

Disability Law Service

Consultation on draft regulations and guidance to implement the cap on care costs and policy proposals for a new appeals system for care and support

DLS has been providing free legal advice and representation for disabled people since 1975. This has included providing specialist legal information, advice, casework and representation for disabled people, their families and carers. Its purpose is to challenge the poverty and inequality of disabled people by securing them equal access to their legal rights and entitlements.

Uniquely we are one of the few organisations controlled by disabled people providing a specialist legal service for disabled people. Our legal team specialise in the areas of community care, welfare benefits, and employment law. We have many years' experience of representing our beneficiaries in tribunals and courts including judicial review. To meet our purpose we provide a range of activities including:

- Acting as a first port of call for disabled people seeking legal advice through our legal access service. This service deals with over 5,000 requests a year for advice and provides diagnostic advice, legal information, referrals to DLS legal advisers and signposting for those whose problems fall outside DLS's areas of legal expertise or capacity.
- Providing specialist legal advice to disabled people in employment/ discrimination and community care law. Some 2,500 disabled people a year benefit from this service.
- Providing legal casework and representation.
- Producing legal information via a range of factsheets, downloadable from our website, on legal issues relevant to disabled people.

The work of DLS in representation of the interests of its clients has led to a number of high profile cases including the following:

1. *Megarry v Chief Adjudication Officer* [1999] All ER (D) 1183
2. *R v Islington ex parte Rixon* (1997-8) 1 CCLR 119,
3. *R (Garnham) v Secretary of State for Health* [2009] EWHC 574 (Admin),
4. *R (on the application of McDonald) v RBKC* [2011] UKSC 33.

Cap on care costs:

In summary we agree with a few caveats to the broad aims of the cap on care costs and welcome any attempt to reduce the level of burden that those with disabilities face when they are met with crippling debts that can amount due to care costs.

1. Do you agree that the draft regulations and guidance will provide a robust framework that will protect the 1 in 8 of us that will face catastrophic care costs? Please state yes or no along with any rationale.

Yes, with two caveats namely that the cap is only as good as long as there is a method that everyone without exception has the ability to enforce the cap. The currently proposed appeal system does not provide access to justice which is deeply concerning. Secondly there is a discrepancy were those of specific conditions that start earlier in life but not before 25 may be badly affected by this and in particular we are thinking of multiple sclerosis and also muscular sclerosis.

2. Do you agree that independent personal budgets should generally be set according to an average of personal budgets allocated to people with similar levels of need? Please state yes or no along with any rationale.

Yes

3. Is the guidance sufficiently clear as to the principles for calculating independent personal budgets? Please state yes or no along with any rationale.

Yes

4. Does the draft guidance provide sufficient clarity about the operation of care accounts to ensure consistency between local authorities and reduce the risk of challenge? Please state yes or no along with any rationale.

Yes

5. Can more be done to ensure that the care account is a useful tool to support people in planning for care costs?

Yes, provide an online nationwide web service were a person can log in and see where they are with the care cap. This system could house copies of needs assessments and care plans which will help those with memory or planning issues.

6. Do you agree that the preferred option best meets the principles and priorities identified? Please state yes or no along with any rationale.

As stated above, we agree to an extent with the caveat that the preferred option does not take into account mid-range age related disabilities and unfairly puts them at a disadvantage. It could be argued that a graduated system which increases with age could be used which would take into account the number of years you were able to work.

7. What are your views on how people of working age can be supported further to enable them to save and plan?

Provide everyone in the nation with a web portal which is linked to their national insurance number where they can view the following:

- Their state pension as it would be expected to be paid,
- Their progress towards the cap (regardless of whether its relevant as it raises awareness)
- Their private pension (this should be possible by regulations requiring providers to provide access to data)
- What they would receive via benefit and pension if they were forced to stop working at that point and at their point of retirement.

This should allow everyone to understand what their future will be like and should have advice for how this can be improved. This could include ideas about paying into private pensions or having insurance.

8. Is there evidence to support further consideration of the level and/or approach to daily living costs? Please state yes or no along with any rationale and provide any evidence you may have to support the rationale.

It is not clear from the documents daily living costs would equate to the costs that a person actually has to pay out on a daily basis. I know that currently three of my clients has this particular problem, all are wheelchair/bedbound and all have being asked to pay over £80 per month with they cannot afford. In one case the client now has over £20,000 with of debts with the local authority but there is no means of challenging the local authority apart from the ombudsman as they have no access to legal aid. It is also not clear what happens in scenarios where a persons living costs are above £230.

