Disability Law Service

Fighting injustice for disabled people

Ending the charging system for non-residential care for Disabled adults in England

Disability Law Service

24th July 2024

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About Disability Law Service (DLS)

DLS was founded in 1975. We are a Deaf and Disabled people's organisation, providing free legal advice, casework and representation for Disabled people, their families and carers. For those who fall outside our remit, we offer referrals to other legal advisers and signposting to relevant organisations. We believe we are the only pan-disability organisation with a national remit, providing specialist legal advice in the following areas of law: community care, employment, housing, discrimination, public law and welfare benefits. We also provide disability law training to civil society organisations, law centres and corporations, and advocate for changes to the law where it disadvantages Disabled people. Our aim is to challenge the poverty and inequality faced by Disabled people by securing equal access to legal rights and entitlements.

Our vision: DLS' vision is to work towards an equitable and accessible society, eliminating discrimination and ensuring that the rights of Disabled people, their carers and families are upheld.

Our mission: Our mission is to provide free legal advice to Disabled people and their carers to ensure that they have access to their rights and justice.

Our values:

- **Accessibility** – Sensitive and proactive to the individual needs and preferences of our users; we will be flexible in the way we make our services available.

- **Inclusivity** – We will carry out our work, in partnership with service users, in a way that is enabling of Disabled people. We will take their views into account, to improve and develop our work.

- **Respect** - We will treat our service users with respect at all times, respect confidentiality, be empathetic to our service users' problems and offer accurate and realistic advice.

- **Excellence** – We will constantly monitor our work to ensure it is carried out to the highest standards and meets the changing needs of our service users.

- **Partnership** – In pursuing our mission, we will actively seek to work with other organisations.

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Biographies of contributors

Alexander Sherman

Alexander is a solicitor at Disability Law Service (DLS), working in the areas of community care and housing. Alexander has worked at DLS since January 2021, having trained at the organisation through the Justice First Fellowship scheme, funded by The Legal Education Foundation. As part of the scheme, Alexander was asked to work on a project, aimed at advancing access to justice. This report is the culmination of that project work.

Linklaters volunteers

A group of dedicated pro bono volunteers from Linklaters collaborated with DLS to produce the supplementary report, analysing responses from local authorities in England regarding their policies on non-residential care charges. Linklaters is delighted to have contributed its time and skills to further DLS' work protecting the legal rights of Disabled people by increasing transparency on the extent to which local authorities' discretionary decisions to charge for home care align with the public sector equality duty.

Michael Carr

Michael is a trainee solicitor at a London-based law firm, where he has spent time working on various pro bono matters. Michael worked as a volunteer at DLS from August 2022 until January 2023. Michael helped with the drafting of the questionnaire reports, focus group reports and real-life stories.

Nour Abdelwahab

Nour is currently a trainee solicitor at Porter Dodson in Somerset. Previously, Nour volunteered at DLS between July 2021 and January 2022. She assisted with the initial stages of the research including the preparation of the freedom of information requests to local authorities. She also helped to prepare the questionnaires and do the preparatory work for the focus groups.

Rashel Alpay

Rashel Alpay is currently undertaking her LLM in Corporate & Commercial Law at The London School of Economics and Political Science. She worked as a volunteer at DLS from February 2022 until August 2022. Rashel assisted with research into the London Borough of Hammersmith & Fulham (H&F) and the development of the document, detailing the H&F model and how H&F facilitated a policy of home care free at the point of use.

Executive summary

Introduction

We all want to have as much control as possible over our own lives, the power to make decisions and to be able to do the things that matter to us. That's a basic human right which most of us take for granted.

Support to live independently at home gives Disabled people that human right, too. But councils across England are charging Disabled people for this vital support. This means Disabled people are having to make the terrible choice between things like heating and eating and whether we're able to get out of bed, wash, dress, get out and about and see friends.

It doesn't have to be a choice. By not charging Disabled people for home care, councils are not only doing the right thing, but they're also using their limited resources sensibly as it prevents more intensive support being needed further down the line.

Overall purpose

The overall purpose of this report is to make the case for the abolition of home care charges and make home care free at the point of use for Disabled adults in England. This will enable Disabled people to live more independently, and have more control over their own lives.

Research aims

Firstly, our aim was to examine if local authorities across England were fully assessing the impact of their home care charging policies by complying with the public sector equality duty (PSED). Secondly, to assess the impact of home care charges on Disabled adults, and thirdly, to learn from the experience of the London Borough of Hammersmith and Fulham (H&F), the only council in England currently providing home care free at the point of use, as an example of how to abolish home care charges.

Research methodology

Disability Law Service (DLS) created a mixed method research design gathering quantitative and qualitative data. These included: 1) making freedom of information (FOI) requests to 40 local authorities, selected to be representative of England as a whole; 2) preparing a supplementary report summarising and analysing responses to those FOI requests, with support from a team of volunteers from Linklaters; and 3) conducting questionnaires, focus groups and real-life story-sharing with a self-selected sample of Disabled adults. In addition, secondary analysis was conducted on data provided by H&F to examine practical solutions to abolish home care charges.

Key findings

FOIs

- 92.5% (37/40) of the local authorities are not fully compliant with all aims of the PSED.
- Nearly all of the local authorities do not record the number of adults forced to decline non-residential care because the individual can't afford it.
- The proportion of Disabled adults being charged for non-residential care is increasing over time.

Participants

- Increased home care charges are having a negative effect on the physical, mental and emotional well-being of Disabled adults and their family members.
- Disabled adults are sometimes unable to afford their basic needs, such as food and heating due to home care charges and are falling deeper into debt.

H&F

- Making home care free at the point of use in H&F has had profound positive outcomes for Disabled adult residents. It has provided them with greater financial resources to spend as they wish and has alleviated the negative physical and mental health effects associated with these charges. It has transformed their lives for the better, granting them greater independence and freedom.

Implications

Our findings are deeply concerning, and clearly demonstrate that local authorities across England are not prioritising a human rights-based approach to social justice. Given the ongoing cost-of-living crisis, (nearly half of all people in poverty are either a Disabled person or live with a Disabled person) home care charges are exacerbating the problems experienced by Disabled people and pushing them deeper into poverty, affecting both their mental and physical health.

Recommendations

Based on these findings, we developed a document detailing the H&F model, showing other local authorities how H&F abolished home care charges and providing practical examples as to how other councils can actively promote independent living for their Disabled residents.

Report limitations

The Disabled adults who took part in our research were a self-selected sample and are therefore not representative of the Disabled community as a whole. However, our findings are consistent with other recent research and ongoing disability campaigns that show that the experiences of our respondents are not unique and reflect a widespread problem.

Secondly, our research was undertaken between September 2021 and February 2023. We recognise that some of the data is now 2 years old. However, in March 2024, a follow-up FOI request was sent to all 40 local authorities and the adult social care teams were contacted to ask whether there had been any significant changes to their policies since we first enquired in 2021. Unfortunately, there is little evidence of any substantial change.

Conclusion

We hope that this research will go some way to highlight the negative effects of home care charges on Disabled people across England. Whilst we recognise ongoing budgetary limitations on local authorities in England, the example of H&F shows other councils what is possible when the human rights of Disabled people are prioritised. The abolition of home care charges has been reported to be overwhelmingly positive in H&F, leaving Disabled adult residents with greater financial resources, and has improved their quality of life.

It is time to end this tax on disability. In the words of 1 of our contributors, “social care is not a luxury. It is a human right. Without social care, some Disabled people will have no quality of life whatsoever”.

Research methodology

Through this research, Disability Law Service (DLS) wanted to examine how local authorities in England manage their home care charging policies, and how they are impacting local Disabled residents. We also wanted to explore what strategies have been employed by the London Borough of Hammersmith and Fulham (H&F) to abolish home care charges, so that other local authorities could learn from this. To do this, we created a mixed method research design gathering quantitative and qualitative data. Data was collected throughout the research process using both primary and secondary research methods.

FOI requests

In September 2021, DLS contacted 40 local authorities seeking a response under the Freedom of Information Act 2000 (the FOI 2000) to 7 questions related to how they charged Disabled adults for non-residential care (the FOI request). DLS selected these 40 local authorities (representing over 25% of the local authorities in England who charge Disabled adults for home care based on their geography, size and political leadership. This ensured the sample size was reflective of the country as a whole. 10 of these 40 local authorities were based in the London area and the remaining 30 in the rest of England.

DLS created a template table to assess each local authority's compliance with the public sector equality duty (PSED). The template provided prompts sourced from relevant case law and guidance. Certain prompts were factual, such as whether the local authority had made available information which demonstrated compliance with the PSED in the form of a written compliance record (WCR), and if so, when this document was dated.

Each local authority was also sent a FOI request with questions, for example the number of Disabled adults who were: (i) provided with non-residential care and support; and (ii) charged for such care. We requested data in each financial year or calendar year since April 2017. The relevant statistics collated from local authority responses were imported into a spreadsheet recording results by year. The results were then analysed and for some of the results, a set of graphs were produced.

In March 2024, we sent a follow-up FOI request to all 40 local authorities and the adult social care teams were contacted to ask whether there had been any significant changes to their policies since we first enquired in 2021. This data was then analysed against the same template previously used to assess their compliance with the PSED.

Questionnaires

DLS designed 2 questionnaires that were completed by a self-selected sample of 113 Disabled adults. The first questionnaire was completed by 96 Disabled adults in England who are currently charged for home care. The second questionnaire was completed by 17 Disabled adult residents in H&F who currently receive home care free at the point of use. The questionnaires were promoted through different platforms including the DLS website, H&F website, and by Action on Disability, a Disabled people's organisation in H&F. Participation was anonymous, although participants were given the option of providing their personal details. The first questionnaire consisted of 19 questions, the second 15. We asked introductory questions in both about their home care experiences and their general background. Subsequent questions related to Disabled residents' opinions on relevant statements. Respondents' possible answers to these questions ranged from 'strongly agree' to 'strongly disagree', alongside the options of 'not applicable', 'neutral' and 'do not know'. Several of these questions ('statement questions') gave respondents the option to provide additional comments alongside their selected answer.

Respondents were able to complete the questionnaires over the period they were 'live'. The questionnaire of Disabled adults in the rest of England was live from the 28th February until the 28th March 2022. The questionnaire of H&F Disabled adult residents was live from the 6th May until the 6th June 2022.

Focus groups and real-life stories

DLS held 2 focus groups. The first focus group was held on the 27th April 2022 with a self-selected sample of Disabled clients and service users from local authorities across England (excluding H&F). The main objective of the focus group was to consider the impact of non-residential care charges on Disabled adults in England. Attendees were asked about the following: their experiences and thoughts on the home care charging system; the financial impact of home care charges; the physical, mental and emotional impact; whether Disabled people are consulted sufficiently when local authorities implement changes in the charging system; the changes they would like to see; and their opinions on the potential abolition of home care charges.

The second focus group was held on the 9th August 2022 with self-selected members of Action on Disability's Direct Payment Peer Support Group who are residents in H&F. The main objective of this focus group was to consider the impact of the abolition of non-residential care charges on Disabled people. Attendees were asked about the following: their experiences of care and charging prior to living in H&F; the physical, mental and emotional impact of home care charges; their experiences of care and the charging system in H&F; and the impact of the abolition of home care charges in H&F.

We also collected 9 real-life stories from Disabled adults in H&F and the rest of England to provide more qualitative evidence as to the effects of home care charges. The real-life stories were shared from people who took part in our questionnaires and focus groups and other non-project participants from H&F who came forward, wishing to share their story.

Secondary analysis

Secondary analysis was also conducted on data provided by H&F to assess how it abolished home care charges. This involved examining key strategic documents and financial information provided to us by H&F and other information and documents available via H&F's website. We also spoke with various staff members, including the Strategic Director of Social Care, the Strategic Leads for Co-production, the Head of Finance and councillors to analyse the process H&F undertook to abolish home care charges. The staff members were happy to answer any follow-up questions we had relating to their strategy.

Introduction

We all want to have as much control as possible over our own lives, the power to make decisions and to be able to do the things that matter to us. That's a basic human right which most of us take for granted.

Support to live independently at home gives Disabled people that human right, too. But councils across England are charging Disabled people for this vital support. This means Disabled people are having to make the terrible choice between things like heating and eating and whether we're able to get out of bed, wash, dress, get out and about and see friends.

It doesn't have to be a choice. By not charging Disabled people for home care, councils are not only doing the right thing, but they're also using their limited resources sensibly as it prevents more intensive support being needed further down the line.

Disability Law Service (DLS) is a Deaf and Disabled people's organisation (DDPO) that provides free legal advice to Disabled people, carers and family members. We also engage in policy work to help improve the rights of Disabled people and their access to justice. Over the period 2021-2024, we undertook an important piece of research examining the current charging system for non-residential care, and its impact on Disabled adults in England. We wanted to ascertain whether local councils in England are complying with the public sector equality duty (PSED) and assess how certain trends in home care charges are changing over time. We also wanted to analyse how home care charges are affecting Disabled adults in England.

