) and help with travel to and from services. We don't think that “services to assist parents and carers” should be limited to evenings, weekends and school holidays, as many families may need support in order to get a child ready for school or to be able to continue in full-time employment, for example. We note your comments in para 9.21 that it may not be necessary to include “cash” in the list of services because of the availability of direct payments, however, we believe that direct payments may not offer the same flexibility as cash to meet one-off costs for holidays or other items.

**Consultation Question 41 (Paragraph 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?***

Yes. We sometimes see local authorities pressuring families into accepting direct payments as a way to absolve themselves from having to provide services directly. It should be made clear that direct payments are not mandatory.

**Consultation Question 42 (Paragraph 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?***

In our experience, parents desperately need local authorities to put support in place to meet their disabled child's needs, but they rarely express strong feelings as to the availability of personal budgets.

**Consultation Question 43 (Paragraph 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?***

Yes.

**Consultation Question 44 (Paragraph 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?***

Yes

**Consultation Question 45 (Paragraph 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?***

Yes

**Consultation Question 46 (Paragraph 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?***

Yes, provided that any resulting document is clear and comprehensive.

**Consultation Question 47 (Paragraph 12.25)**

***We invite consultees to provide examples of local authority charging practices.***

No response.

**Consultation Question 48 (Paragraph 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?***

We have not yet had any direct casework which involves local authorities charging for services. We do not consider there should be a power to charge. The current power should be repealed - all services should be free for the child and family as they relate to the child's disability. This is in line with Part 1 Article 23(3) of the UN Convention on the Rights of the Child which requires assistance to be provided free of charge whenever possible to disabled children with special educational needs.

Further, see our answer to Q1 regarding the quantifiable losses incurred by families who have to plug gaps in support with their own resources, as set out in Contact's online survey [Counting the Costs Online Survey](#) (2024)

**Consultation Question 49 (Paragraph 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.***

We would generally be in favour of alignment between SEND and disabled children's social care law (as described in 13.28) if such alignment would lead to a system which was clearer and easier for families to navigate. However, we are mindful of the risk that the social care needs of disabled children could be overlooked if too closely aligned with a system which focuses on special educational needs – and families could also be subjected to the same well-documented difficulties facing those seeking SEN support for their children.

**Consultation Question 50 (Paragraph 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?***



We don't have the expertise or experience to respond directly, but would endorse Professor Luke Clements' submission.

**Consultation Question 51 (Paragraph 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?***

We don't have the expertise or experience to respond to this question.

**Consultation Question 52 (Paragraph 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?***

As with our response to Q50 above, we share the views set out in Professor Luke Clements' submission.

**Consultation Question 53 (Paragraph 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.***

Cerebra supports children aged 16 and under, so we have limited direct experience of the transition to adult social care, but are aware of the well-documented 'cliff edge' faced by young people - see for example Kids' report, [On The Cliff Edge](#).

**Consultation Question 54 (Paragraph 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?***

Yes.

**Consultation Question 55 (Paragraph 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.*

We would suggest that transition planning should start at the age of 14, to align with existing provisions relating to children with EHC plans.

**Consultation Question 56 (Paragraph 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.*

N/A.

**Consultation Question 57 (Paragraph 16.25)**

*We invite consultees' views on, and experiences of, the sufficiency of disabled children's social care provision in the local area.*

We do not have the data to comment on the sufficiency of disabled children's social care provision in local areas, but our experience in general is that families from across the country struggle to access social care provision that is sufficient and appropriate to meet their children's needs.

**Consultation Question 58 (Paragraph 17.21)**

*We invite consultees' views on whether it should be mandatory for local authorities to have a designated social care officer.*

We have not yet had any direct experience of the practical impact of a designated social care officer's role in individual cases (and we suspect that many families aren't aware that this role exists). Such an officer might well serve a useful purpose in improving communication and cooperation across departments, but they would need to have the authority and resources to perform the role effectively, and be accessible to families.

**Consultation Question 59 (Paragraph 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.*

Our experience mirrors that set out by the Commission at para 17.17(3) - we frequently see a lack of cooperation between social care and education departments when carrying out EHCNAs and "not being known to service" appears too often in EHC plans.

We are aware that during annual reviews, local authorities too often leave the reviews to the school the child attends - with no local authority staff in attendance. That said, it is more likely that a SEN officer will attend the annual review meeting compared to a social work professional.

