# Inclusion London’s Response to the EHRC Inquiry into Challenging Decisions About Adult Social Care

## Inclusion London

Inclusion London is a London-wide user-led organisation which promotes equality for London’s Deaf and Disabled people and, provides capacity-building support for over 70 Deaf and Disabled People’s Organisations (DDPOs) in London. Through these organisations, our reach extends to over 70,000 Disabled Londoners.

## Introduction

Inclusion London works extensively on the issues of independent living and social care, and campaigns for the UN Convention on the Rights of Disabled People, including article 19, the right to independent living, to be incorporated into UK law. Recently, we have been undertaking research into the state of social care and independent living in London, examining whether the Care Act 2014 and the Wellbeing Principle that is included within it go anyway to securing Disabled people’s right to independent living. Through that research and the literature review conducted previously to undertaking the research, we have made findings about the ability of Disabled people to challenge decisions about their support and more broadly how their local authority delivers and makes decisions about adult social care.

## Key Points

* Social care service users struggle to access advice and information services to know their rights regarding their support, and their local authorities policies and practises on different aspects of social care.
* Most service users do not use the local authority website to access information and advice about their social care, instead they approached family and friends, user-led organisations or charities for support.
* The lack of appropriate advice and information has a direct impact on their ability to challenge decisions, and more broadly on their ability to exercise choice and control and live independently.
* Often the people who are most able to challenge decisions about their social care are those that have professionally gained knowledge of the Care Act, and can rely on their experience of self-advocacy.
* Local authority complaints processes are lacking in transparency and due process, and service users do not have confidence in them as a means of challenging decisions.
* There is no appeals process despite what was initially anticipated and included in the Care Act to challenge assessment and review decisions, meaning that service users must go to court if their complaints to the local authority and ombudsman are unsuccessful.

## Key Recommendations

* Local authorities must ensure that their policies, and where they are located on websites, are fully up to date and accessible to service users.
* Deaf and Disabled People’s Organisations must be funded to provide information, advice and advocacy to adult social care service users.
* The government needs to urgently enact the appeals system as was anticipated in the Care Act and ensure it allows social care users to challenge decisions to an independent, impartial body with accessible and user friendly processes.
* Local authority complaints processes must be overhauled and subject to external scrutiny to ensure that due process is followed and service users can have trust in them.

## Access to Advice and Information

Whilst undertaking our literature review, we found multiple reports detail the difficulty that social care service users have in accessing information and advice services. Whilst the *POET Report for Adults in Receipt of Social Care Support* found that 62% of respondents rated the information and advice they had to make about their support as good or very good, it is notable that a significant minority of 17% rated this as poor or very poor (p.7)[[1]](#footnote-2). *The Care Act 2014: Survey Results* also found 51% of people had found it quite or very difficult to find information (p.2)[[2]](#footnote-3). This is supported by the Merton CIL Report: *Choice, Control and Independent Living: Putting the Care Act into Practice*, who when they searched for information and policies on the London Borough of Merton website, found that as well as multiple different advice pages, some of the advice pages were in the wrong place, e.g. information for carers was on the page for older people (pp.28-29). Furthermore, much of the information was out of date and pre-dated the Care Act 2014 or referred to service providers who the council no longer used (pp.29-30)[[3]](#footnote-4).

Service users who required information and advice went to friends or family (46%), user led organisations (30%) or local charities (30%), as reported by the*Independent Living Survey 2016* (p.20). Far lower numbers used local authority websites (p.20). 61% of those needing advice and information needed help understanding their rights under the Care Act (p.22), and 47% said they needed help sorting out problems with their local authority (p.20)[[4]](#footnote-5).

The struggle to access advice and information relating to managing direct payments, understanding service users’ rights under the Care Act 2014 and solving problems with the local council, was also a frequent theme in *One Year On: Evaluating the Impact of the Independent Living Fund*, pp.44-45. It discusses this issue in relation to the value of Deaf and Disabled People’s Organisations and their campaigns (pp.44-45), particularly how DDPOs are providing day to day advice and information, but also how they are helping former ILF recipients to access legal aid or indeed paying for solicitors due to increased ineligibility under legal aid cuts[[5]](#footnote-6).