To help us undertake this research, we engaged and collaborated with other DDPOs, including Action on Disability (AoD). We also worked with the London Borough of Hammersmith and Fulham (H&F), the only local council in England that currently does not charge Disabled adults for their home care. Even though, this research and the resulting report were carried out with the collaboration and support of H&F, the conclusions and any views expressed are those of DLS alone.

As the foundation of this research - with support from a team of Linklaters volunteers - we made freedom of information (FOI) requests to 40 local authorities about their non-residential care charging policies to help us examine whether they are adequately assessing their policies' impact on Disabled adults. We conducted 1 questionnaire with Disabled adults who receive home care in H&F, and to compare, another questionnaire with Disabled adults from other parts of England who are charged for their home care. Similarly, we held 2 focus groups: 1 with members of AoD's Direct Payment Peer Support Group, based in H&F; and 1 with Disabled clients and service users residing in other local authorities who have been impacted by home care charges. We also compiled real-life stories from residents across England, showing the impact that different home care policies are having on Disabled adults. Finally, by interviewing key council personnel in H&F and analysing important strategic

documents, we developed a document, detailing the H&F model and how the council facilitated a policy of home care free at the point of use.

The findings of our research are deeply concerning. As Disabled people continue to face discrimination and inequality on an unparallelled level, we hope this report can shine a light on the unlawful actions of local authorities across England as they continue to fail their local Disabled residents through unjust charging policies. We hope our findings will inform local authorities about effective strategies, and practical solutions that they can reference and integrate as part of their own policies, ensuring the human rights of Disabled people are upheld.

In the first section of the report, we detail the responses we received from local authorities from our FOI requests and provide an analysis of the implications of these responses. Secondly, we look at the responses from Disabled people to our 2 questionnaires about their personal experiences of home care policies. Thirdly, we look at the impact of home care policies in more detail through the lens of our focus group participants, and the fourth part shares real-life stories which demonstrate the profound negative effects home care charges are having on the lives of Disabled people and the positive impact that the abolition has had in H&F. The final section of the report provides an analysis of the H&F model, highlighting some practical steps that other local councils can take to abolish home care charges, and promote the independence and equality of their Disabled residents.

DLS adopts the social model of disability (that people with impairments are 'disabled' by the barriers operating in society that exclude and discriminate against them). We have therefore used language in line with this as far as possible. We have used the terms home care and non-residential care throughout this research report, to describe the support that Disabled adults receive at home to live independently. We have used the terms local authority and local council interchangeably throughout this report. The font sizes of 14 and 16 have been used throughout this report for the purposes of accessibility.

Disability Law Service

Fighting injustice for disabled people

Report on local authorities' freedom of information responses on their non-residential care charging policies

Disability Law Service with support from a team of Linklaters volunteers

24th July 2024

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1 Introduction

Disability Law Service (DLS) made requests for information to 40 local authorities in England, in an effort to understand: (i) how local authorities manage their non-residential care charging policies; and (ii) how local authorities consider non-residential care charges impact their adult Disabled residents. This research aimed to determine whether local authorities across England were meeting their statutory obligations in respect of non-residential care charging policies and what impact the charges have on Disabled adults.

At the time we conducted this research in September 2021, there were 152 local authorities in England which managed adult social care.[1] Under s.14 of the Care Act 2014, local authorities are permitted to charge a contribution towards meeting care and support needs (Contribution). In September 2021, only 1 local authority in England, the London Borough of Hammersmith and Fulham, did not charge Disabled adults for their non-residential care. This figure remains accurate today. [2]

This report summarises the research methodology used in preparing this report, as well as the local authorities' responses provided to each question included in our requests for information. A team of volunteers from Linklaters supported DLS with the analysis of the local authorities' responses and with the compiling of this report.

2 Research methodology and analysis

In September 2021, DLS contacted 40 local authorities seeking a response under the Freedom of Information Act 2000 (the FOI 2000) to 7 questions related to how they charged Disabled adults for non-residential care (the FOI request). For questions 2 – 7, we requested data for each financial year or calendar year since April 2017. The template letter containing these questions is set out in Appendix 1.

DLS selected these 40 local authorities (representing over 25% of the local authorities in England who charge a Contribution) based on their geography, size and political leadership. This ensured the sample size was reflective of the country as a whole. 10 of these 40 local authorities were based in the London area and the remaining 30 in the rest of England.

[1] 'Adult Social Care Activity and Finance Report, 2021-22' (2022) <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2021-22> accessed 8 April 2024.

[2] 'Home Care' <https://www.lbhf.gov.uk/health-and-care/assistance-home/home-care> accessed 26 June 2024.

In 20 cases, the local authority failed to provide the requested data within 20 working days – the statutory limit set under the FOI 2000. DLS followed up with these local authorities, and in 7 cases made complaints to either the individual local authorities and/or the Information Commissioner's Office to obtain a response to the FOI request.

An average of 5 local authorities failed to provide information to each question, citing the s.12 FOI 2000 exemption. Under s.12 FOI 2000, public authorities can refuse requests for information where the cost of dealing with them would exceed "*the appropriate limit*". For public authorities, the appropriate limit is set at £450, which equates to 1 person spending 18 hours: (i) determining whether the department holds the relevant information; and (ii) locating, retrieving and extracting the relevant data. In these cases, DLS sought to refine their data requests to a shorter time period than the original request of data for 4 full financial years. However, even with this revision, several local authorities still failed to provide responses to each question (as detailed further below).

2.1 Question 1 : Local authority compliance with the public sector equality duty (PSED)

Background

Further to the decision in *SH v Norfolk County Council* [2020] EWHC 3436 (Admin) (Norfolk, summarised below,) this question assesses whether local authorities' non-residential care charging policies comply with the PSED.

> *The High Court found that Norfolk County Council's charging policy discriminated against SH as a severely Disabled person. SH was required to pay a larger care contribution as more of her benefits were taken into account as part of the financial assessment. SH was deemed to have a high level of need as she was in receipt of the enhanced rate of the daily living component of Personal Independence Payment. SH was deemed to be unable to work or have limited prospects of working in the near future, evidenced by being in the support group of Employment and Support Allowance. Mr Justice Griffiths noted that Norfolk County Council had failed to consider a less intrusive measure of setting a maximum percentage of disposable income over and above the minimum income guarantee (the level of income that the government states an individual must be left with before any charge may be made for their care and support) as set out in paragraph 8.47 of the Care and Support Statutory Guidance. The decision in Norfolk was specific to the*

individual facts of the case. Whilst it does not follow that every local authority with similar charging policies will automatically be deemed unlawful, each local authority, following this case, has a duty to assess whether its severely Disabled residents are being discriminated against. Local authorities should do this by discharging the PSED in accordance with s.149 Equality Act 2010.

To comply with the PSED, local authorities must have due regard to the need to:

- Eliminate discrimination, harassment, victimisation (Aim 1);
- Advance equality of opportunity between Disabled people and non-Disabled people (Aim 2);
- Foster good relations between Disabled people and non-Disabled people (Aim 3).

Methodology

DLS created a template table (see Appendix 2) to assess each local authority's compliance with the PSED. The template provided prompts sourced from relevant case law and guidance. Certain prompts were factual, such as whether the local authority had made available information which demonstrated compliance with the PSED in the form of a written compliance record (WCR), and if so, when this document was dated. Other prompts required qualitative analysis, such as whether the local authority had demonstrated due regard to all 3 of the PSED aims. Where a FOI response did not provide a WCR or charging policy, the website of the relevant local authority was reviewed and information found online was used to supplement the analysis.

Analysis

The local authorities' responses demonstrated that reviewing, updating and making available a WCR is a clear area for improvement. Many of the local authorities contacted (15/40) did not make available a WCR at all. Generally, this meant the local authority was considered not to have sufficiently demonstrated its full compliance with the PSED. Case law has determined that it is very difficult to show PSED compliance without a WCR. [3]

[3] 'The Essential Guide to the Public Sector Equality Duty: England (and Non-Devolved Public Authorities in Scotland and Wales)' (2022) <https://www.equalityhumanrights.com/en/publication-download/essential-guide-public-sector-equality-duty> accessed 16 December 2022.

Of those local authorities that did provide a WCR, many were deemed non-compliant because their documents had not been recently updated. A local authority must regularly evaluate the impact of its policies on Disabled people, and so it is crucial that a WCR is kept up to date and is regularly reviewed. Approximately a third (8/25) of those local authorities which provided a WCR had failed to update their documents since the 1ˢ January 2018, and 1 had not produced a WCR since 2015 – around the time that the Care Act 2014 came into force (on the 1st April 2015). Only 2 local authorities appear to have updated their charging policies to reflect the decision in *Norfolk*.

The Equality Act 2010 and the Equality and Human Rights Commission guidance highlights the importance of complying with each aim of the PSED. [4] In certain cases, the WCR provided seemed to reflect very little information that related to the substance of the PSED. More often, a WCR demonstrated that a local authority had made efforts to comply with Aim 1. However, the WCR was usually silent in relation to Aims 2 and 3. Overall, a very small number of local authorities, only 7% (3/40), were found fully compliant with all aims of the PSED.

Most WCRs did not assess risks which could stem from charging Disabled people for non-residential care. This suggests that local authorities do not sufficiently consider these risks, and fail to comply with the requirements post-*Norfolk*. This finding was reinforced by the lack of discretion to waive some or all of the Contribution (discussed in question 7 below).

In summary, most local authorities were deemed non-compliant with the PSED. Many local authorities had outdated policies and WCRs, which failed to provide relevant information (or consider relevant law). DLS recommends that local authorities incorporate certain activities that are associated with PSED compliance:

- Requiring a policy to be reviewed and updated regularly: local authorities compliant with this requirement were often found to have accounted for relevant case law and the ongoing nature of the PSED.
- Structuring the WCR to reflect the PSED aims: for the small number of compliant local authorities, each of the 3 PSED aims was explicitly considered. Local authorities with WCRs that are designed to require commentary on each PSED aim were most frequently found to have demonstrated that they considered and engaged with these aims.
- Consulting with relevant stakeholders: local authorities which reported on their consultations with groups who were impacted by the relevant charges (including

[4] Ibid.

service users, family members, carers, Disabled people's organisations and the public) were often found to have kept the PSED considerations central in their policy formulations.

- Facilitating active participation of Disabled people in any consultation process: some local authorities had taken positive steps to ensure this, including by producing an eligibility factsheet and schedule of fees and charges on the local authority's website, publishing impact assessments online (and making these documents easy to locate) and creating taskforces to advertise and facilitate upcoming consultation processes.

2.2 Questions 2 and 3: Adults provided with, and charged for, non-residential care and support

Methodology

As noted above, each local authority was sent a FOI request with questions concerning the number of Disabled adults who were: (i) provided with non-residential care and support; and (ii) charged for such care. The relevant statistics were imported into a spreadsheet recording results by year. The results were then analysed to produce the graphs set out below. In some instances, to calculate the number of adults provided with non-residential care in each year, DLS added together the total number of people having to pay the full charge, an assessed charge and no charge.

Analysis

As shown on the graph below, several local authorities provided incomplete data to questions 2 and 3. The reasons for this varied – including that data had been lost, or that it would be too time consuming to collate the information. Local authorities often provided figures for some years and not others.

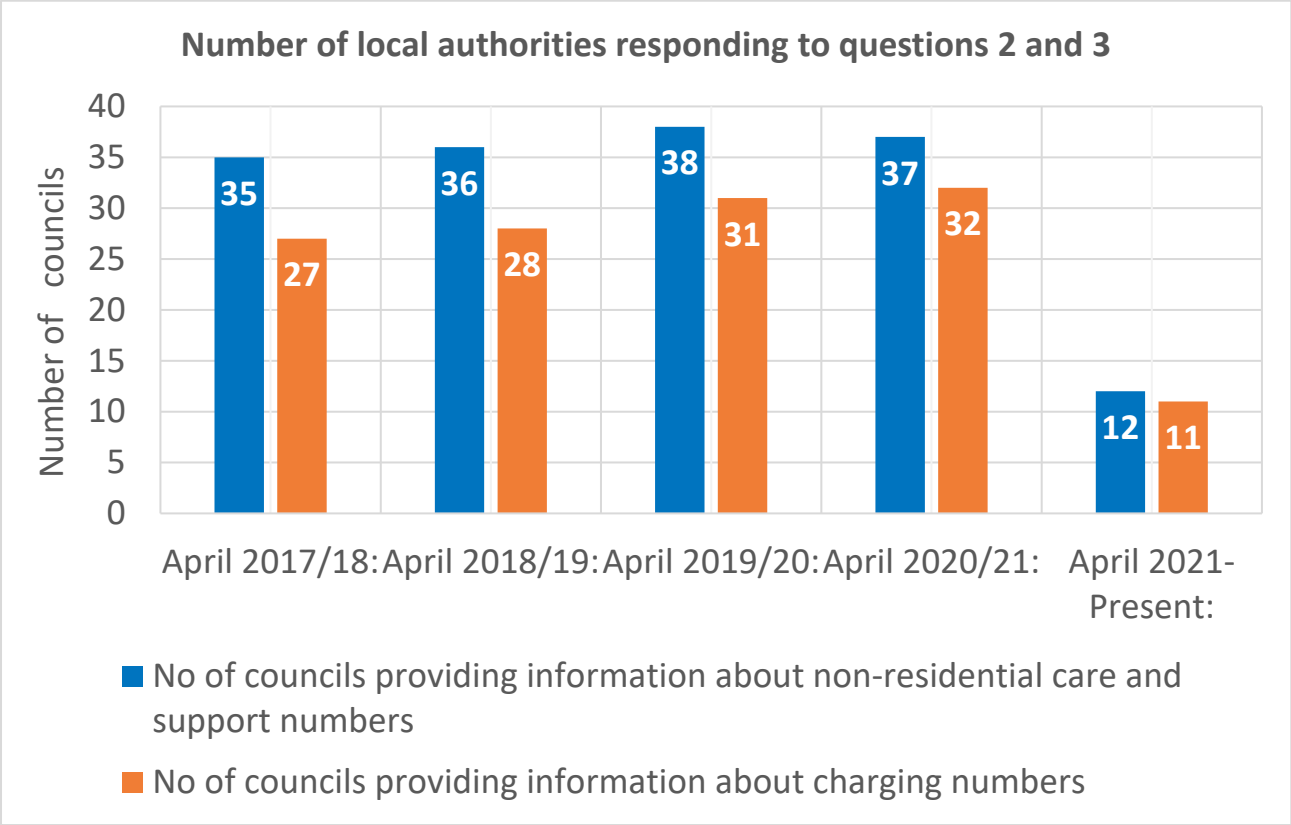

Figure 1: Number of local authorities providing answers to questions 2 and 3

As the graph illustrates, the majority of local authorities did not provide any information for the category "2021 – present". This suggests that many local authorities do not maintain this data "live", and that the information cannot be easily accessed on an ongoing basis. This, combined with the high numbers of missing answers for previous years, illustrates that data collection is a key area for improvement. It is important that local authorities monitor this data to assess the impact on Disabled adults and comply with the PSED.