**Consultation Question 60 (Paragraph 17.25)**

***We invite consultees' views on the factors that help and hinder effective co-operation and joint working.***

We would refer the Commission to Professor Luke Clements' submission and to the themes discussed in chapters 5 and 7 of Professor Clements' *Clustered Injustice and the level green* (Legal Action) 2020

**Consultation Question 61 (Paragraph 18.79)**

***We invite consultees' views of the statutory complaints procedure (either through making or handling a complaint).***

The complaints process is beset by systemic delays which result in unsatisfactory outcomes, where a family may wait for months, possibly years, simply for the matter to be remitted to the council for reconsideration. In our experience the process is too slow, investigations lack rigour and there is little evidence that local authorities implement any lessons learned in practice.

Our research report, [Unacceptable delay: Complaints procedures for disabled children and their families](#), published in November 2019 (see also Luke Clements, '[Delay and the ombudsman: how depressing](#)') described serious and systemic failings in the way that a number of English councils investigate children's social services complaints. In particular, the report emphasised the impact of delays, the lack of effective penalties to address repeatedly dysfunctional complaints handling by some local authorities and the failure to recognise that significant delay is in itself an injustice and a substantive harm to disabled children for which compensation should be paid.

As well as outlining problems with the operation of the complaints process, the above report concluded that the statutory 3 stage process was itself responsible for built-in delays and should be replaced by a two stage process – along the lines of the system operating in Wales (para 6.21). Local authority corporate complaints procedures also comprise of only two stages, leading to a peculiarly unfair position where a relatively minor refuse collection complaint attracts swifter attention than a family in crisis. In referring to the corporate complaints process, the [LGO's Complaint Handling Code](#) states (at para 6.20) that "A process with more than two stages will make the complaint process unduly long and delay access to the relevant Ombudsman." The Equality and Human Rights Commission's [Inquiry Into Challenging Social Care Decisions](#) (2021) reported in relation to adult social care (see p15) that "lengthy timescales – even when they comply with statutory requirements – can make formal complaints processes unsuitable for resolving urgent issues for people in crisis". As such, we do not see how a more prolonged process can be justified in the case of disabled children or indeed any child in need. While we acknowledge the Commission's comments regarding its terms of reference, we believe that the continuation of a statutory complaints process which is not fit for purpose will fundamentally undermine the rights of disabled children to redress under any new legislative framework.

Some local authorities require parents to jump through a number of 'pre-complaint hoops' before they can even access the statutory process. For example, [Hampshire's website](#) advises parents whose children have been refused specialist services to consult the eligibility criteria, ask for a review by a senior officer and attend a meeting with a service manager before resorting to the complaints process. While these steps may be offered out of a genuine desire to resolve matters less formally, in reality they simply make it more difficult for many families (often already exhausted from their caring responsibilities) to obtain meaningful redress.

Parents are often left bewildered by circuitous complaints handling and they have no right to advocacy support (unlike those with a complaint about the NHS who have access to independent NHS complaints advocacy services). We have recently supported a parent who progressed through what she had been led to believe were the first and second stages of an official complaints process, culminating in a meeting with a district manager, only to be advised by the local authority that they had been using an 'unofficial' process and that she must now move to stage 1 of the official complaints process. The same parent was subsequently contacted by the council's Data Protection Officer who (much to the parent's confusion) initially treated her concerns about the accuracy of a child in need assessment as a data protection matter, before referring her back to the complaints team.

More generally, the complaints process is overly focused on process and fails to offer any effective means of challenging the rationality of local authority decisions. While we understand that the current framework does not permit investigators to substitute their own judgment for that of a social work professional, we believe that this principle is widely misinterpreted by investigators as preventing any examination at all of whether the decision-making process was rational in light of the available evidence. We recently dealt with a case where an independent investigator told a parent, "*I can't really challenge social worker decisions because I don't have the training. I can only look at procedure*".