9. Do you agree that the extension of the existing requirements for third party top-ups to cover first party top-ups will provide both the local authority and the person with the necessary clarity and protection? Please state yes or no along with any rationale.

Yes as it is important the service users have the choice and if they can afford to choose but also no, as top ups have existed before this point but have been used by local authorities to escape their legal duties. This occurs where a local authority decides in some cares to not fund a particular residential home. They will state another home may meet the needs of the client. They will use

the standard argument that they only need to meet the needs not the one of preference which would cost more.

There are cases where the local authority are correct but there are also many cases where they are not correct. In the majority of these cases the client either has to pay the top up or go into a supported living or home which does not meet their needs.

The client would not have no option but to agree unless the client can have access to legal aid so that they can obtain expert evidence (such as an independent social workers report or independent psychologist/psychiatrist or a specialist in autism depending upon the condition). Then the legal aid lawyer can and client can force the local authority to follow the law.

We had two cases last year where two local authorities did exactly this and it took experts reports, barristers, legal aid and the threat of judicial review for the local authorities to back down. I have to note that in both cases the local authorities would not provide a needs assessment as there was none which could be drafted which could be lawful. But there was also no way to challenge them without legal aid. The costs in these cases are so high to the local authority expenditure per case that there appear to be very few people following any guidance within the local authorities.

10. Do you agree that the guidance is clear on how the extensions to the means test will work and that the draft regulations achieve their intended purpose? Please state yes or no along with any rationale.

Yes I would say the guidance generally makes sense and achieve on the whole their purpose. It could be argued that the cap could be lower. It could definitely be argued that age related conditions have not been fully considered apart from those aged under 25. But aside from those issues this is a welcome step forward.

Appeals

In summary we welcome the proposal to put in place an appeal system for adult social care. We must raise concern at some of the proposals which could overshadow the work put into the appeal process so far, namely the issues we raise over the independence of the appeal system. We recognise that the proposals are at an early stage and so hope that we are able to work with the department of health to shed light on the concerns regarding the importance of an independent appeal system.

11. Do you think there is a need to introduce a new appeals system to allow people to challenge care and support decisions? Please state yes or no along with any rationale.

Yes, there is a clear need for a new appeals system for people to be able to challenge care and support decisions. Currently we are contacted on every day by severely disabled people, their carers and family from across the country report to us failures by local authorities to follow their legal duties under the current legislative framework. They report breaches from across the range of duties in social care law by local authorities and their agents who are usually social workers or occupational therapist such as their care packages being cut or removed completely without lawful assessments to the refusal to assess at all. When we investigate matters we usually find the changes have been unlawful primarily due to local authorities attempting to reduce budgets by reducing care packages below the legal minimum that the person in question should receive under the law.

We are not able to help everyone because many are not eligible for legal aid. It is only with legal aid that an expert report can be obtained and it is usually only with legal aid that judicial review proceedings would be mooted due to the costs. Currently the only option for challenging an unlawful decision is via the high court or the complaints procedure. The high court will only assist in a limited number of cases due to the limitations of the high court and the restrictions upon legal aid.

This only leaves the complaints procedure which is run by the same local authority who is attempting to save money. We have found that this is effectively useless in the majority of cases unless a solicitor is acting for the individual and is able to put enough evidence together so that if the matter was to go to the ombudsman, there would be a prima facie case to such an extent that the local authority will back down.

But as it is unlikely that the majority of persons will be able to have a solicitor act on their behalf or be able to obtain expert reports to refute the social worker from the local authority who is trying to reduce their care package then they are unlikely to receive access to justice.

One way of providing an additional safeguard would be to allow clients to record their needs assessments as these are usually the most contentious part of any case.

12. Do you think that the appeals reforms are a priority for reforming care and support redress? Please state yes or no along with any rationale.

Yes, this is an urgent priority of human rights level proportions for the most vulnerable section of society. If the government do want those with disabilities to have access to care then they must have access to justice when that care is not provided by the body with a duty to provide that care. Currently we are seeing human rights breaches on a daily basis by local authorities where social workers fail to assess or reduce care packages unlawfully. We have seen persons placed in situations which are unimaginable in this day and age in a western society.