After removing incomplete data (i.e. only considering figures when a local authority had provided a response for both questions 2 and 3), the sample of responses decreased to 27 local authorities in 2017/2018, 28 local authorities in 2018/2019, 31 local authorities in 2019/2020, 31 local authorities in 2020/2021 and 9 local authorities in 2021-present.

In total, this sample suggested that 48.3% (364,429 out of 753,892) of adults have been charged for their non-residential care and support. The graph below illustrates that this percentage has been generally increasing over time.

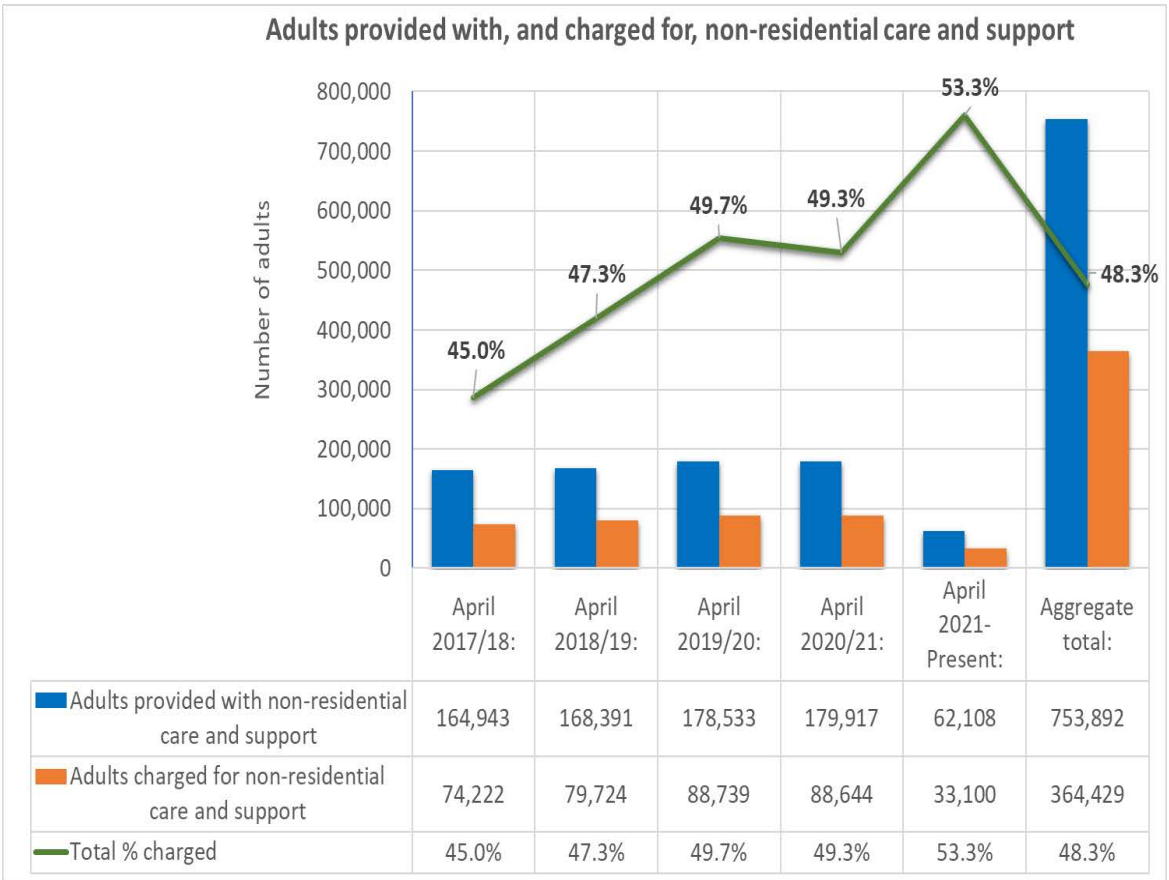

Figure 2: Proportion of adults charged for non-residential services (on basis of local authorities who provided answers to both of Questions 2 and 3)

2.3 Questions 4 and 5: Gross Income received from charging and the costs incurred in collecting charges

Background

A 2018 study by the Independent Living Strategy Group (ILSG) found that income raised from social care charging contributes to only 12% of the money spent by each local authority on community services. [5] This study concluded that charging raises modest revenues, unlikely to significantly impact the quality and quantity of support provided by a local authority. However, on an individual level, charging creates barriers to health and social integration, specifically for Disabled people, often pushing them into poverty. In this context, DLS compared the cost that local authorities bear in collecting non-residential care charges against the actual collected income.

[5] Independent Living Strategy Group, 'Charging for Social Care: A Tax on the Need for Support' (2018).

Analysis

While most local authorities provided figures for the gross income raised from charging for 2017-2021, 88% (35/40) of local authorities did not provide information for 2021-2022, or provided data that was not in an analysable format. 1 local authority, for instance, did not distinguish between income raised from non-residential care charges and other sources of income, and DLS determined that it was not able to use this data reliably. Furthermore, only 38% (15/40) of local authorities provided costs of collection, for which most local authorities did not provide the relevant information for 2021-2022. The remaining 62% (25/40) either did not record this data at all (and if they did, the information had not been retained), or refused to provide it under s.12 FOI 2000, or provided it in a format that could not be analysed.

The failure to record this data is telling, especially in light of the ILSG study. If local authorities do not collect or record this information, it is unlikely that they assess if they are deploying their finances effectively to collect non-residential care charges. This also makes it unlikely that they comprehensively evaluate the costs and benefits of non-residential care charging against the disproportionate impact on Disabled adults. The failure to provide information for 2021 – 2022 also indicates that this data is not tracked on an ongoing basis.

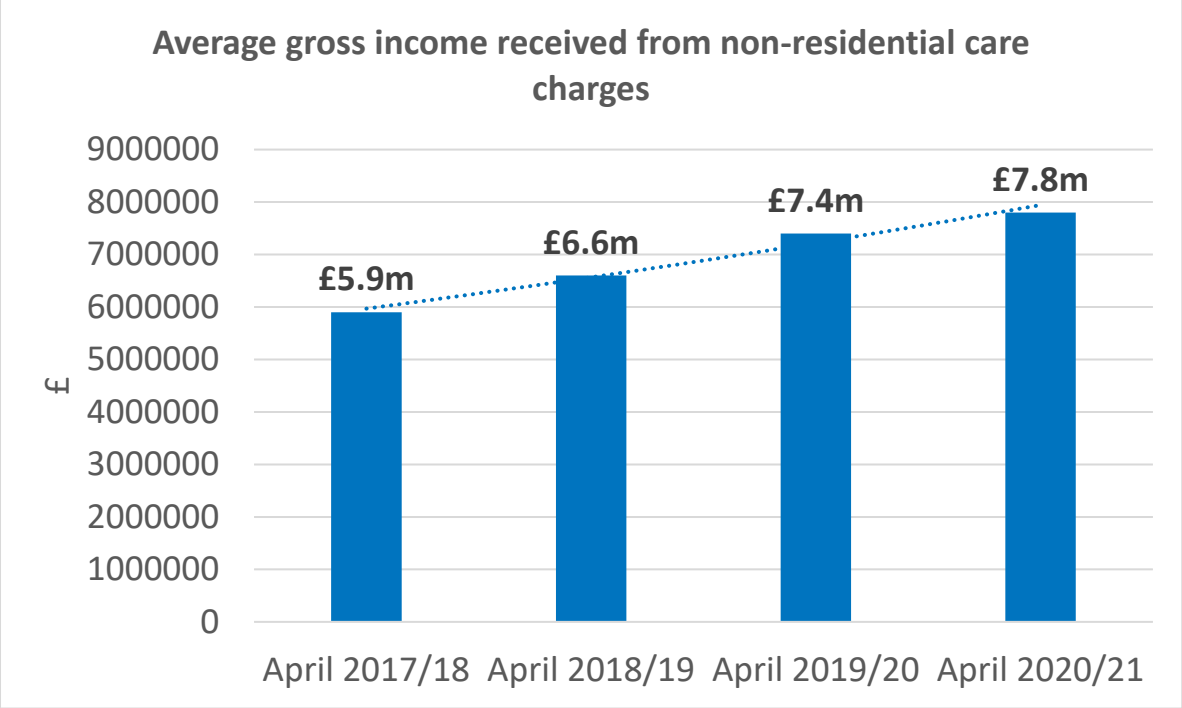

Figure 3: Average gross income received from collecting non-residential care charges (on basis of local authorities who provided answers to question 4)

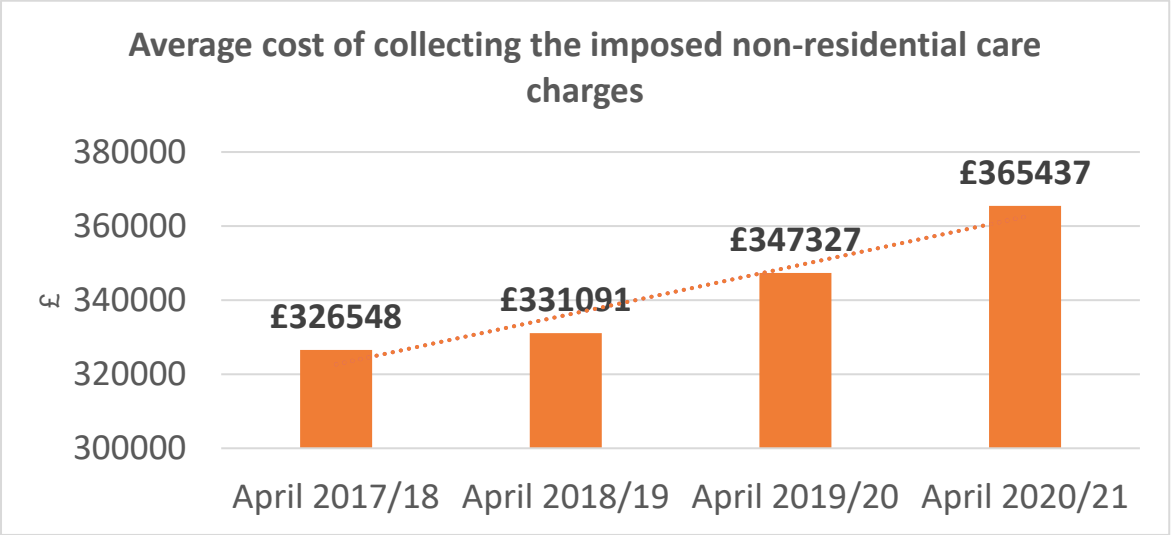

Figure 4: Average cost of collecting the non-residential care charges imposed by a local authority (on basis of local authorities who provided answers to question 5)

From the available data, local authorities received, on average, £6.9 million annually from non-residential care charging across 2017-2022. This figure grew from £5.9 million in 2017/2018 to £7.8 million in 2020/2021. Local authorities incurred costs of £342,600 per year on average to collect these charges.

Only 30% (12/40) of local authorities responded with appropriate sets of data for both questions 4 and 5. For these local authorities, the data supported the conclusion that the administrative cost of collection undermines the value of charging. While on average a local authority spent 7% of its gross income on collection, in some instances the collection costs were very high as a percentage of overall charges realised, making collection not worth the exercise: for example, a London local authority spent between 30%-35% of the gross income it realised on collecting the charges imposed between 2017 and 2020 (i.e. £1 for every £3 collected).