As well as being time critical, complaints about disabled children's social care will often necessarily involve a legal issue, i.e. in terms of what a local authority's legal duties are and whether those duties have been discharged in an individual case. The complaints process is a fundamentally unsuitable remedy for disabled children's social care complaints because it is unable to deal with legal issues of this type. Investigators and panels lack the knowledge or expertise to question whether the council has acted in accordance with its legal obligations. For example, we supported a family in one case where a senior Children's Services officer dismissed the Chronically Sick and Disabled Persons Act 1970 as being of questionable relevance because of its age – a claim which went unchallenged by investigators who agreed, after a cursory internet search, that the CSDPA 1970 was indeed irrelevant because it was 'old legislation'. There is a lack of legal literacy among professionals involved in the complaints process, which leads to flawed decision making. This problem is then compounded by the focus on process, which can result in the LGSCO refusing to investigate a complaint because the local authority stage two process appears to have been competently executed, regardless of the quality of the investigation.

Unfortunately, we strongly doubt that a 'disability review officer' would lead to significantly improved outcomes for families. While we have no experience of the internal review process under the Housing Act 1996, we have dealt with numerous school transport appeals which have involved a review by a more senior officer and we have yet to see an initial decision being overturned at this stage. In our experience, senior officers are highly unlikely to depart from or challenge a local authority's established policy and practice.

**Consultation Question 62 (Paragraph 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?***

Having supported many families to complain to the LGSCO, we do not consider that the current system enables timely and appropriate resolution of disabled children's social care complaints. In our experience, these complaints are time-critical, require some interpretation and application of legislation and/or guidance and usually concern the adequacy of an assessment or care package. In our view, the LGSCO is unable to consistently resolve complaints of this nature.

The LGSCO investigation process is too slow to deal effectively with time-critical complaints – it also generally requires complainants to have fully completed the 3 stage statutory complaints process and often results in matters being referred to local authorities for reconsideration, compounding delays even further. As noted in a recent article on [Special Needs Jungle](#):

*LGSCO complaints are grinding bureaucratic processes that investigate someone else's grinding bureaucratic processes. That means there's always a long time between a local authority's act of maladministration and the LGSCO officially opining on it. Sometimes, it's a year: more often, it's up to two years. In extreme cases where multiple acts of maladministration have occurred, it can be over five years.*

These delays are not simply an administrative inconvenience – they have potentially serious and long-lasting consequences for disabled children whose social care needs are not being met. Moreover, significant delay in reaching the LGSCO's office is not considered to be an injustice and therefore usually results in relatively small awards for 'time and trouble' in pursuing a complaint. See our research report, [Unacceptable delay: Complaints procedures for disabled children and their families](#) and Luke Clements' [Delay and the ombudsman: how depressing](#)).

In our experience, complaints about disabled children's social care commonly concern a local authority's legal duties, in terms of properly assessing and meeting a family's needs. Given that the LGSCO does not resolve factual disputes or decide what the law means or how it should be applied (as noted in para 18.16), we do not believe that it can offer an appropriate remedy to families whose complaints concern the lawfulness of local authority decisions.

The families we support usually have complaints about inadequate assessments and/or insufficient care packages. Their children have either been refused support or have had their care packages reduced or withdrawn. The LGSCO can review whether a local authority's decision was procedurally correct, but it will not question the merits of a decision or challenge a social worker's professional judgement. Families need access to a system which can consider the merits of a decision and direct service provision. It is of little consolation to a family in crisis that a local authority has followed the correct procedure in reducing a care package. The LGSCO's position is exemplified in a recent report on a complaint against [London Borough of Bexley \(24 004 916\)](#), where the investigator concluded that:

- *The disagreement between Miss X and the Council concerns the application of social work judgment, which – unless it has been applied in such a way that it is obviously irrational, even to a layperson – I cannot question. The irrationality threshold is very high.*
- *Having seen the Council's assessment of Y's needs, I have seen nothing which would obviously point to irrationality in the Council's decision-making. This, therefore, is likely a matter of professional judgment which I would not be able to question if I investigated further.*

The LGSCO does not impose meaningful penalties on local authorities which fail to meet their obligations. In its [Triennial review](#), the LGSCO itself concluded that "if a council or social care provider is simply unable to provide an important service because of resources or skilled workforce shortages then there is sometimes little we are able to do to effectively put this right."

We have also struggled to convince the LGSCO to investigate what we consider to be systemic problems within a local authority. On one occasion when we provided evidence of persistent and systemic delays in a local authority's complaints handling in the case of three separate families, the LGSCO was satisfied that an apology in each case was sufficient and then referred the complaints back to the local authority for further consideration.