Service users lack of access to advice, information and advocacy from their local authority, or a service commissioned by the local authority, directly contravenes the Care Act Statutory Guidance, particularly Section 3.

Section 3.1 reads:

*“3.1 Information and advice is fundamental to enabling people, carers and families to take control of, and make well-informed choices about, their care and support and how they fund it. Not only does information and advice help to promote people’s wellbeing by increasing their ability to exercise choice and control, it is also a vital component of preventing or delaying people’s need for care and support.[[6]](#footnote-7)”*

The lack of appropriate and accessible advice and information on service users’ rights under the Care Act has a direct impact on their ability to exercise choice and control. It also has a material impact on the other aspects of the wellbeing principle, as described in the Care Act Statutory Guidance, as the result of not understanding their rights, and the assessment, reassessment and review processes could result in cuts to their packages, or their packages being removed altogether. Many people feel frightened, intimidated and made to feel as though they should be grateful for what they are given. Further, not having access to appropriate and well resourced information and advice services means that the vast majority of service users would not be aware of their rights and entitlements under the Care Act 2014, and would not have access to the support needed to effectively challenge decisions about social care.

The Covid-19 pandemic exposed many failures of local authorities to provide adequate and accessible information and advice. There was great disparity across London, with some authorities taking a proactive approach, like Hammersmith and Fulham and Tower Hamlets by contacting all social care service users directly with advice and information about support that was available and direct contact numbers to reach someone who can help. Other local authorities did nothing.

## Access to Advocacy Services

Three of the reports we examined in our literature review talk about advocacy during the assessment or review process, and all three highlight how often advocacy is not offered or the service user is not informed they can have an advocate, or in some cases, requests for an advocate are turned down (*Choice, Control and Independent Living: Putting the Care Act into Practice*, pp.49-50[[7]](#footnote-8); *The Care Act 2014: Survey Results*, p.2[[8]](#footnote-9); *One Year On: Evaluating the Impact of the Closure of the Independent Living Fund*, p.29[[9]](#footnote-10)).

*The Care Act 2014: Survey Results* shows that whilst 11% of service users were offered and accepted an advocate, 3% asked for an advocate and were refused and a further 68% were not offered an advocate at all (p.2). This is in a wider context where the survey had also found that the local commissioning of advocacy services was “tentative, uncertain or reducing” (p.9)[[10]](#footnote-11).

*Choice, Control and Independent Living: Putting the Care Act into Practice* portrays a similar situation within the London Borough of Merton, and examines some of the consequences of a lack of advocacy services being offered. In one case where statutory advocacy was not provided to someone who was eligible, their children were forcibly adopted (p.49). In other cases, carers reported that social workers had told them their family members were perfectly happy with decisions being made about their care, but advocacy hadn’t been provided to these people who needed support to make their views and needs known. Further to this, assessments have been carried out without the caseworker being informed by the council, and there is a need for a partnership approach (p.50)[[11]](#footnote-12).

Very little research appears to have been done regarding advocacy and the Care Act. One piece of research, published in 2016, found that between April and September 2015 only 2.1% of the 253,000 people assessed under the Care Act had an independent advocate provided to them, despite the government’s impact assessment estimating 7% of those assessed would qualify for and accept an advocate[[12]](#footnote-13).

This under provision of independent advocacy has a drastic effect on Disabled people’s ability to challenge decisions made about their social care. The Care Act states that local authorities must offer an advocate if the service user would experience “substantial difficulty” in understanding, retaining or using relevant information, or communicating their views about their support[[13]](#footnote-14). If the majority of people who are likely eligible for an independent advocate are not receiving one, or even being offered one, then this points to potentially large numbers of people being unable to challenge decisions due to this, with, as the Merton example demonstrates, potentially drastic and tragic consequences.

## Needing Expert Knowledge of the Care Act to Challenge Decisions

In our research, we found that amongst the interviewees who have managed to successfully challenge the decisions that their social workers have made, they report that this is due to their extensive, often professionally gained, knowledge of the Care Act, and their experience in being able to self-advocate.