Some examples:

Case no1:

A London local authority provides reduces a care package for an elderly couple who are both severely disabled. The husband is bedbound and lives in the living room and has to use the kitchen as a toilet. His wife is upstairs and is wheelchair bound, she is not able to go downstairs or walk or propel her wheelchair.

The local authority social worker reduced their care package to 50 hours between them per week though they under the facts criteria (critical) in every area. They are not given any hours for accessing the community and are not given any hours for carers to allow them to go between floors so they are not even able to spend time with each other. The local authority social worker tells them it is the policy not to provide night time care or time for accessing the community.

We have been able to secure a reassessment but the local authority will not provide the needs assessments or interim care and so judicial review appears to be the only option. The complaints process was not helpful and the social workers blamed the clients stating they did not want to access the community.

Case no 2:

A different London local authority held a review of a client's needs with myself in the room and their senior care manager another social worker. The client had a 45 hour care package which was not able to meet his needs to such an extent that although he has had the package for 12 months, he has found no agency or individual to undertake the package. The client has muscular dystrophy and his 81 year old father has been forced to provide 24 hour care. He is not able to propel his wheel chair or provide any self-care.

The manager stated he could provide 4 visits per day with an agency. He stated the local authority do not provide night time care and so he did not need to assess it but could request a continuing health care assessment if 24 hour care was required. He said that they could put double ups of carers in place but not for accessing the community as they do not provide agency staff for accessing the community.

In this case it took 8 months to get a response via the complaints process which resulted in the complaints manager repeating the statements of a social worker and their solicitor. The Local Authority would not comment or even reply as to what happened at the needs assessment. We are now considering funding for legal action. In addition, the client has been sitting on a sofa for over 7 years and in response to a complaint was threatened with legal proceedings by the local authority for an issue which did not exist. This was stopped when we investigated the matter.

Case no 3:

A different London local authority again, we attended the needs assessment of a client whose case we had already been to the high court with. The client was not able to walk or access the community and required night time care. The social worker stated categorically that it was the policy not to provide night time care or care for accessing the community. We asked her and her colleague a number of times.

In what was a rare case, in this matter the solicitors for the local authority did admit the comments were made by the local authority in error and not the policy of the local authority. But as the social workers were adamant then it then means that at each other assessment which did not have a solicitor present the same statements would have been made in needs assessments.

Case no 4:

In this matter in a different local authority, a person with severe autism was informed he would be losing the funding for his care home within two weeks. No needs assessment had taken place and he had been there for over a decade.

The complaints system was ineffective and an immediate remedy was required as there was only days before the funding was to be removed. Judicial Review was threatened, expert reports had to be obtained and the service user was and is still in the same care home.

These are just a sample from the calls we receive every day on our advice line stating issues like the above and more with a variety from failure to agree Disabled Facilities Grants for required adaptations through to failing to assess clients at all.

13. Do you agree the areas identified should be within the scope of the appeals system? Are there any other areas under Part 1 of the Care Act 2014 that should be included?

No, there appears to be many areas missing from the list. The consultation document appears to not allow the right to an appeal a number of the key duties under the care act which will remove access to justice from those who this section of the care act was designed to protect. It must be questioned as to why a duty have been placed within the care act part one and then excluded from the duties that a person has the right to enforce. We are hoping this is a misunderstanding but some of the key sections which appear to have been missed out yet contain duties under the care act include:

Section - [7.Co-operating in specific cases](#)

Section - [10.Assessment of a carer's needs for support](#)

Section - [11.Refusal of assessment](#)

Section - [12.Assessments under sections 9 and 10: further provision](#)

Section - [14.Power of local authority to charge](#)

Section - [15.Cap on care costs](#)

Section - [16.Cap on care costs: annual adjustment](#)

Section - [17.Assessment of financial resources](#)

Section - 18. Duty to meet needs for care and support
Section - 19. Power to meet needs for care and support
Section - 20. Duty and power to meet a carer's needs for support
Section - 24. The steps for the local authority to take
Section - 27. Review of care and support plan or of support plan
Section - 29. Care account
Section - 30. Cases where adult expresses preference for particular accommodation
Section - 32. Adults without capacity to request direct payments
Section - 37. Notification, assessment, etc.
Section - 38. Case where assessments not complete on day of move
Section - 42. Enquiry by local authority
Section - 47. Protecting property of adults being cared for away from home
Section - 48. Temporary duty on local authority
Etc...