These results reinforce the conclusion in the ILSG study: the value of charging is very low when weighed against actual and figurative costs. On an individual level, charging for non-residential care can cause hardship and potentially push Disabled adults into poverty. Charging generates a fraction of a local authority's actual spend on care but brings additional administrative costs, which are hefty in proportion to the income generated. Consequently, charging may be a poor economic choice.

Furthermore, 26/40 local authorities provided data to deduce the per capita charges imposed for non-residential care between 2017 and 2021. Over this period, the per capita charges imposed increased for 46.15% (12/26) of local authorities, were variable over time

for 53.85% (14/26), but concerningly, did not decrease for any local authority. The present cost-of-living crisis compounds the detrimental effect of increasing charges. The exercise of discretion in not charging Disabled adults who cannot afford these charges is thus all the more necessary.

2.4 Question 6: Adults declining non-residential care due to charges imposed by the local authority

As noted above, each local authority was sent a FOI request asking for this information to be provided.

Analysis

Just over 67% of local authorities (27 out of 40) were unable to provide data in response to this question, as the information was either not held or was missing. A further 11 local authorities declined to provide this information under the s.12 FOI 2000 exemption. Together, this equates to 95% of the sample population who were unable to provide any information in response to this question. This is highly problematic as the collection of accurate, relevant data is key to ensuring that local authorities are complying with the PSED. It appears the vast majority of local authorities are not fully considering the impact that non-residential care charges are having on Disabled people.

Out of 40 local authorities, only 2 local authorities, both located outside of London, provided full data relating to this question. The figures are shown on the graph below.

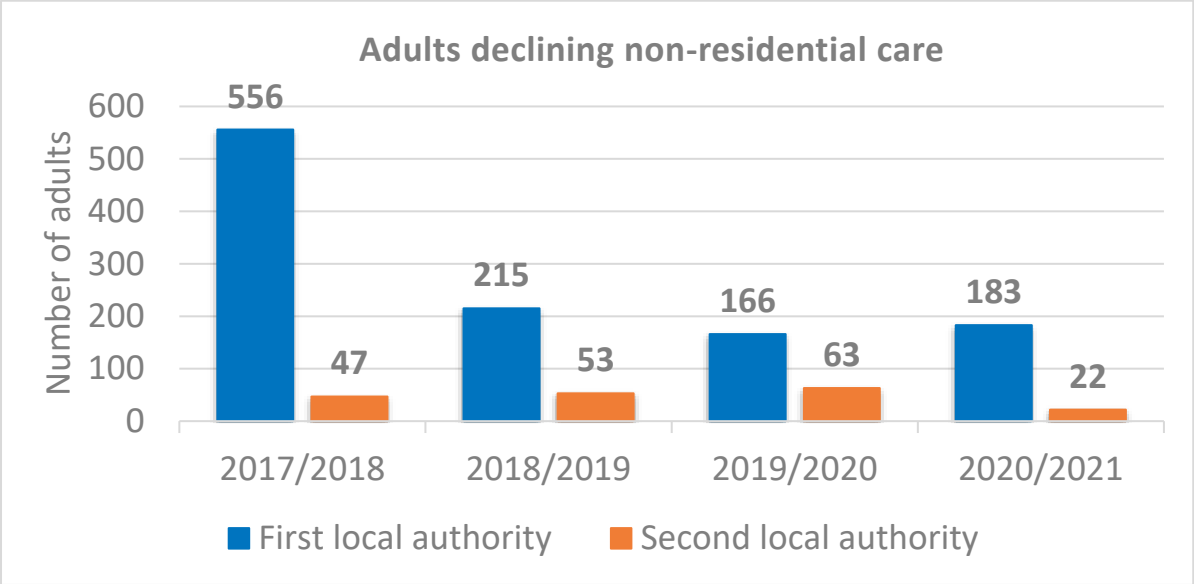

Figure 5: Adults declining non-residential care

When an offer of support was declined, the local authorities did not record or monitor the nature of the service declined or the specific reason(s). However, from anecdotal evidence, it appears likely that a high percentage of these refusals would have been due to the level of charge imposed.

The data above indicates that the number of Disabled adults refusing non-residential care due to the level of charge imposed by the local authority has dropped over the years. However, these findings are limited, due to the small sample size on which they are based (2 local authorities only equates to 5% of the sample). This data should not be used as a reliable measure of how the imposition of the charge has influenced Disabled adults in refusing non-residential care.

DLS also notes that social care charges can have a detrimental impact, even if an individual has accepted care and support. Disabled adults can be substantially affected by care charges without taking the decision to decline care and support. Disabled adults are often left without any other option as they rely on this support for their independent living.

We recommend that local authorities start gathering this data as a priority. This will allow the impact of non-residential care charges being levied on Disabled adults to be properly assessed and show how many are refusing non-residential care as they are unable to afford it. In addition, it will help determine whether local authorities are in compliance with the PSED.

2.5 Question 7: Adults the local authority has exercised its discretion not to charge

Methodology

Each response was considered, and the relevant statistic was recorded by year. In 1 case, where a local authority indicated it considered itself exempt from providing the requested information under s.12 FOI 2000, DLS followed up to narrow the request to a more recent time period (post April 2019). The relevant local authority maintained that it was exempt from providing any information under s.12 FOI 2000, even in respect of the narrowed request for information.

Analysis

62.5% (25/40) of local authorities did not provide any data in respect of this question, either because they indicated they did not record this information, hold the information in a reportable format, or that they were exempt from providing it under s.12 FOI 2000. We were not able to use data provided by 1 local authority as it was not provided in a format that could be analysed. Over half of the local authorities contacted were therefore not able to provide a meaningful record of where such discretion has been exercised. This indicates that data collection is an area for improvement.

Local authorities do not have to charge Disabled adults for care and support. It is a choice. It is therefore important that local authorities monitor this data, to assess where discretion has been applied in the exercise of their power to charge for non-residential care under s.14 of the Care Act 2014.

Of the local authorities who did provide analysable data (14/40 – 35%), 5 recorded no adults for whom discretion was exercised not to charge. This strongly indicates that these 5 local authorities were not exercising any discretion to waive charges for those who may not have been able to afford them. These local authorities do not appear to have had regard to the PSED in making charging decisions, as some level of discretion could be expected to have due regard to eliminate discrimination faced by Disabled individuals.

1 of these 5 local authorities explicitly noted that it always enforces fees when the outcome of a financial assessment is that a Disabled adult is “liable to contribute”, unless waived following a complaints procedure, with no instances of discretion at the outset not to apply “legitimate charges”. This indicates that many local authorities are seeing their ability to

charge under s.14 of the Care Act as a duty or a right, rather than a power or ability, to charge. These 5 local authorities do not appear to be fully considering the impact of charging each Disabled adult prior to implementing charging decisions. In the case above, it is clear this is only considered when this local authority is forced to review its decision through complaints, showing a lack of awareness of the need to eliminate discrimination. Discretion in waiving charges would assist with this.

Of those local authorities who provided data, all but 1 local authority whose figures were not nil (14/40) had exercised discretion each year for between 0-60 people; most had exercised discretion for less than 20 individuals per year. Whilst the number of adults requiring non-residential care varies between local authorities, on average, the percentage of instances where discretion was exercised not to charge was around 0.1-1.5% of all cases where charges were calculated as being due (where 100% equals the number of individuals reported as being charged in a given year plus the number not charged due to exercise of discretion). This exercise of discretion indicates these local authorities are considering the impact of charging decisions before the charges are applied, though in a limited number of cases.

1 local authority had exercised discretion in respect of approximately 3.5% of adults who would otherwise have been charged for their care in 2017/2018. This dropped to approximately 2.5% of overall adults in 2018/2019, approximately 1.5% in 2019/2020, and approximately 1% in 2020/2021. This local authority is considering the impact of charging, but exercise of discretion decreased between 2017 and 2021. As a trend, this indicates that the local authority may have felt less able to exercise its discretion over time.

3 Conclusion

Very few local authorities demonstrated compliance with the PSED in charging Disabled adults for non-residential care. The failure to discharge the PSED stemmed from 1 or more of the following:

i. Failure to produce an updated WCR that addresses all aims of the PSED;

ii. Lack of consultation with relevant stakeholders (Disabled people's organisations, service users);

iii. Absence of a mechanism to regularly review the charging policy;

iv. Failure to assess the costs and benefits of the charging policy in force;

v. Limited exercise of discretion in waiving some or all charges.

The data requested for responses to questions 2 – 7 was often refused or provided in an incomplete fashion. The limited numbers provided indicate some clear and concerning trends: the proportion of adults charged for non-residential care is increasing over time; the costs incurred by local authorities in collecting non-residential care charges are significant and increasing and there is minimal exercise of discretion in waiving charges. That nearly all local authorities do not record the number of adults forced to decline non-residential care because they cannot afford it, is equally concerning and directly indicative of local authorities' failure to assess the impact of non-residential care charges on Disabled people.

Appendix 1: Template letter to local authorities

Formal Freedom of Information Request

Dear [name of local authority]

We request that you provide the following information in compliance with your duties under the Freedom of Information Act 2000.

The purpose of the request
We are currently working on a research project into the current charging system for non-residential care in England. We will use the information provided to help us to assess the impact that care charges are having on Disabled people in England.

Statutory cost compliance limit note
If your authority considers that complying with this request in its entirety will exceed the statutory cost of compliance limit (specified in The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004) then we ask that you respond to the following questions in the order they appear until that limit is reached. The questions that comprise this freedom of information request are as follows:

Requested Information
We request that you provide us with details of the following information:

- *A copy of your most recent compliance with the public sector equality duty, regarding the impact of charging adults in need for the non-residential care and support they receive under the Care Act 2014, in accordance with s.149 Equality Act 2010.*

- *The number of adults in need provided with non-residential care and support under the Care Act 2014 by your authority in each financial year or calendar year, if this is the period used for data recording purposes since April 2017.*

- *The number of adults in need your authority has charged for their non-residential care and support in each financial year or calendar year, if this is the period used for data recording purposes since April 2017.*

- *The gross income your authority has received from non-residential care charges under the Care Act 2014 for each financial year or calendar year, if this is the period used for data recording purposes since April 2017.*

- *The administrative and other costs incurred by your authority in collecting non-residential care and support charges under the Care Act 2014 for each financial year or calendar year, if this is the period used for data recording purposes since April 2017.*

- *The number of adults in need who have declined receiving services for non-residential care and support due to the level of charge imposed by your authority in each financial year or calendar year, if this is the period used for data recording purposes since April 2017.*

- *The number of adults in need your authority has exercised its discretion not to charge for non-residential care and support in each financial year or calendar year, if this is the period used for data recording purposes since April 2017.*

We understand that under the Act we are entitled to a response within 20 working days of your receipt of this request.

If this request is denied in whole or in part, we ask that you justify all refusals by reference to specific exemptions of the Act. We will also expect you to release all non-exempt material. We reserve the right to appeal your decision to withhold any information or to charge excessive fees.

If you require any clarification, please contact [●] by email on [●] in accordance with your duty under s.16 to provide advice and assistance if you find any aspect of this Freedom of Information request problematic.

Please acknowledge receipt of this request by the above email. We look forward to receiving the information in the near future.