*“It just meant several lost days of my life, arguing to keep what I had. So having to learn the Care Act properly, having to go through the process, being told that these were health needs, go through additional processes to prove that they weren't, and eventually getting to where I needed to be. But I suspect it was, I don't know, 5, 10 days of activity just to keep what I had which when you work full time was quite hard work and stressful.”*

*“No [cuts to care package], and I believe that this is because, social services know that I know more about the Care Act than they do. And because I did some training around the implementation of the Care Act when the closure of the lLF was happening. And they were aware of it because we went through them to try and contact as many direct payment service users as possible.”*

*“When I had the review after the ILF closed the social worker came and said that you're on ILF that's going to stop now. So you would just revert back to what you are going to have with the council. I did point out that they were still receiving funding through central government for care. And I was able to obtain some figures from central government, which showed how much the council would receive throughout the lifetime of that parliament, which was to 2020. So they were backtracking then and said okay I have to go away and review that.”*

*“There weren't any restrictions, but that's mainly because I was able to self-advocate very strongly using the relevant provisions of the Care Act. And because my package is also part funded by access to work. And if it wasn't for those two things I'm certain I would have had restrictions.”*

All the quotes provided above are from former ILF users who also work in Deaf and Disabled People’s Organisations, or have set up peer support groups of Disabled direct payment users. Collectively, they have spent decades providing advice, advocacy and support to Disabled people to challenge the decisions that local authorities and other public bodies have made about Disabled people’s social care. Therefore, it is very concerning that these people are reporting that in order to challenge decisions they have had to spend days learning the legislation, gathering information about central government funding to local authorities and arguing with their local authority in order to successfully challenge decisions about their support. For most Disabled people, this would not be possible to do, meaning that decisions could not be successfully challenged. This indicates that the Care Act is not strong enough in putting the power into Disabled people’s hands to have control over their support, and the processes for challenging decisions are too complicated and not robust enough to be used by most Disabled people successfully.

## Complaints Processes

Concerningly, we also found an example of where local authorities had received complaints and had not seemed to have logged them.

One interviewee said:

*“I was told that when, when I went to council meeting it said did anyone... did any user complain about their care changing after the ILF. And they answered no. And yet, I put in three complaints, so there you go.”*

Furthermore, in Freedom of Information Requests to this local authority, they were asked, “How many complaints have been received from former ILF recipients concerning their re-assessments and the outcomes thereof?” This local authority replied, claiming that there had been no complaints made of this nature. This indicates that either the local authority is responding falsely to Freedom of Information Requests, or that they are not properly logging complaints that have been made to them. In either case, this presents a lack of transparency to service users and other relevant parties that cast their complaints procedures into doubt. Being formally able to complain about the processes and actions is one means of challenging decisions, and so this local authority not logging and responding to complaints is yet another barrier to service users being able to input into their own support and effects their ability to make meaningful choices about their social care support.

Even when complaints are properly logged, service users feel that the local authority’s response is tokenistic and it does not result in material, long term change. Another interviewee, who lives in a different London borough said:

*“I've just had instead of my concerns, just being sort of brushed off and said, oh well they are normally good like that, which is really frustrating… I kind of feel like even if you make a complaint, it doesn't really change anything.”*

Service users should have trust in the processes which can be used to challenge decisions otherwise they will not use them as a means to be able to exercise choice in their social care support.

Evidence collected by Independent Age also points to local authority complaints processes not being suitable for instances where service users wish to challenge decisions. Firstly, the connotations of a complaints process mean many people see it as a means to express unhappiness with a service rather than a way of having a decision re-examined and potentially changed (p.13)[[14]](#footnote-15). Furthermore, looking at the 169% increase in social care complaints put to the Local Government and Social Care Ombudsman over eight years, and the 66% “upheld rate”, this is an indication that local authority complaint procedures are not working as the means to challenge decisions, as service users are escalating complaints[[15]](#footnote-16).

## Appealing Decisions

We believe, at present, there is no effective remedy for those people who want to challenge decisions about their social care.

There are key challenges social care users who disagree with local authority decisions about their care face, especially if they went through a complaints process and did not get a satisfactory outcome.

Both the Local Government and Social Care Ombudsman and courts will only look at whether or not local authority complied with the law, there is no way to dispute questionable decisions and the recommendations of social workers unless those are irrational. In the present context, especially when decisions may be budget driven, it is very difficult for people to challenge social worker’s opinions about their needs, the level of risk they should take, or how their support should be provided and what would promote their wellbeing. Our experience shows that as long as there is some rational explanation, which could even be provided after the event, the decision is practically unchallengeable. The Care Act still leaves all decisions for local authority to make. Although there is a duty to involve a service user and consider their views, it is entirely possible to make a decision which goes against what a service user thinks is best for them.