**14. Do you think that charging should be part of the adult social care appeals system?
Please state yes or no along with any rationale.**

Yes, charging should be part of the appeal system as what would the point be of creating a set of rights which contain what is an excellent idea with the care cap and then not allowing anyone the right to appeal which the local authority decides not to implement the right.

15. Do you have suggestions as to the expertise, knowledge and person specification for the role of an Independent Reviewer?

After looking at the matter we were not able to find a just way of putting together an appeal system without it containing a legal professional and a medical professional. We have spoken to a number of organisations and it's been said by a number that they did not wish to state this on the basis that this option was already off of the table in relation to the department of health. While we are concerned that the government may be approaching this consultation with a closed mind to this particular aspect, we are still not able to find a viable alternative which will affectively provide access to justice or a remotely effective appeals system.

The basis for this is the following:

- The system being designed requires a body or person to be making decisions regarding appeals under the care act 2014.
- They must be able to make decisions based upon complex evidence from two parties with a scope of decision greater than that of the local government ombudsman and only equalled by the First Tier Tribunal.
- They must be able to know and be able to interpret evidence containing complex medical conditions.

- They must be able to deal with those with disabilities in way which is seen as just/fair way and independent of the local authority.

From this we obtain the following skill set:

1. The ability to understand and make decisions regarding the law
2. Ability to understand and make decision regarding medical matters,
3. To be able to understand and deal with those with disabilities as well as claimants, defendants and evidence.

We do not think it is viable to put all of this into a single person as the person effectively needs the legal mind and knowledge of a lawyer as well as the experience and background of a doctor.

The system/person must therefore be able to interpret the (the Care Act 2014) legislation, its associated guidance and any relevant case law. This is a complex piece of legislation and so for this task to be put in the hands of someone inexperienced at making decisions regarding the law would bring into questions why such legal skills are required by the governments matters when dealing with matters it also calls important such as tax law, social security law or any other piece of legislation. One would only say that a lesser person was required if it was seen that this was either such a simple area of law that a non-qualified person could undertake it and that the consequences of a failure were not serious so as to justify the costs.

We note the Equality Act document attached to this consultation only considers one option which is social workers hired by and working inside the local authority and that no other option appears to have been costed.

16. Do you think the local authority or another body should be appointing the Independent Reviewer? If another body, please specify.

No, we do not think a local authority should be appointing the independent reviewer as this would bring into question the fairness of the decision. In adult social care matters, the local authority has an interest in the case as they are almost always be the defendant in such an appeal. It would appear irrational to have the defendant employing the independent reviewer. It would also be bring into question fairness if the reviewer was managed by a person employed by the defendant in a particular case. If the Independent reviewer worked in the offices of the defendant in a case on a daily basis then this would also call into question the independence of any decision by such an appeal system.

There are multiple bodies that could be placed into this including the following:

- The First Tier Tribunal System could manage the reviewers and also provide a place for oral hearings if they were necessary.
- A new body could be set up to manage and recruit the new reviewers and appeal system.
- The department of health could manage and recruit the new reviewers and appeal system.
- The SRA or the Law Society or the LGO or even the local government ombudsman.

But the only organisation that one would think should not be managing the appeal system or having anything to do with the reviewers should be the defendants in the appeals.

17. Do you think a 3 year gap in the Independent Reviewer's employment from the local authority concerned is sufficient to provide independence, or should this period be longer, or should they never have been previously employed by the local authority concerned?

The independent reviewer should not have worked for the Defendant in the case as this would call into question the fairness of any decision that had been made. We have had this issue with instructing independent social workers and have in the past had to un instruct a social worker because they directly contacted the defendant because they had known them and then had one of our clients in tears due to a variety of negative comments made by telephone because they had believed their local authority 'friend' in relation to our clients care needs rather than just assess the client.

It must be noted that In this case the complaints procedure completely failed and we had to issue proceeding just to obtain a carers assessment, and only upon the matter reaching the high court did the local authority back.

18. Do you agree that the Independent Reviewer's role should be to review decisions with reference to relevant regulations, guidance, facts and local policy to ensure the local authority's decision was reasonable?

The above is correct apart from the question of 'local policy' which could make it appear that this will be postcode justice.