Yours faithfully,

[●]

Disability Law Service

Appendix 2: DLS social care charging – Template for analysing compliance with PSED

Local authority (LA) name:	[●]
Volunteer name:	[●]
Date of analysis:	[●]
About the LA policy and WCR:	The policy in force is [*Name and hyperlink*], implemented on [*date*]. The WCR is dated [●]. [*Internal note: please include any additional documents that supplement the policy and WCR.*]
Summary	[●]
Compliance with s.149 of the Equality Act 2010 (PSED)	
Analysis – eliminating discrimination, harassment and victimisation	[*Internal note: Does the Local Authority ("LA")'s WCR and policy show an awareness of the need to eliminate discrimination, harassment and victimisation?* • *Discriminatory policies likely include those which (a) reduce the minimum income guarantee ("MIG") to the statutory minimum; (b) choose not to disregard certain disability benefits; (c) have poorly functioning disability-related expenditure schemes; and (d) do not consider alternative approaches, are likely to discriminate against severely Disabled people.* • *Examples of reducing the discriminatory impact of policies include: (a) exercising discretion to increase MIG for affected individuals, in a rational way which is related to their income; (b) disregarding elements for the MIG (such as the daily living component of PIP, and SDP); (c) requiring a percentage of an individual's Disability benefits to be protected; (d) applying a maximum percentage of disposable income; (e) consulting those affected and introducing*

	mitigation measures to achieve a fairer overall scheme]
Analysis – ensuring equality of opportunity	[*Internal note: Does the LA's WCR show awareness of the need to ensure equality of opportunity between Disabled and non-Disabled individuals? Have they taken steps to:* ○ *Reduce the disadvantages suffered?* ○ *Meet the needs of Disabled individuals?* ○ *Foster opportunities for Disabled persons to participate in public life/activities in which Disabled people have a disproportionately low participation rate?*]
Analysis – advancing good relations	[*Internal note: Does the LA's WCR show an awareness of the need to advance good relations between Disabled and non-Disabled people? Have the authorities considered addressing prejudices and/or creating awareness and understanding?*]
Other	[*Internal note: Please consider the following prompts and comment where relevant* • *<u>Written record</u>: Is there a written record? This is not a legal requirement, but it will be difficult to show compliance with the PSED without one.* • *<u>Case law:</u> Has the LA considered relevant case law, such as SH v Norfolk County Council [2020] EWHC 3436 (Admin)?* • *Has the LA considered the application of the Norfolk case to Disabled people living in their local authority, in particular those who receive the enhanced rate of the daily living component of PIP and are in the support group of ESA?* • *<u>Dates:</u> When was the LA's non-residential care policy/PSED compliance issued? The PSED requirement is ongoing. Ideally, a policy would*

	be considered and updated after the Norfolk case in December 2020. PSED compliance should be dated <u>before</u> the latest non-residential care charging policy, because the LA should have considered how Disabled people would be impacted by the new policy before it was implemented. • *<u>Continuous duty:</u> Do the authorities have a systematic method of review?* • *<u>Box-ticking:</u> Has the LA ensured that its approach to fulfilling s.149 is not simply one of "box-ticking"?*] • *<u>Other principles:</u> consider if you can comment on any of the case law principles below:* o *PSED involves a conscious approach and state of mind* o *PSED must be exercised in substance, with rigour and an open mind* o *PSED considerations should be at the centre of policy formulation* o *LAs cannot justify a decision after it has been taken* o *There must be sufficient evidence on which to base consideration of the impact of a policy or decision* o *PSED applies to exercise of all public functions*

Disability Law Service
Fighting injustice for disabled people

Analysis of follow-up freedom of information requests

Background

Following our freedom of information requests (FOI) in 2021, we sent a follow-up FOI request to all 40 local authorities to reassess their public sector equality duty (PSED) compliance. When we first contacted them, we deemed that 92.5% of the local authorities were not complying with the PSED in relation to non-residential care charges. More recently, when we contacted the local authorities in March 2024, we had planned to publish the report by the end of May. However, following the announcement of the general election, we decided to delay the date of our publication.

At the time of our second FOI request in March 2024, there were now 153 local authorities in England which manage adult social care. [1] We realised there had been some changes to the geographical representation of some local authorities since we sent our initial FOI request in 2021. 1 local authority has expanded, changing its name and 1 has split into 2 local authorities. For the continuity of our analysis, we contacted just 1 of the split local authorities, therefore maintaining our sample group at 40.

Research methodology

In our most recent FOI request, we asked local authorities whether they had updated their compliance with the PSED regarding the impact of charging adults in need for the non-residential care and support they receive under the Care Act 2014, in accordance with s.149 Equality Act 2010, since our initial enquiry. If they had, we requested their latest compliance information. The template letter is provided in Appendix 1.

As well as making the FOI requests, we also contacted the adult social care teams at each local authority to ask whether there had been any significant changes to their policies since we first enquired in September 2021. The template email is set out in Appendix 2.

Analysis

1 of the 40 local authorities did not provide us with any substantive response to our FOI request. 6 local authorities informed us that their non-residential care charging policies were currently under review. 24 of the local authorities either provided us with the same PSED compliance or confirmed that there had be no significant change to their non-residential care

[1] 'Introducing Assessments of Local Authorities'<https://www.cqc.org.uk/guidance-regulation/local-authorities/introducing-assessments#:~:text=We%20aim%20for%20our%20initial,complete%20initial%20assessments> accessed 24 May 2024.

charging policy. Only 9 of the local authorities provided us with a new written PSED compliance. Case law has determined that it is very difficult to show PSED compliance without written evidence. [2] Of the 9 local authorities that provided us with a new compliance, we assessed that only 3 were complying with all aims of the PSED. We found that that the other 6 written compliances were more box-ticking exercises rather than carefully considering the issues with substance and rigour. 2 of the local authorities that we had deemed compliant previously, may no longer be compliant as they were 2 of the local authorities who failed to provide us with new compliance information. Therefore, we found once again that 92.5% of the local authorities were not complying with the PSED. The PSED is an ongoing responsibility on local authorities. Whilst local authorities may put forward that a yearly compliance is not required unless substantial changes are made to their policies, we would strongly dispute this. Local authorities make decisions each year in relation to the non-residential care charging policies that have a significant impact on the lives of their Disabled residents, such as deciding the level of the minimum income guarantee each year. Therefore, we urge local authorities to carefully consider the impact of all yearly changes on their Disabled residents before these are implemented. This should be done by carefully considering the relevant issues affecting Disabled residents and completing an equality impact assessment in a substantive manner. This will ensure ongoing compliance with the PSED in relation to non-residential care charging policies.

Most of the adult social care teams we contacted from each local authority did not respond. Among those that did, some reported changes such as adjustments to fees, the maximum weekly charge and the standard weekly disability-related expenditure amount. 1 local authority informed us that it had used its discretion to disregard a proportion of disability benefits for certain Disabled residents.

Conclusion

It is deeply concerning and disappointing that we found no significant change in the PSED compliance of local authorities in relation to the impact of their non-residential care charging policies on Disabled residents. We assessed that 92.5% of the local authorities we contacted are still non-compliant. We strongly urge local authorities to stop acting unlawfully and comply with the PSED on an ongoing basis by completing equality impact assessments each year in a substantive manner.

[2] 'The Essential Guide to the Public Sector Equality Duty: England (and Non-Devolved Public Authorities in Scotland and Wales)' (2022) <https://www.equalityhumanrights.com/en/publication-download/essential-guide-public-sector-equality-duty> accessed 16 December 2022.

Appendix 1: Template letter for follow-up on FOI requests

Dear [name of local authority]

We request that you provide the following information in compliance with your duties under the Freedom of Information Act 2000.

The purpose of the request

Disability Law Service is currently finalising a research project into the current charging system for non-residential care in England which will be published in May 2024. As part of this research, we previously submitted a FOI request to you on XXX. Before we publish, we would like to ensure that we are accurately reflecting your current policy. All information provided will help us to assess the impact that care charges are having on Disabled people in England.

Requested information

We previously requested that you provide us with your most recent compliance with the public sector equality duty, regarding the impact of charging adults in need for the non-residential care and support they receive under the Care Act 2014, in accordance with s.149 Equality Act 2010.

Please see your response enclosed/attached.

Please can you confirm if you now have a more recent compliance with the public sector equality duty, regarding the impact of charging adults in need for the non-residential care and support they receive under the Care Act 2014, in accordance with s.149 Equality Act 2010.

If so, please outline what changes have occurred since XXX, and provide us with your more recent compliance.

We understand that under the Act we are entitled to a response within 20 working days of your receipt of this request.

As previously mentioned, we are planning to publish our report in May 2024, and confirm that once the 20 working days have passed, we will be proceeding to publish whether you

have provided a response or not.

If you require any clarification, please contact *[●]* by email on [●] in accordance with your duty under s.16 to provide advice and assistance if you find any aspect of this Freedom of Information request problematic.

Please acknowledge receipt of this request by the above email. We look forward to receiving the information in the near future.

Yours faithfully,

[●]

Disability Law Service

Appendix 2: Template letter for Departments of Adult Social Care

Dear Colleagues,

Please pass this email onto your local authority's adult social care team.

We are writing to you regarding your non-residential care charging policies and whether you are assessing the policies' impact on Disabled adults. Disability Law Service is currently finalising a research project into the current charging system for non-residential care in England which will be published in May 2024. As part of this research, we previously submitted a FOI request to your local authority in September 2021.

We have written up these findings, but before we publish, we wanted to give you the opportunity to inform us about any significant changes to your non-residential care and support charging policy in accordance with the Care Act 2014.

If there have been any significant changes, please provide us with a response within 20 working days by the 2nd May 2024. If we have not heard back from you by this date, we will proceed to publish our research paper without your update.

If you require any clarification, please contact [●] by email on [●].

We thank you for supporting us with this important research project to make sure local policies are being designed to prioritise the needs of Disabled adults in line with a human rights-based approach.

We would appreciate if you can acknowledge receipt of this email. We look forward to receiving the information soon.

Yours faithfully,

[●]

Disability Law Service

Disability Law Service

Fighting injustice for disabled people

Ending the charging system for non-residential care for Disabled adults in England

Report on questionnaire of Disabled adults who are charged for their home care in England

Disability Law Service

24th July 2024

Table of contents

1. Introduction

1.1 The purpose of this report is to review and analyse the results of Disability Law Service's (DLS) 2022 questionnaire of a self-selected sample of Disabled adults who are charged for their home care in England ("The Questionnaire"). In doing so, the report will examine the impact non-residential care charges have had on these Disabled residents within England.

1.2 The Questionnaire ran from the 28th February until the 28th March 2022. The Questionnaire was designed to provide an opportunity for respondents to provide their feedback - online and anonymously - where they could provide their opinions on the home care charging system and its impact (if any) within England. The Questionnaire was also designed to be as objective as possible, with focus on the day-to-day impact of the home care charging system.

1.3 We hope that the results of The Questionnaire contribute to other factual evidence gathered to support the abolition of non-residential care charges for Disabled adults in England.

2. Questionnaire respondents

2.1 The Questionnaire was completed by 96 respondents. The Questionnaire was promoted on the DLS website and social media platforms. The Questionnaire was also promoted by other organisations. The Questionnaire was hosted on the DLS website via an Alchemer® link. Participation was anonymous, although participants were given the option of providing their personal details. We also gave respondents the option if they required reasonable adjustments to access The Questionnaire to contact us.

2.2 Respondents could also answer The Questionnaire in an alternative format, via an easy-read version. This helps to widen accessibility. Respondents were then able to send the easy-read version to us by email.

3. Questionnaire methodology

3.1 The Questionnaire was targeted at a self-selected sample of Disabled adults in England who are charged for their home care.

3.2 The Questionnaire consisted of 19 questions where respondents could, if they chose to, indicate whether they would be happy to be contacted further to expand on their experiences in the real-life stories. We asked introductory questions about their home care experiences and their general background. Subsequent questions related to Disabled residents' opinions on relevant statements. Respondents' possible answers to these questions ranged from 'strongly agree' to 'strongly disagree', alongside the options of 'not applicable', 'neutral' and 'do not know'. Several of these questions ('statement

questions') gave respondents the ability to leave comments accompanying their chosen response. Some respondents chose not to answer certain questions.

4. Analysis

4.1 The majority of respondents thought the level of home care received from their local council was insufficient. This is reflected in the comments made by the respondents. For example, 1 commented that they received "basic care but that is it"; another said that they do not receive any help as they "cannot afford it"; and finally, 1 respondent said that their family were having to provide the "bulk" of their care each week, so despite being an adult, they were having to "depend heavily" on their parents on a regular basis. Indeed, another remarked that their "friends and clients are charged to within an inch of their lives for their care and support", and that care charges should be "scrapped". A broad analysis of the respondents' comments reveals that the home care charging system in its current form is not meeting the needs of this group of Disabled residents in England. The care received is both poor and unaffordable.

4.2 72.9% of respondents believed that they were not charged only for what they could afford for home care by their local council. Significantly, of those 72.9%, almost two thirds – 65.7% - strongly disagreed. This demonstrates the strength of opposition to the non-residential care charging system, and the extent to which Disabled residents cannot afford home care as currently provided. This impression is further strengthened when one considers that over 25% of respondents incurred debt because of home care charges by their local council. Disabled residents should not be acquiring debt to receive support to live an independent life. This is unsurprising given that when it came to how much respondents were charged per week, the option which received the most answers – 27.1% - was the highest amount, £100 or more. That such a large proportion of respondents are paying £100 or more is a serious concern.

4.3 The comments of the respondents reveal that of those who did not incur debt, it was mostly because their family covered the shortfall, with their parents supporting them financially whilst they live at home. Moreover, any financial resources which they have left over are reportedly minimal, with debt imminent. 1 respondent said that they were "increasingly using…savings to pay non-residential care charges", meaning that it would not "be long before" they "incur debt". The comments of the respondents are testament to the pressures the home care charging system imposes upon Disabled residents. 1 respondent stated that cost of care rose 194%, which they were only told about 2 weeks after the fact, whilst another has "sacrificed having any care at all" from the council because they do not wish to be indebted to them. Damningly, 1 commented that their debt is "entirely caused by council imposed contribution charges", which function to "the detriment of Disabled persons' financial and personal well-being".

4.4 Interestingly, only 22.9% of respondents have opted to stop receiving home care at some point because of the pressure that home care charges imposed on their financial situations. However, it would be misleading to read too much into this. Just because the majority still receive home care, irrespective of the financial stress it places upon them, does not absolve the care charging system of its faults. Disabled residents can be adversely affected by the system in place without necessarily stopping receiving the care it provides, because often there is no other option. 1 commented that they may have chosen to stop receiving care had they "not got legal help". Another said that they would have "if it was possible", but they could not "get to the toilet" by themselves, and so "never had the choice", likening it to "being held ransom". Essentially, despite the mounting debt, as 1 respondent said, they would "not be able to manage without the home care", irrespective of the cost. They cannot "survive without the care provided", leaving them "no choice to but to pay whatever they say…leaving little for having a meaningful life or even just covering basics".