In our experience, compliance with recommendations in individual cases is not always monitored by the LGSCO and even where a policy is updated, local authorities appear reluctant to implement any 'lessons learned' in practice. For example, we have supported families to successfully complain to the LGSCO about flawed school transport decisions, only to be contacted later by other families in the same area about the same problem.

As a result of our work in supporting families to make complaints, we can provide detailed analysis of other shortcomings in the service provided by the LGSCO (should this be of assistance to the Commission) but for the purposes of this response, we have summarised these failings below:

*(1) Quality of decision-making / Quality assurance*

The LGSCO reviews 61 decision statements across all investigation areas each year to consider whether they are 'reasonable and defensible'<sup>4</sup> and publishes the results in its annual review. It sets a target of 60 out of 63 decisions, which equates to approx 95 percent of decisions. In 2023-24, 56 out of 63 statements met the target<sup>5</sup>, meaning that approximately 11 percent of decisions did not meet the target. In that year there were 6852 complaints dealt with by initial investigation<sup>6</sup> (i.e. considered at the assessment stage) which extrapolates to 760 decision statements not meeting the target, and 4165 detailed investigations equating to 462 decisions not meeting the target. These extrapolated numbers are open to error because we don't know if the decision statements were randomly sampled and because the sample size is small compared to the total number of complaints, so extrapolating data in this way could produce large errors. The actual number of decision statements not meeting the threshold could be larger or smaller and may vary by complaint category. However, we believe these figures may indicate that a significant number of LGSCO investigations may result in incorrect decisions. Similar figures are available for previous years.<sup>7</sup>

*(2) No right of appeal*

The quality of the LGSCO's decision-making is particularly important as there is only a narrow right to request a review<sup>8</sup> – either because the decision was based on demonstrably inaccurate facts, or that new evidence has come to light which was not previously available. The LGSCO decision letters we have seen do not notify complainants of the right of review. Because of these narrow grounds for review, it is likely that decisions which fail the quality assurance process could still be rejected by the LGSCO's review process because getting the law wrong is not part of the criteria the LGSCO uses when reviewing a decision.

We think there should be a transparent right of appeal against LGSCO decisions, including where the LGSCO has misunderstood or misapplied the law and/or not followed its own guidance, at no cost to complainants. We note there is a right of appeal against Pension Ombudsman decisions in the High Court, which, although in principle sounds attractive, runs into problems already identified by the Commission with respect to costs, legal aid, availability of representation etc. A judicial review of the LGSCO is out of reach of all but the smallest number of complainants for reasons already identified by the Law Commission. In any case, it would only allow challenge on points of law and still allows for 'poor decision making' to occur due to the limitations in the court's jurisdiction.

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<sup>4</sup> The LGSCO does not define this term, but we are concerned that this may be a higher test than should be in place.

<sup>5</sup> Page 12: <https://www.lgo.org.uk/assets/attach/6692/Annual-Report-2023-24-FINAL.pdf>

<sup>6</sup> Page 6: *ibid*

<sup>7</sup> Page 16: <https://www.lgo.org.uk/assets/attach/5960/Annual-Report-2019-20-FINAL-web-accessible.pdf>

<sup>8</sup>

<https://www.lgo.org.uk/information-centre/about-us/our-performance/challenging-our-decisions#:~:text=To%20request%20a%20review%2C%20you,review%20or%20change%20our%20decision.>

(3) *Threshold for Investigation*

The LGSCO has too much latitude in deciding whether to investigate a complaint. In March 2024 the LGSCO told *Schools Week* that it had increased the threshold at which it would investigate complaints because its budget had been cut by 40 percent, investigating only more severe cases<sup>9</sup>. The assistant ombudsman said “*It’s not something we necessarily feel comfortable with, and it doesn’t sit well in terms of our values. But we have to make difficult decisions on the resources we have available... we are sending people away on cases we historically probably would have investigated.*”

(4) *Remedies*

Currently the financial remedies recommended by the LGSCO are derisory, and inadvertently incentivise unlawful decision-making by local authorities because the LGSCO complaints process saves them money. The LGSCO will continue to remain ineffective until the total cost to local authorities of complying with recommendations exceeds the total savings made by failing to put provision in place in the first instance.