Challenges to LGSCO take a long time and are ineffective when people have lost their support and, in some cases, have to make staff redundant if their direct payments are cut. So even a positive outcome of a complaint to the ombudsman may not make a huge difference in reality to an individual, when their support package has already broke down.

Strict means-testing for legal aid and the fact that legal cases in effect lead to endless reassessments and reviews with minor concessions mean there are very few social care users who are able to access legal advice. Moreover, there are fewer and fewer solicitors specialising in this field. Our experience shows it is now much harder to find a lawyer who would take a pure social care case that is a dispute about an individual care package even for people who do qualify for legal aid.

Because the current system is so adversarial many people are worried about the consequences and possible victimisation they might face from a local authority if they did challenge decisions legally.

At current, there is no statutory mechanism for appealing decisions that have been made by local authorities about someone’s social care. This is despite the government consulting on the issue in 2015, and the Care Act giving power to Secretary of State for Health and Social Care and to local authorities to introduce one – clearly demonstrating that the government acknowledge the importance of an appeals process (p.2)[[16]](#footnote-17). Research from Independent Age found that one in five local authorities have introduced an appeals process, however, because there are no statutory guidelines on how these should run, there is a high level of variation between them. Processes were pulled from different forms of guidance to create policies, and time limits ranged from 10-40 days (pp.8-9)[[17]](#footnote-18). This shows that in the event that a statutory appeals process is introduced in the Care Act, there must also be accompanying guidelines, to ensure that there is not a postcode lottery as to which service users are most able to effectively challenge decisions.

## For Further Information

Please contact Inclusion London’s Policy and Parliamentary Officer, Rachel O'Brien, at Rachel.obrien@inclusionlondon.org.uk

1. http://s557941885.websitehome.co.uk/wp-content/uploads/2017/02/independent-living-survey-2016-v3.pdf [↑](#footnote-ref-2)
2. https://www.thinklocalactpersonal.org.uk/\_assets/Resources/TLAP/CareActSurveyResults-002.pdf [↑](#footnote-ref-3)
3. https://www.mertoncil.org.uk/assets/documents/choice-control-and-independen [↑](#footnote-ref-4)
4. http://s557941885.websitehome.co.uk/wp-content/uploads/2018/01/independent-living-survey-2016-v3.pdf [↑](#footnote-ref-5)
5. https://www.inclusionlondon.org.uk/wp-content/uploads/2016/09/InclusionLondon\_ILF\_Report\_2016.pdf [↑](#footnote-ref-6)
6. https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance [↑](#footnote-ref-7)
7. https://www.mertoncil.org.uk/assets/documents/choice-control-and-independen [↑](#footnote-ref-8)
8. https://www.thinklocalactpersonal.org.uk/\_assets/Resources/TLAP/CareActSurveyResults-002.pdf [↑](#footnote-ref-9)
9. https://www.inclusionlondon.org.uk/wp-content/uploads/2016/09/InclusionLondon\_ILF\_Report\_2016.pdf [↑](#footnote-ref-10)
10. https://www.thinklocalactpersonal.org.uk/\_assets/Resources/TLAP/CareActSurveyResults-002.pdf [↑](#footnote-ref-11)
11. https://www.mertoncil.org.uk/assets/documents/choice-control-and-independen [↑](#footnote-ref-12)
12. https://www.communitycare.co.uk/2016/01/13/social-workers-urged-review-practice-given-low-care-act-advocacy-case-numbers/ [↑](#footnote-ref-13)
13. https://www.legislation.gov.uk/ukpga/2014/23 [↑](#footnote-ref-14)
14. https://independent-age-assets.s3.eu-west-1.amazonaws.com/s3fs-public/2019-10/IA-PI-092-SocialCareAppeals\_WEB\_0.pdf [↑](#footnote-ref-15)
15. https://independent-age-assets.s3.eu-west-1.amazonaws.com/s3fs-public/2019-10/IA-PI-092-SocialCareAppeals\_WEB\_0.pdf [↑](#footnote-ref-16)
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