4.5 Moreover, nearly half of respondents answered that they were sometimes unable to afford their basic needs, such as food and heating, because of home care charges. This exhibits the negative impact that non-residential care charges have on the finances of Disabled residents, to the degree that they can struggle to afford basic necessities which many take for granted.

4.6 The resounding majority of respondents – 73.9% - agreed that increases in home care charges have had a negative impact on their lives – mentally, physically, and emotionally. For example, 1 respondent said that they "felt suicidal…like" they were "going mad with stress". Another said that they had been "left with less money to enjoy independence such as leisure activities", with 1 respondent separately saying they had experienced "stress and sleepless nights". Even the most fundamental parts of Disabled residents' lives were impacted. 1 resident noted that they could not "afford to save up for a new wheelchair", which has knock-on effects on their capability to live an independent life. The physical effects were similarly negative, because of their constrained budgets. A respondent said they ate "cheaper food", which made them "weaker", compounded by their lack of heating as they could not "afford to have it on as much" as they needed.

4.7 When asked whether their home care charges have increased during the COVID-19 pandemic, 49% either agreed or strongly agreed. Only 17.8% disagreed or strongly disagreed. All in all, this shows non-residential care charges are becoming increasingly unaffordable, with the above effects. Respondents noted that they had been "priced out"; "everything is the same but care costs more". This lack of affordability is particularly unjust given that over a third – 36.4% - of respondents answered that they had received less home care from their local council since the start of the COVID-19 pandemic. Of those 36.4%, 57.1% strongly agreed that the amount of home care they had received was depleted relative to before. A specific injustice - according to 1 respondent – was that they didn't "receive any care during the lockdown", but were "still charged". Likewise, for 1

respondent, their care needs rose yet they received “far less care during the pandemic due to staffing shortages”. This is characteristic of most respondents’ experiences. Another commented that their care “has not been as consistent since COVID”.

4.8 64.5% of respondents indicated that not all of their disability-related expenses were considered when they were charged for home care by their local council. In fact, only 9.4% thought their expenses had been adequately taken into account by their respective local authority. This is borne out by the comments made by respondents. For example, 1 council “refused to take into account” “disability related expenditures”. The local authorities were accused of “fobbing” residents “off” and laughing at Disabled residents despite 1 respondent’s illnesses “drastically worsening”. Local authorities took an inconsistent approach, picking and choosing, and frequently respondents said that councils do not accept their disability-related expenditure (DREs).

4.9 Most respondents – 56.1% - said the majority of their benefits went towards paying for their home care from their local council. This is an indictment of the failed system of non-residential care charging which operates in England, when Disabled residents are having to use their vital welfare benefits to pay for the care they should be receiving unconditionally and free at the point of use. The comments of the respondents reinforce this impression. 1 respondent said that they felt that their local authority was “stealing” from them, likening the situation to a “school bully going right into the scrawny kid’s lunch box”. Another noted that the council “shouldn’t be allowed to decide what they charged [given]…it’s effectively a tax on our benefits”. To echo a recurrent theme, 1 respondent answered that there was “no way” that they could pay “without help from parents”. The home care charging system appears to necessitate Disabled residents having to rely on family support.

5. Questionnaire data

Below are a selection of the 19 questions asked.

Initially the respondents were asked some introductory questions:

5.1 Do you self-identify as a Disabled person?

1. **Yes**: 94% of the respondents
2. **No**: 6% of the respondents

5.2 Do you receive home care from your local council?

1. **Yes**: 81.3% of the respondents
2. **No**: 16.7% of the respondents

5.3 For how many years have you been receiving home care?

1. **0-1**: 11.5% of the respondents
2. **1-3**: 13.5% of the respondents
3. **3-6**: 9.4% of the respondents
4. **6-10**: 14.6% of the respondents
5. **10+**: 47.9% of the respondents

5.4 How many hours of home care do you receive per week?

1. **0-7:** 18.8% of the respondents
2. **8-14:** 8.3% of the respondents
3. **15-24:** 20.8% of the respondents
4. **24+:** 39.6% of the respondents

5.5 How much are you charged for your home care by your local council per week?

1. **0-£25:** 20.8% of the respondents
2. **£26-£50:** 20.8% of the respondents
3. **£51-£75:** 9.4% of the respondents
4. **£76-£100:** 18.8% of the respondents
5. **£100+:** 27.1% of respondents

Statement questions:

Respondents were then asked questions where a statement was posed on which they could make a comment. Below are a selection of those questions:

5.6 I receive sufficient home care from my local council.

1. **Strongly disagree**: 22.9% of the respondents
2. **Disagree**: 29.1% of the respondents
3. **Neutral**: 11.5% of the respondents
4. **Agree**: 19.8% of the respondents
5. **Strongly agree**: 8.3% of the respondents

6. **Don't know**: 2.1% of respondents
7. **Not applicable**: 6.3% of respondents

5.7 I am only charged what I can afford for home care by my local council.

1. **Strongly disagree**: 47.9% of the respondents
2. **Disagree**: 25% of the respondents
3. **Neutral**: 7.3% of the respondents
4. **Agree**: 2.1% of the respondents
5. **Strongly agree**: 2.1% of the respondents
6. **Don't know**: 5.2% of respondents
7. **Not applicable**: 9.4% of respondents

5.8 I have incurred debt as a result of home care charges by my local council.

1. **Strongly disagree**: 4.1% of the respondents
2. **Disagree**: 14.6% of the respondents
3. **Neutral**: 32.3% of the respondents
4. **Agree**: 9.4% of the respondents
5. **Strongly agree**: 17.7% of the respondents
6. **Don't know**: 2.1% of respondents
7. **Not applicable**: 17.7% of respondents

5.9 I have opted to stop receiving home care at some point as a result of the pressure that home care charges have placed on my financial situation.

1. **Strongly disagree**: 8.3% of the respondents
2. **Disagree**: 30.2% of the respondents
3. **Neutral**: 8.3% of the respondents
4. **Agree**: 14.6% of the respondents
5. **Strongly agree**: 8.3% of the respondents
6. **Don't know**: 4.2% of respondents

7. **Not applicable**: 24% of respondents

5.10 I am sometimes unable to afford my basic needs (e.g., food, heating, etc.) as a result of home care charges.

1. **Strongly disagree**: 2.1% of the respondents
2. **Disagree**: 14.6% of the respondents
3. **Neutral**: 20.8% of the respondents
4. **Agree**: 26% of the respondents
5. **Strongly agree**: 20.8% of the respondents
6. **Don't know**: 0% of respondents
7. **Not applicable**: 13.5% of respondents

5.11 The increases in home care charges have had a negative impact on my life (e.g., mental, physical and emotional well-being).

1. **Strongly disagree**: 1% of the respondents
2. **Disagree**: 7.3% of the respondents
3. **Neutral**: 2.1% of the respondents
4. **Agree**: 29.1% of the respondents
5. **Strongly agree**: 44.8% of the respondents
6. **Don't know**: 1% of respondents
7. **Not applicable**: 11% of respondents

5.12 My home care charges have increased during the COVID-19 pandemic.

1. **Strongly disagree**: 6.3% of the respondents
2. **Disagree**: 11.5% of the respondents
3. **Neutral**: 11.5% of the respondents
4. **Agree**: 27.1% of the respondents
5. **Strongly agree**: 21.9% of the respondents
6. **Don't know**: 6.3% of respondents

7. **Not applicable**: 13.5% of respondents

5.13 I received less home care from my local council since the start of the COVID-19 pandemic.

1. **Strongly disagree**: 8.3% of the respondents
2. **Disagree**: 17.7% of the respondents
3. **Neutral**: 14.6% of the respondents
4. **Agree**: 15.6% of the respondents
5. **Strongly agree**: 20.8% of the respondents
6. **Don't know**: 2.1% of respondents
7. **Not applicable**: 15.6% of respondents

5.14 All my disability-related expenses are considered when I am charged for my home care by my local council.

1. **Strongly disagree**: 39.5% of the respondents
2. **Disagree**: 25% of the respondents
3. **Neutral**: 8.3% of the respondents
4. **Agree**: 7.3% of the respondents
5. **Strongly agree**: 2.1% of the respondents
6. **Don't know**: 6.3% of respondents
7. **Not applicable**: 7% of respondents

5.15 The majority of my benefits goes towards paying for my home care from my local council.

1. **Strongly disagree**: 2.1% of the respondents
2. **Disagree**: 7.3% of the respondents
3. **Neutral**: 16.7% of the respondents
4. **Agree**: 32.2% of the respondents
5. **Strongly agree**: 23.9% of the respondents
6. **Don't know**: 2.1% of respondents
7. **Not applicable**: 13.5% of respondents

6. Conclusion

6.1 The results from The Questionnaire demonstrate clearly that the home care charging system is hugely problematic for Disabled adults, and poses a substantial barrier to any prospect of living a fully independent life in England. Disabled adults are, by and large, charged extortionate amounts by local authorities who do not take their individual needs into consideration. Disabled adults are not necessarily charged for what they can afford, leading a large proportion to incur debt as a direct result of the non-residential charging system in place.

6.2 This assessment is borne out by both the results and the comments of the respondents. Home care charges ensure that frequently, Disabled adults cannot meet their basic needs, such as food and heating. Consequently, this has adversely affected the lives of Disabled adults, be it financially, mentally, socially, emotionally, and physically. This is particularly unjust given that Disabled people are amongst the most disadvantaged in society, with their concerns scarcely considered. Hence for many of the respondents, their home care charges increasing during the COVID-19 pandemic simultaneously whilst receiving less care was wholly unreasonable.

6.3 Abolition of this complex and callous non-residential care charging system is needed. Ultimately, whilst respondents were not directly asked if they favoured the abolition of non-residential care charges as implemented in the London Borough of Hammersmith & Fulham, a consistent theme running through the responses here is that the home care charging system is not fit for purpose. It is worth repeating that nearly 75% of respondents – with only 8.3% disagreeing – thought that increases in non-residential care charges had negatively affected their lives. Continuing to persist with such an unpopular and inequitable system is nonsensical. It does not take individual cases into account, instead applying a one -size-fits-all approach to Disabled residents; it is damagingly expensive; and finally, presents an impediment to Disabled adults living their lives to the fullest, which they deserve and should have the opportunity to do.

Disability Law Service

Fighting injustice for disabled people

Ending the charging system for non-residential care for Disabled adults in England

Report on questionnaire of Disabled adults who receive home care in the London Borough of Hammersmith and Fulham

Disability Law Service

24th July 2024

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1. Introduction

1.1 The purpose of this report is to consider the results of Disability Law Service's (DLS) 2022 questionnaire of a self-selected sample of Disabled adults who receive home care in the London Borough of Hammersmith and Fulham ("The Questionnaire"). In this respect, the report will assess the impact that the abolition of non-residential care charges in April 2015 by the London Borough of Hammersmith and Fulham (H&F) has had on Disabled residents within the area.

1.2 The Questionnaire ran from the 6th May until the 6th June 2022. The Questionnaire was designed to provide an opportunity for respondents to provide their feedback - online and anonymously - where they could provide their opinions on the home care charging system and the impact (if any) of its abolition within H&F. The Questionnaire was also designed to be as objective as possible, with focus on the day-to-day impact of the abolition of home care charges.

1.3 We believe that the results of The Questionnaire will contribute to evidence already gathered and support our campaign to abolish non-residential care charges for Disabled adults in England.

2. Questionnaire respondents

2.1 The Questionnaire was completed by 17 respondents. The Questionnaire was promoted on the DLS website and by H&F. The Questionnaire was also promoted by Action on Disability, a Disabled people's organisation in H&F. The Questionnaire was hosted on the DLS website via an Alchemer® link. Participation was anonymous, although participants were given the option of providing their personal details. We also gave respondents the option if they required reasonable adjustments to access The Questionnaire to contact us.

2.2 Respondents were also given the opportunity to complete The Questionnaire in an easy-read version, to make The Questionnaire as accessible as possible. Respondents were then able to send the easy-read version to us by email.

3. Questionnaire methodology

3.1 The Questionnaire was targeted at a self-selected sample of Disabled adults in H&F who receive home care.

3.2 The Questionnaire consisted of 15 questions where respondents could, if they chose to, indicate whether they would be happy to be contacted further to elaborate on their experiences in the real-life stories. We asked introductory questions about their home care experiences and their general background. Subsequent questions related to Disabled residents' opinions on relevant statements. Respondents' possible answers to these

questions ranged from ‘strongly agree’ to ‘strongly disagree’, alongside the options of ‘not applicable’, ‘neutral’ and ‘do not know’. Several of these questions (‘statement questions’) gave respondents the option to provide additional comments alongside their selected answer. Some respondents chose not to answer certain questions.

4. Analysis

4.1 The overwhelming majority of respondents thought that home care charges prior to April 2015 had a negative impact on their lives, be it mentally, physically, financially or emotionally.

4.2 Only a small minority of respondents indicated that home care charges had not had a negative impact on them in some way or another (5.9%). That almost 60% of respondents said that their experience of the non-residential care charging system had been unfavourable signals how problematic it was. This question was not applicable to 29.4% of respondents. If you remove these people from the calculation, the percentage of respondents negatively affected by home care charges before its abolition increases to 83.3%.