19. How do you think we can promote consistency in decision making for care and support appeals?

The only way to promote consistency would be to have a system which is independent of local authorities and which has rigorous reviews. There should be a system of reviewers which are area based across multiple local authorities. They should publish reports on types of complaints and success rates etc every 12 months per local authority per type of issue.

This should as with the first tier tribunal annual report, start to show the effects of the system. Data on reviewer's decisions making should be available as they now are starting to do with doctors so that if there is an issue with a particular reviewer then it will be clear to see as it should be noticeable from the crowd. This should also show areas of the country with specific issues which should help the government and local authorities plan for the future care needs or address specific issues.

20. Do you think the timescales proposed to process appeals are right? If not, which timescales would be more appropriate?

We agree with the proposed timescales with one caveat which is with urgent appeals where a care package is cut or care refused where the matter is urgent. It would make sense to have some

method of triaging these so that an appeal reviewer can take urgent action should it be required in urgent cases such as the one we advice above in example case 4. It must be remembered the while we were able to utilise legal aid in that matter, this is not available for all and generally if legal aid is not available then neither is the option of judicial review and by default justice.

We would also suggest that an additional process be added where the claimant is sent a form by the Reviewer to clarify their views on the process and if they would like to appeal the decision further to the high court (judicial review) or the ombudsman. The review should then report back to the central review organisation as to the claimants next stage or if the appeal system in the particular case was a success. This should also be designed so that it clarifies how many claimants are not happy with the response but have no effective appeal mechanism where the local authority refuse to follow review decisions or where the claimant is not happy but has no further option potentially because the matter is outside of the area of limitations of the local government ombudsman.

21. Do you feel that the Appeals system, as set out, will aid the early resolution of disputes and thus help avoid costs and delays associated with challenging decisions in the courts? Please state yes or no and any rationale.

No, while there are some great proposals that have been raised throughout the process looking into appeals, the current options listed as being preferred as is currently proposed appears to be a complaints system with a different name and is not likely to make a great difference other than to provide quicker complaints/review responses.

It does potentially have the ability to substantially increase the amount of litigation as claimants across the board will for the first time be told they have the right to appeal decisions. Even if the system does not do (what it says on the tin) it will provide an avenue to the ombudsman and the courts/lawyers rather than the few who come to request legal advice at the moment. The new changes should also see positives such as claimants finally being provided with their documents such as needs assessments and care plans in a more timely fashion. It will remind all claimants of their rights to appeal decisions and this should bring with it a greater understanding of the rights they should have which may see more then taking legal advice and then challenging decisions via the court or ombudsman.

In many cases there will be cases going to the courts and ombudsman which may be have been fairly decided by the reviewer but as it appears that the reviewer will be working for the defendant, making the decision in the defendants offices and being managed by the defendant then there is not likely to be a great deal of appearance of independence. This is likely to build mistrust and so for the claimant then to be told they have an appeal from a reviewer inside the local authority is not likely to bolster confidence in any decision regardless of how fair it may have been.

We would say that if the key issue of independence is corrected and if the specification of the reviewer are amended then there is a potential for the department of health to achieve something truly historic.

22. In the accompanying Impact Assessment we have set out the costs to administer the Appeals system. We would welcome your comments on this and any evidence that you are able to provide.

We are extremely concerned that only one design of system appears to have been financially considered by the government in this system. Namely a design whereby local authorities supervise themselves and hire social workers as reviewers. We would have expected the following matters considered:

- Costs of implementation of adding this area to the tribunal system. This matter is very akin to the SEN tribunals in that they consider a needs assessment and have a legally qualified member of the tribunal and can have a medical member and consider what is required to meet the needs of the claimant bringing the appeal. The defendant being local authorities usually. This would be easier as the tribunal already has the entire process from recruitment through to hearing centres already in place so could be less expensive than setting up a new organisation.
- The costs of bringing this into the Local Government Ombudsman so that they can recruit manage and oversee the process.
- The cost of setting up a new appeal system to manage the new independent reviewers.

We also noted that there appears to be a number of omissions in the costings as they do not appear to show costs for managing the new system, dealing with recruitment, office space, and administration staff for the appeal officers etc. Without this data it would be practically impossible to compare this to another system.

We would ask the government to explain what difference a social worker with a different title of reviewer hired by the same local authority is in any way different from the social worker hired to carry out the needs assessment to reduce the care package.

Dated 30th March 2015

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Disability Law Service