(5) *Compliance with recommendations*

We believe that the LGSCO’s reported compliance rate of over 99 percent may not adequately reflect what happens in practice. The LGSCO published a Focus Report on Home to School transport in 2017<sup>10</sup> which outlined systemic problems with home to school transport nationally. It issued a [report](#) about a Birmingham City Council home to school transport complaint in 2021 in which it made a number of service improvement recommendations. The LGSCO has upheld eight home to school transport decisions against Birmingham City Council since that report was issued, which does not suggest an annual compliance rate of over 99%. More broadly, if local authorities did comply with LGSCO recommendations to such a level, there should have been a significant reduction in complaints made year on year. We would be seeing a system-level effect. This has not happened.

(6) *Jurisdiction*

Please see response to Q65.

If the Commission does intend to recommend the LGSCO is given powers to determine disputes of fact or law, we believe that each of the above issues would need to be addressed, in order to ensure that the LGSCO was able to apply any such additional powers appropriately and consistently. It would also need to be given the power to direct remedies, rather than make recommendations.

**Consultation Question 63 (Paragraph 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.***

While we would support the introduction of an express power to initiate legal proceedings as a means of addressing systemic issues, we believe that in practice the threshold for the exercise of such a power is likely to be very high and therefore of limited application for the majority of families seeking an effective remedy.

<sup>9</sup> <https://schoolsweek.co.uk/trauma-expense-and-delays-symptoms-of-a-send-system-in-complete-crisis/>

<sup>10</sup> Focus reports highlight common or systemic problems to help councils and care providers make improvements: <https://www.lgo.org.uk/assets/attach/4087/School-Transport-FINAL-FINAL.pdf>

#### **Consultation Question 64 (Paragraph 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.***

As outlined above, the existing avenues available to families focus on process and fail to provide an effective means of directing a local authority to provide specific services. The Equality and Human Rights Commission's [\*Inquiry Into Challenging Social Care Decisions\*](#) (2021) reported that while it should be possible to challenge the substance of a decision (e.g. disagreeing with the number of hours of care provided) through formal complaint mechanisms, "*sometimes complaints processes focus only on whether the assessment or other processes were carried out correctly.*" As such, we believe that families need access to a well-resourced, independent, merits-based appeals body which can interpret the law, direct local authorities to make social care provision and impose effective sanctions for non-compliance. There also needs to be advocacy support available to help parents access the appeals process. We have not carried out any formal research on how such an appeals process would work in practice, but the SEND Tribunal and the First-tier Tribunal (Social Security and Child Support) appear (in part) to perform this type of role in respect of educational provision and benefits.

Fairness is not achieved by merely recording and processing concerns in accordance with a set procedure - it should mean having those concerns listened to and understood by people who have the knowledge and power to resolve them wherever possible. We believe one way to achieve greater accountability may be to involve people with lived experience, in adjudicating complaints (as with the involvement of a lay disability member on the First Tier Tribunal panel in social security cases), training staff and possibly via local democracy arrangements (for example as co-optees on relevant overview and scrutiny committees).

In the course of our work, we have found it frustratingly difficult to persuade local authorities of the existence of systemic problems - resolving a problem for one family rarely seems to result in broader changes to policy and practice. We have also struggled to persuade the LGSCO to address systemic problems within local authorities and have little faith that 'lessons are learned'. As such, we believe that any system of redress must have an effective means of addressing 'repeat offending' by public bodies.

We also believe that accountability calls for more than just an effective mechanism which 'kicks in' at the end of a decision-making process. Broader changes are necessary to improve families' experience of dealing with local authorities, including stronger parent carer advocacy (see below), effective training to embed legal literacy and an empathetic approach as well as more prescriptive guidance on the conduct of assessments. We would therefore ask the Commission to consider ways of embedding accountability throughout the decision-making process and promoting a transparent, empathetic culture within organisations - in order to both minimise individually poor decisions and address systemic issues.

#### **Consultation Question 65 (Paragraph 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.***

We believe that extending the SEND Tribunal's powers and jurisdiction has the potential to provide an effective remedy for social care complaints, given that the Tribunal can make merits decisions. However, further reforms would be required for this to work in practice, including better training of judges and panel members on social care law, increased



resources to enable effective case management and to reduce backlogs, powers to make orders rather than recommendations and powers to enforce decisions . It would also need the power to award meaningful costs/compensation that, in part, must act as a deterrent to recurrent poor decision-making. We realise increasing the jurisdiction and remit of the Tribunal in this way may not be realistic given the Commission's terms of reference and Tribunal capacity issues, however we consider a more effective solution can only be found by looking at wider changes to the legislative framework.