4.3 According to the comments they left when answering, Disabled adults experienced numerous problems with the home care charging system when it was in place.

4.4 First, the home care charging system did not adequately account for people with a wide range of impairments. Consequently, respondents commented that it was “very difficult to access” for those with mental health impairments, who on the surface had no physical impairments or problems with mobility. In other words, at times H&F tended to adopt a one-size-fits-all approach which did not account for the individual on a case-by-case basis.

4.5 Second, there were many layers of bureaucracy to wade through, costing time and money, to the extent that it constituted “an additional barrier to have the best life” that they could have, respondents remarked.

4.6 Third, the cumulative impact damaged the mental health and emotional well-being of respondents. Questionnaire respondents commented that this led to “many traumatic experiences” and worrying “every day”. Indeed, 1 respondent remarked that home care charges made them feel like a “burden” because of “personal circumstances” over which they had “no control”.

4.7 The deficiencies in the home care charging system were reflected in its lack of affordability. Only 11.8% of respondents said that they could afford all the care they required, prior to its abolition, symptomatic of the issues which non-residential care charging provides. The pressure this placed on their income really impacted their “quality of life” said 1 respondent, adding to their pre-existing issues from being house bound. For another, the only way they made up the shortfall was because they had a job.

4.8 When asked whether the abolition of home care charges since April 2015 had a positive impact on their lives, 64.7% of the respondents said that it had. Of those 64.7%, around 72.7% 'strongly agreed'. This strength of feeling exhibits the benefit abolition has provided to Disabled adults within H&F.

4.9 The effects of abolition were undoubtedly positive, as the data proves. First, it eased respondents' financial hardships, to the extent that 1 respondent was able to continue living in their own home, which may not have been the case had the care charges continued – abolition "allowed" them to continue residing there. In effect, said another, abolition removed a "financial barrier" and in doing so "promotes independent living and inclusion". Moreover, 1 respondent noted that they now had enough money to pay their personal assistants a "decent salary". Second, the abolition of home care charges has added an element of certainty into their lives. 1 respondent noted that they were now able "to save and plan for the future", which they could not previously do with the frequent changes in the home care charging rates. Following abolition, "there is no pressure on a Disabled person". Third, there were benefits to respondents' mental health. There was "less to worry about" because they had greater money to spend on other disability-related costs.

4.10 The abolition of non-residential care charges has freed up financial resources to be spent elsewhere. When asked, 52.9% of respondents stated that they had more money to afford their basic needs, such as food and heating, following abolition. In fact, only 5.9% disagreed with that assessment at all.

4.11 Such unanimity of feeling reveals the impact the home care charging system – and its subsequent abolition – has had. For example, because they are now retaining more of their income, 1 respondent said that they could "think of eating a healthy diet now". This is especially acute, because Disabled residents, in their own words, described themselves as "disproportionately impacted by poverty".

4.12 Encouragingly, abolition has not seen a decline in the quality of home care which H&F provides. The majority of respondents – 58.9% - said that they receive sufficient home care, with only 23.6% disagreeing to any degree. 1 respondent remarked that they received a "very good service", with another saying that there were at least 4 visits per day. This suggests that the non-residential care charging system is not pivotal to a quality service of care and support for Disabled residents.

4.13 The need for Disabled adults to have fewer barriers to independent living is clear, as 100% of respondents said that living independently was an 'important goal' for them.

4.14 That 58.8% of respondents strongly agreed that the abolition of home care charges across England was something they would like to see is testament to the success of the policy as implemented in H&F, and the beneficial impact it would have on Disabled adults in the rest of England if it was carried out.

5. Questionnaire data

Below are a selection of the 15 questions asked.

Initially the respondents were asked some introductory questions:

5.1 Do you self-identify as a Disabled person?

1. **Yes**: 82.4% of the respondents
2. **No**: 17.6% of the respondents

5.2 Do you receive home care from the London Borough of Hammersmith and Fulham?

1. **Yes:** 94.1% of the respondents
2. **No:** 5.9% of the respondents

5.3 For how many years have you been receiving home care in the London Borough of Hammersmith and Fulham?

1. **0-1**: 29.4% of the respondents
2. **1-3**: 17.6% of the respondents
3. **3-6**: 17.6% of the respondents
4. **6-10**: 17.6% of the respondents
5. **10+**: 17.6% of the respondents

5.4 How many hours of home care do you receive per week?

1. **0-7:** 23.5% of the respondents
2. **8-14:** 41.2% of the respondents
3. **15-24:** 11.8% of the respondents
4. **24+:** 23.5% of the respondents

Statement questions:

Respondents were then asked questions where a statement was posed on which they could make a comment. Below are a selection of those questions:

5.5 Before April 2015, home care charges (either through the London Borough of Hammersmith and Fulham or the Independent Living Fund) had a negative impact on my life (e.g., mental, physical, financial, emotional well-being).

1. **Strongly disagree**: 5.9% of the respondents
2. **Disagree**: 0% of the respondents
3. **Neutral**: 0% of the respondents
4. **Agree**: 11.8% of the respondents
5. **Strongly agree**: 47.1% of the respondents
6. **Don't know**: 5.9% of the respondents
7. **Not applicable**: 29.4% of the respondents

5.6 Before the abolition of home care charges in the London Borough of Hammersmith and Fulham in 2015, I could afford to get all the care I needed.

1. **Strongly disagree**: 23.5% of the respondents
2. **Disagree**: 23.5% of the respondents
3. **Neutral**: 5.9% of the respondents.
4. **Agree**: 5.9% of the respondents
5. **Strongly agree**: 5.9% of the respondents
6. **Don't know**: 5.9% of the respondents
7. **Not applicable**: 29.4% of the respondents

5.7 The abolition of home care charges since April 2015 had a positive impact on my life (e.g., mental, physical, financial, emotional well-being).

1. **Strongly disagree**: 0% of the respondents
2. **Disagree**: 0% of the respondents
3. **Neutral**: 5.9% of the respondents
4. **Agree**: 17.6% of the respondents
5. **Strongly agree**: 47.1% of the respondents
6. **Don't know**: 11.8% of the respondents
7. **Not applicable**: 17.6% of the respondents

5.8 Leaving aside welfare benefit cuts, I have more money to afford my basic needs (e.g., food, heating, etc.) as a result of the abolition of home care charges in April 2015.

1. **Strongly disagree**: 5.9% of the respondents
2. **Disagree**: 0% of the respondents
3. **Neutral**: 11.8% of the respondents
4. **Agree**: 29.4% of the respondents
5. **Strongly agree**: 23.5% of the respondents
6. **Don't know**: 11.8% of the respondents
7. **Not applicable**: 17.6% of the respondents

5.9 I receive sufficient home care from the London Borough of Hammersmith and Fulham.

1. **Strongly disagree**: 11.8% of the respondents
2. **Disagree**: 11.8% of the respondents
3. **Neutral**: 11.8% of the respondents
4. **Agree**: 47.1% of the respondents
5. **Strongly agree**: 11.8% of the respondents
6. **Don't know**: 5.9% of the respondents
7. **Not applicable**: 0% of the respondents

5.10 Living independently (Disabled people of all ages to have the same rights as everyone else to live in the community how they choose) is an important goal for me.

1. **Strongly disagree**: 0% of the respondents
2. **Disagree**: 0% of the respondents
3. **Neutral**: 0% of the respondents
4. **Agree**: 35.3% of the respondents
5. **Strongly agree**: 64.7% of the respondents
6. **Don't know**: 0% of the respondents
7. **Not applicable**: 0% of the respondents

5.11 I wish to see the abolition of home care charges in England more generally.

1. **Strongly disagree**: 0% of the respondents
2. **Disagree**: 0% of the respondents
3. **Neutral**: 0% of the respondents
4. **Agree**: 23.5% of the respondents
5. **Strongly agree**: 58.8% of the respondents
6. **Don't know**: 11.8% of the respondents
7. **Not applicable**: 0% of the respondents

6. Conclusion

6.1 The findings of this questionnaire demonstrate the positive impact that the abolition of non-residential care charges has had on Disabled adults within H&F. Abolition of these charges has left Disabled adults with greater financial resources to spend as they wish, has relieved the substantial negative physical and mental health effects which home care charges had imposed upon them, and by-and-large provided them with a sufficient standard of care. Over 80% of respondents when asked believed that the rest of England should implement the same policy with no one disagreeing. There is a simple explanation for that statistic: the abolition of non-residential care charges within H&F has been received overwhelmingly positively.

6.2 Before the abolition of home care charges in 2015, a sizeable proportion of questionnaire respondents could not afford all the care they required. 58.9% were of the opinion that the home care charging system had adversely impacted their lives. Consequently, abolition has allowed them to live more independently. This is particularly important given that 100% of respondents view living independently – and possessing the same rights as everyone else to live in the community as they choose – as important for them.

6.3 We believe that the positivity towards the prospect of abolition is indicative of the barrier which home charges represent to Disabled people living independently. Abolition, as implemented within H&F, is therefore the correct course of action to be taken elsewhere, and its success so far speaks to the effectiveness of such a policy. In order to address the unfairness which the non-residential care charging system represents, and the impediment it amounts to for Disabled adults, local authorities should look to emulate the example H&F has set.

Rest of England focus group report

1. Introduction

1.1 On the 27th April 2022, Disability Law Service (DLS) held a focus group with a self-selected sample of Disabled clients and service users from parts of England. 1 attendee was accompanied by a family member who supports them in their daily living. The main objective of the focus group was to consider the impact of home care charges on Disabled adults in England.

1.2 Attendees were asked about the following: 1) their experiences and thoughts on the home care charging system; 2) the financial impact of home care charges; 3) the physical, mental and emotional impact; 4) whether Disabled people are consulted sufficiently when local authorities implement changes in the charging system; 5) the changes they would like to see; and 6) their opinions on the potential abolition of home care charges.

2. Experiences and thoughts on the home care charging system at their local council

2.1 The experiences and thoughts of the attendees were universally negative.

2.2 First, local authorities do not fully consider disability-related costs when calculating home care charges. They adopt a one-size-fits-all approach which does not account for the individual on a case-by-case basis. Local authorities find it difficult to deviate from the model which they use for those who receive benefits.

2.3 An example of the difficulties faced in financial assessments is demonstrated by self-employment. 1 attendee noted that their local authority did not know how to deal with them, suggesting that there is no expectation that people receiving support are working.

2.4 Second, local authorities are not fully responsive or proactive in dealing with issues Disabled people face. For instance, 1 local authority only responded to an issue eventually because an attendee contacted a law centre.

2.5 Third, Disabled people face a struggle year-on-year because of home care charges. Attendees noted a changed culture in the last decade, where local authorities and social workers were not looking to proactively help Disabled residents as they had done before.

3. Financial impact of home care charges

3.1 The attendees were asked about the financial impact of home care charges. The non-residential care charges impose a large financial burden upon Disabled people. 1

attendee stated that their care charges were increased (incorrectly) from £16 per month to over £300 per month.

3.2 Home care charges constrain the budgets of Disabled adults, so choices are made between receiving care, and essentials such as food and heating. Financial support from family members was also relied upon by other attendees, but this is not available to everyone. Some Disabled residents have given up care altogether, which is indicative of the impact non-residential care charges have on Disabled people.

3.3 Some of the increased financial burden can arise because of errors made by local authorities. In some cases, they mistakenly charged too much for home care, and took years to notify Disabled residents and their families that the hourly rates for support packages had risen.

3.4 There is a lack of certainty over contributions, even when contributions are reduced. Attendees observed that their contributions could increase substantially at the next financial assessment; they had no confidence in the future. There is a lack of stability.

4. Physical, mental and emotional impact

4.1 Higher non-residential care charges are having a negative effect on the physical, mental and emotional well-being of Disabled people and their family members.

4.2 First, because of the financial issues arising from the increased charges, an attendee stated that they had lost 20kg, having cut down on their food consumption to save money to pay for heating.

4.3 Second, home care charges create a mental strain. Attendees said that those they supported became significantly more agitated and disruptive because of the reduced activities they could do. They also had anxiety, and pre-existing mental health impairments intensified. 1 attendee remarked that the possibility of higher fees – resulting in an inability to pay for care – would increase their sense of isolation and loneliness, leaving them with no one to talk to.

4.4 Family members themselves suffered stress, with some being unable to sleep at night because of the emotional turmoil and worrying about making ends meet. Family relationships have been damaged because of the choices higher care charges have forced families to make, with a resulting loss of trust between family members and Disabled adults.

4.5 Disabled residents on low incomes who struggle to make ends meet have become less independent, affecting their emotional well-being and social lives. 1 attendee remarked that they do not go outside anymore as they would need to pay for assistance to do so.

4.6 Third, the way in which assessments are carried out is perceived by some Disabled adults and their families as insensitive, and can damage self-esteem.

5. Taking the needs of Disabled residents into account when local councils implement their charging policies

5.1 The attendees believed that the needs of Disabled residents are not considered sufficiently when local authorities design and change their charging policies.