We have summarised below other issues that we think would need to be addressed to make the Tribunal a more effective solution (and would be happy to provide further details if the Commission felt it would be of benefit):

(1) Mediation

Mediation requires, in the case of education and/or social care, the attendance of a decision-maker from the local authority. In our experience this generally does not happen because decision-making is usually carried out by a local authority panel which must be consulted post-mediation. This non-compliance does not result in any consequences or penalties for the local authority. We do not consider there should be mandatory mediation as is currently being considered by the Government, as this would delay access to justice.

(2) Capacity / Delay

Unacceptably long delays in completing appeals are well-documented, with some taking up to one year. These delays are both inherently unjust and have a tendency to increase the complexity of proceedings as annual reviews, further amended EHC plans and social care re-assessments take place while the appeal is ongoing. We recognise that there are practical issues, including issues with instructing experts to produce timely assessments, which could necessitate a longer appeals process, but in our view Tribunals should aim to dispose of appeals within 3 months. However, consideration would need to be given to increasing the Tribunal's capacity, as we believe that it may be necessary for additional time to be set aside for the consideration of social care issues at hearings.

(3) Case management

It appears the Tribunal has for some time had a limited ability to case manage appeals effectively because it is so overstretched. This generally works to the advantage of local authorities (and to the detriment of most parents acting as litigants in person) because case management directions and deadlines are not consistently enforced, resulting in, for example, delayed disclosure of information. While the Tribunal has the power to strike out a party, in practice it can be reluctant to do so because the local authority could still provide important evidence, meaning that there is very little effective sanction against local authorities that do not comply with directions.

(4) Panel expertise

The Practice Direction "[Panel composition in the First-tier Tribunal, Health, Education and Social Care \(HESC\) Chamber](#)"(December 30, 2024) does not necessarily require the panel to have a member with expertise in disabled children's social care, or adult social care, for an extended appeal. We consider there should be an absolute requirement that the panel consists of one member with expertise in disabled children's social care or adult social care (in the case of appeals involving the Care Act 2014 or transition issues) if social care issues are to be decided.<sup>11</sup>

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<sup>11</sup> We note an equivalent argument can be made from the point of view of health, which may necessitate further recommendations by the Commission. Expertise in respect of continuing care or continuing healthcare - which may involve substantive input from health and social care - needs to be carefully considered.

(5) Expert witnesses and evidence

Most witnesses called by local authorities have a connection to the local authority, and generally “toe the party line”. This places parents at a significant disadvantage, particularly those that cannot afford independent witnesses and have to rely solely on evidence produced by local authority staff or schools. The Tribunal currently has a 50 page per party limit for social care written evidence in an extended appeal (and a similar limit for health).<sup>12</sup> We consider this may need to be revised upwards, particularly where there are factual disputes.

(6) Legal Aid and legal representation.

We do not consider the Tribunal is a level playing field for appellants given that most parents are litigants in person facing specialist SEN officers or lawyers. Parents often do not have the knowledge, technical skills or resilience to navigate the appeals process effectively. In our limited experience, Tribunals do not always make appropriate allowances for litigants in person.

We consider that legal aid representation (based on the child’s means, not the parents’) should be available for hearings (in line with the view of Coram Children’s Legal Centre<sup>13</sup>) as well as for advice and assistance outside of tribunal, including funding independent assessments, reports and independent witnesses. Where families are eligible for legal aid, access to available legal aid practitioners is increasingly difficult. In order for legal aid to be genuinely extended and more widely available, rates and terms of legal aid contracts will also need to be improved otherwise any such extension would be meaningless in practice.

(7) Specificity of provision

The Tribunal is currently not under the same rigid requirements when specifying health or social care provision compared with special educational provision (see VS and RS v Hampshire CC [2021] UKUT 187 (AAC) at paras 46-47 and 57, and MM v Greenwich at para 108j). We consider it should be under a duty to quantify and specify social care provision. In the absence of specific recommendations, it becomes effectively impossible for an appellant to hold a local authority to account, or the LGSCO to provide meaningful redress should a local authority refuse to comply with recommendations.

(8) Jurisdiction

The Commission at para 18.14 references R (Milburn) v Local Government and Social Care Ombudsman, in which the Court of Appeal upheld the decision by HHJ Sephton QC in the High Court concerning the jurisdiction of the LGSCO. In the lower court, HHJ Sephton QC stated that “*There are several authorities which recognise that the existence of a remedy in a court or tribunal, even though inadequate or incomplete, is fatal to the jurisdiction of the Ombudsman.*”<sup>14</sup> We think gaps in remedies between the LGSCO and SEND Tribunal must be identified, and proposals brought forward to resolve them. We do not think it is acceptable that an inadequate or incomplete remedy should be tolerated within the statutory schemes.

(9) Judicial review and interim relief

One significant benefit of judicial review is the speed by which matters can be resolved, often at the pre-action protocol stage. If there is a risk that judicial review becomes a remedy parents could not rely on as a result of changes to the Tribunal’s powers, then we urge the Commission to find an alternative means by which the speed and functions of the judicial review process are effectively transferred to the

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<sup>12</sup> <https://assets.publishing.service.gov.uk/media/5b963c65e5274a423c4fa7fc/send40-eng.pdf>

<sup>13</sup> <https://www.childrenslegalcentre.com/wp-content/uploads/2024/02/Coram-Childrens-Legal-Centre-response-to-RoCLA-FINAL-Feb-24-1.pdf> (page 9)

<sup>14</sup> <https://passle-net.s3.amazonaws.com/Passle/5b3f2cb9780ebf0410d034b3/MediaLibrary/Document/2022-07-07-14-01-10-698-RMilburnvLGSCOJudgment12.pdf> (para 19)

SEND Tribunal, so that those issues that would have been within the remit of the High Court can be potentially resolved just as speedily and for interim relief to be available. It should be noted that the increased ability of judicial review to secure resolution at pre-action stage is considered to link squarely to the difference in cost jurisdiction between the High Court and the SEND Tribunal. There is a cost risk to local authorities of unreasonably defending a judicial review which is simply not the case for tribunal appeals, as explained above. We think there needs to be a re-evaluation of what constitutes unreasonable behavior in the SEND Tribunal given local authorities are losing almost all appeals (though it is accepted there is a bluntness to how success is currently defined by the Tribunal).

**Consultation Question 66 (Paragraph 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?***

Yes, but in our view the Tribunal should be able to direct rather than recommend, as noted in our response to Q65 above.

**Consultation Question 67 (Paragraph 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?***

Yes.

**Consultation Question 68 (Paragraph 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?***

Yes.

**Consultation Question 69 (Paragraph 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.***

We don't have the expertise or experience to respond directly, but would endorse Professor Luke Clements' submission.

**Consultation Question 70 (Paragraph 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?***

Yes.

**Consultation Question 71**

***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?***

We endorse the position of Professor Luke Clements, which is copied below for convenience. We particularly support his point regarding ‘the importance of beginning with the assumption that parents are best placed to judge the well-being of their disabled child’.

*“In addition to the considerations listed in this Consultation Q (71), I suggest that consideration be given to including the principles detailed in the ‘Draft Guidance Assessing the Needs of Disabled Children and their Families 2023 (pages 2-4). These have been developed by parent carers and their adoption would be practical evidence that the Law Commission is in earnest in its advocacy for co-production. Perhaps the most compelling of the principles included in the 2023 publication is ‘the importance of beginning with the assumption that parents are best placed to judge the well-being of their disabled child’.”*

#### **Consultation Question 72**

***We invite consultees’ views on the operation and practical effect of the list in section 1(3) of the Care Act 2014.***

We endorse the views expressed in Professor Luke Clements’ submission.

#### **Consultation Question 73**

***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.***

We endorse the position of Professor Luke Clements, which is copied below for convenience.

“It is a complex, wide ranging question – as to how the nature and extent of a disabled child’s participation in the social care processes should vary according to their age. One mechanism could be for the legislation simply to acknowledge that this will inevitably vary depending on many factors, including the child’s age, understanding, maturity etc etc.”

#### **Consultation Question 74**

***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).***

We agree, although there is a concern that it could become a mechanism to sideline the views of parents.

**Consultation Question 75 (Paragraph 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?***

Yes.

**Consultation Question 76**

***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.***

We do not have the requisite expertise to respond to this question.

**Consultation Question 77**

***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?***

Yes.

**Consultation Question 78**

***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?***

We endorse the position of Professor Luke Clements, which is copied below for convenience.

"I agree that the new legal framework 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. I believe, however, that the right to independent advocacy should exist:

- regardless of whether they have difficulty in participating in the assessment and planning process around their social care needs – as the child may not have sufficient understanding of the assessors/care planners' legal duties or to appreciate if the correct processes are being followed; and
- even if the child has an appropriate person who can represent and support them – unless that person is also willing and able to fulfill this role.”

#### **Consultation Question 79**

***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.***

We have no experience of a child being supported by an independent advocate.

#### **Consultation Question 80 (Paragraph 22.44)**

***We invite consultees to provide us with experiences of culturally competent advocacy (both positive and negative).***

We have no experience of culturally competent advocacy.

#### **Consultation Question 81 (Paragraph 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?***

We agree that parent carers should have access to advocacy support when their own needs as carers are being assessed, but we do not believe that this should be limited to those who would otherwise have '*significant difficulty in participating*'.

As mentioned above, we believe that the system must acknowledge that parenting a disabled child is qualitatively different from raising a typically developing child. Meeting the needs of any child is inherently emotionally demanding – parents of disabled children face the additional emotional demands of meeting a child's disability-related needs and engaging with the systems which are supposed to deliver support. And yet we find that parents of disabled children are expected to demonstrate superhuman levels of patience and reasonableness in order to stand any chance of being listened to - and that any display of emotion risks them being labelled 'uncooperative' or 'difficult'. We have supported parents from all backgrounds, who, without exception, have encountered '*significant difficulty in participating*' in the process of getting the right support - not because of their personal capacity, capability or resources, but because of the culture within local authorities. We have supported working parents such as special needs teachers and social workers whose professional expertise provided little or no protection from the trauma generated by the system itself. In one case, a local authority referred a senior special needs professional to a parenting course which she herself had written. Until such time as that culture has demonstrably changed, we believe that all parents of disabled children should have access to advocacy support when their own needs as carers are being assessed. We believe that a

skilled advocate can perform a vital role in empathising with parents, upholding their legal rights and engaging productively with local authorities.

We note (from para 22.49) that the Commission is not proposing any form of advocacy support for parents or carers during the assessment of a disabled child's social care needs. The consultation paper explains that a separate right to advocacy for parent carers might not be necessary (or desirable) where a child has an appointed advocate and where they are viewed through the lens of their needs, rather than through a child protection lens. We share the hope that the proposed changes to the assessment process will lead to a more respectful and empathetic approach, but remain cautious as to how far and how quickly these changes will take root in practice. Unfortunately, in our experience, local authorities' practices can stray very far from the written law and as such there need to be additional safeguards in place, including parent carer advocacy, to combat the pervasive 'parent blame' culture evidenced by our research. We believe that parent carers should therefore have access to advocacy support during their child's assessment process, as well as during any assessment of their own needs.

We believe that some of the reservations expressed by the Commission at para 22.47 might be addressed by re-framing advocacy support as a service for the family as a whole. In our experience, parents invariably prioritise their children's best interests and have a deep understanding of how their child's needs can best be met. We believe that the distinction between parent carer advocacy and child advocacy may inadvertently create a 'silo' effect in terms of focusing on the needs of individuals in isolation rather than as part of a family unit. We believe that 'family advocacy' of this nature would be consistent with the statutory principle and considerations in 20.33, particularly "*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*" and the recognition of parents' knowledge and expertise of their child's condition and needs.

Funding of advocacy services will need to be considered - and in the event of services being directly commissioned by local authorities, we believe that there will need to be sufficient safeguards in place to promote transparency and avoid conflicts of interest.

**Consultation Question 82 (Paragraph 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?***

Yes.

**Consultation Question 83 (Paragraph 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?***

No - we do not see any need for this and think that two versions could lead to confusion and conflicting interpretations. For example, there are two guides concerning special educational needs - "*Special educational needs and disability: A guide for parents and carers*" and the *SEND Code of Practice*. In our experience, the parents' guide is very rarely referred to in practice. The Commission itself refers to the SEND Code of Practice multiple times in the



consultation document, but makes no reference to the parents' guide. Any guidance should be drafted to a standard which makes it accessible to both parents and practitioners, obviating the need for multiple versions.

**Consultation Question 84**

***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).***

We have no experience of supporting disabled children who are not in family-based care (for example, children in custody).

Legal Rights Service

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<https://cerebra.org.uk/get-advice-support/legal-entitlements-problem-solving-project/>

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