5.2 Attendees agreed that the needs of Disabled residents are taken for granted, and that local councils know they will acquiesce to any change they make. Attendees believed that the local authorities considered them to be a burden.

5.3 Local authorities tend to adopt a binary – rather than holistic – approach towards Disabled residents, and neglect to consider the full range of circumstances.

5.4 Attendees expressed scepticism towards the policy of co-production, which is when Disabled residents are included as part of the decision-making process. If they are not properly part of the process, then their thoughts are not fully considered. Attendees suggested that such a policy could amount to tokenism. However, they were receptive towards the idea if the local authorities would genuinely listen, and if co-production was led by an independent figure. They would be open to the idea if they were at the centre of the process of co-production, working in a fully co-operative manner with local authorities.

6. Changes in the charging policies of local councils

6.1 The change which attendees most wanted was to disability-related expenditure (DRE). The local authorities should account for the individual circumstances of Disabled adults more than they currently do. The attendees said they would welcome greater direct contact with the local authorities, seeing people in person. 1 attendee said that having the same person conducting the assessment each year would be helpful, as that person would have in-depth knowledge and familiarity with the Disabled resident.

6.2 More broadly, local authorities should look to be more proactive regarding DRE. The burden should not lie with the Disabled resident to initiate proceedings if there is a problem.

7. Thoughts on the abolition of non-residential care charges for Disabled adults in England

7.1 Upon hearing the decision of the London Borough of Hammersmith and Fulham to abolish home care charges in April 2015, the response of the attendees was universally positive.

7.2 The attendees believed that such an action, if taken by local authorities elsewhere, could stop the negative impact home care charges are having on Disabled adults' mental and emotional well-being. Abolition would give Disabled adults (and their family members) greater independence and freedom, which would enable them to spend their money and benefits as they wished, rather than on home care charges.

7.3 Attendees agreed that charging Disabled people for their non-residential care is a tax on disability.

8. Conclusion

8.1 The experiences of the attendees show that the impact of home care charges on them was overwhelmingly negative, not only financially but also mentally, physically, and emotionally.

8.2 Disabled adults struggle to make ends meet and their ability to live independent lives is severely constrained. Non-residential care charges amount to a tax on disability. This is exacerbated by the cost-of-living crisis.

8.3 The abolition of non-residential care charges is long overdue when home care charges can lead to Disabled adults having to choose between eating, heating and receiving support. Consequently, DLS is advocating for the end of the charging of Disabled adults for non-residential care in England.

Disability Law Service
Fighting injustice for disabled people

London Borough of Hammersmith and Fulham focus group report

1. Introduction

1.1 On the 9th August 2022, Disability Law Service (DLS) held a focus group with self-selected members of Action on Disability's Direct Payment Peer Support Group. Action on Disability is a Disabled people's organisation in the London Borough of Hammersmith and Fulham (H&F).

1.2 The main objective of the focus group was to consider the impact of the abolition of non-residential care charges on Disabled people. H&F is the only council in England that home care is currently free at the point of use, having abolished non-residential care charges in April 2015.

1.3 Attendees were asked about the following: 1) their experiences of care and charging prior to living in H&F; 2) the physical, mental and emotional impact of home care charges; 3) their experiences of care and the charging system in H&F; and 4) the impact of the abolition of home care charges in H&F.

2. Experiences and thoughts on the home care charging system at H&F and other local authorities before April 2015

2.1 Attendees' experiences of the home care charging system at H&F and the rest of England were negative.

2.2 An attendee who moved to H&F in 2015 said that under their previous local authority, it was difficult to obtain any hours of care at all, and any care that was secured was extortionate. Only the essential tasks were done by carers in the hours available to them.

2.3 The local authorities were reportedly incompetent at times, offering incorrect instructions and guidance.

3. Financial impact of home care charges

3.1 The attendees were asked about the financial impact of home care charges. The non-residential care charging system in H&F and other local councils imposed a large financial burden upon Disabled adults.

3.2 1 attendee noted that they had purposefully avoided using public transport to get to and from the hospital, in order to save money. The cost of having to contribute to

home care charges resulted in them diverting their income from their Personal Independence Payments (PIP). This placed financial pressure on other aspects of their life, leading them to require food parcels.

3.3 Another attendee noted that they had to choose between paying for food or electricity, because of the costs imposed by the home care charging system.

4. Physical, mental and emotional impact of home care charges

4.1 Non-residential care charges had a negative effect on the physical, mental and emotional well-being of Disabled people and their family members, prior to their abolition.

4.2 Attendees remarked that their poor living conditions – resulting from spending a large proportion of income on care and support – adversely affected their mental well-being. This led to feelings of anxiousness, and worrying about everyday concerns such as how to get to places.

4.3 Additionally, family members suffered mentally and physically. Because the care was so expensive in some cases, family members had to make up the shortfall, for example by cleaning and doing other menial tasks. This increased their own workload, and their levels of stress.

4.4 The difficulties faced extended to Disabled adults' diets. For some, because of their constrained budgets, little cooking was done, with ready meals frequently necessary.

5. Experiences and thoughts on the impact of the abolition of non-residential care charges since April 2015

5.1 The response of Disabled residents towards the abolition of home care charges has been positive.

5.2 Disabled residents' PIP money is now used for its intended purpose, as there is no longer any need to worry about home care charges. Indeed, an attendee noted that they had received a generous budget. Similarly, some attendees experienced an improvement in accommodation, as H&F provides for assisted living abodes.

5.3 The system in place is not perfect according to the attendees, with some degree of negotiation necessary with external agencies, but H&F was said to go 'above and beyond' in adult social care relative to other local authorities.

5.4 Attendees expressed positivity towards the physical, mental and social impact of not

having to pay a care contribution in H&F for non-residential care. They no longer have to devote time and energy worrying about home care charges. 1 attendee remarked that it was a "big weight off their shoulders", leading them to be more comfortable and relaxed.

5.5 Disabled residents in H&F no longer need to choose between food, heating and electricity, or care and support. They are less anxious and suffer less stress because of this. There is a greater sense of stability and permanence.

6. Conclusion

6.1 The impact of the abolition of home care charges on the attendees was beneficial, not only from a financial standpoint but also mentally, physically, and emotionally.

6.2 We acknowledge that whilst the abolition of home care charges has removed a barrier to independent living, to a certain extent, certain issues remain over home care. Simply because the care is free at the point of use does not mean that the system is perfect, as Disabled residents have reported.

6.3 However, overall, the abolition of home care charges in H&F has proven to be a large net positive for Disabled residents. It has granted Disabled adults in H&F greater independence and freedom. Abolition has enabled them to spend their money as they wish, rather than going towards home care charges. The constant concern for Disabled residents and their family members as to how they would meet the cost of home care charges has been eliminated, permanently. That is an unequivocal success.

6.4 This explains why DLS is campaigning to abolish non-residential care charges for Disabled adults in England. In a time of rising costs, now more than ever, Disabled adults should not be charged to live a full and independent life as charging is a barrier to their independent living, as demonstrated by actions taken by H&F.

Real-life stories

On the next pages, there are 9 real-life stories which demonstrate the impact non-residential care charges are having currently on Disabled adults within England, and the effect abolition of these charges has had within the London Borough of Hammersmith and Fulham (H&F). The real-life stories were shared from people who took part in our questionnaires and focus groups and other non-project participants from H&F who came forward, wishing to share their story.

The testimony from those in England shows the heavy burden home care charges represent, weighing down Disabled residents on a day-by-day basis. The system in place forces Disabled residents to compromise on key elements of their life: choosing between putting on heating or electricity, and eating a healthy diet. Indeed, 1 person details that they go without any care because of its considerable expense. These real-life stories told by Disabled adults point to the charges crushing any prospect of independence or a flourishing social life. Ultimately, these testimonies speak, unequivocally, to the misery that home care charges impose mentally, physically and emotionally on Disabled residents. The charges operate in a bureaucratic system which does not take into account the difficulties Disabled adults face. Disabled residents enduring home care charges can never be at ease, for their charges could rise dramatically overnight. There are no constants, instead just uncertainty and stress. Extortionate, unjust and demoralising to the point of despair: the themes which unite the real-life stories from within England.

This is then contrasted with the accounts of Disabled adults within the London Borough of Hammersmith and Fulham (H&F). They are unified in their opinion that abolition of home care charges has been hugely positive, and transformed their lives for the better. In the words of 1 respondent, they felt liberated, as abolition made them feel like an equal citizen. There is 1 less thing for these Disabled residents to worry about, with the mental anguish which the charges created eliminated. Abolition of home care charges has allowed Disabled residents in H&F to become more independent and live more fulfilling lives. It has freed up time for Disabled residents to do other activities instead, going out and about rather than being concerned about how to afford the charges. 1 resident spoke about the positive impact which an extra £26 per week – now made available due to abolition – has had. This amount would be taken for granted by many people, but here it is genuinely transformative. The stress the charges created – and the difficult choices it forced people to make – were eliminated. The quality of life for these residents has been transformed, and Disabled adults elsewhere in the country should be able to feel this way and benefit from the positive effects.

Disability Law Service

Fighting injustice for disabled people

Real-life stories in the rest of England

Name: Aneta

Impairments: depression, spondylodiscitis, fibromyalgia

Age: 55

Ethnicity: White Eastern European

Preferred pronouns: She/her

The local authority offered me an increase to 16 hours of care per week - including food preparation, house cleaning, helping with bills, and collecting my medication – which I rejected. This is because the council raised the amount I had to contribute in August 2022, from £140 per month to £168 per month. Even if I use less care than the allotted 16 hours, I must contribute for the whole duration. I need money to pay for increased energy bills, so if I gave up the surplus to give towards the care charges, then I will have no money left for winter. When I am in cold temperatures, the pain I feel dramatically increases.

No care - because of the increased charges - means that I rely on my sister to visit every 2 weeks, and my daughter and her friend to help to cook food for a few days. For personal care, they wash me every 3 days in the bath, whereas the carer used to do it daily. I am dirtier. I am still able to wash my face and brush my teeth, but cannot wash my body – I cannot bend forward because of my spine, so cannot reach to my legs, nor can I turn. I feel more pain because I cannot wash every day.

Sometimes I skip meals because the pain is not worth preparing the food and bringing it back to a position where I can eat it, especially on bad days when I prefer not to eat. Without a carer bringing things to me, I can fall and injure and burn myself, for example when I carry a hot tea. On an average day, I have lunch and a snack when having medication, such as rice crackers. I have lost 20kg because of my diet. Before, I had a healthy diet, but when the council asked me to contribute more, I had to change my diet, eating whatever was cheap, like eggs and baked beans.

I am homebound. Before I had a carer who supported me in going places, like the park, but now, my family work during the day, so I can only go places in the evenings. I cannot go to my appointment with the dentist, so I will have to wait until my teeth fall out.

Life is very difficult. My impairments include depression and anxiety. I must live my whole life in pain, in a cold home, with no help, alone. Before, at least I had some help, which improved my mental health. I am not suicidal currently but I recognise suicidal symptoms returning.

If care charges were abolished, life would be much easier. I could have my daily bath, my warm meal, I could go outside, because otherwise I do not get fresh air or sun in my room. The carer would give me warm tea, life would be easier as it was a few years ago, I would have mental health support and someone to talk to and rely on if something were wrong. I would be cleaner.

Name: Gabriel

Impairment: autism spectrum conditions, long-term illnesses, visual impairment

Age: 53

Ethnicity: White British-Jewish

Preferred pronouns: He/him

Since April 2024, I have paid £132.95 per week for the care I receive. I was previously double charged by my local authority for 5 years for invalid reasons, which traumatised me. Because of the care charges, I am in a constant battle all the time to try and find the money to pay. I have had to be really frugal and careful all the time. I have to ensure that I have £132.95 per week.

My mental well-being has suffered because of the care charges. I have been psychologically damaged. I feel at times that I am on the verge of going off the rails, which is connected to the stress of the charges. I am treading water all the time, trying to keep my head above water. It is very hard to juggle it all, and I wonder in the long-term how long I will be able to do it for. I feel stress every day. I have been challenging the local authority since 1999 non-stop, which has turned me into a very strong person. Regarding the emotional impact of paying £132.95 per week, I am not doing badly, I am still here. That being said, I am angrier now than I have ever been. Care charges contribute to this anger.

Physically, I am in a lot of pain due to problems with my hip, knee, and from irritable bowel syndrome (IBS). They are the real stresses – I do not need the stresses from the charges which the local authority is putting on me on top of that. It feels like a knee on my neck, 1 more stress after another. My IBS is related to stress – the charges are making it worse, but the local authority does not want to help at all. The local authority tries to dehumanise us and make us like robots.

What gets on my nerves about the care charging system is that the local authority does not take into account the extra spending Disabled people incur.

The charges have affected me financially. I have to live within my budget. I am relatively well insulated from the cost-of-living crisis because I have experienced it for years anyway. I have always been conscious of my spending. I make a deliberate effort to turn off the lights and the heating if they are not being used. I am very conscious of that, more than anyone else that I have known. I would say that I am obsessive about it, which has been brought about by the double-charging from years ago: the effect of being double charged before means that I always live within my means, and think all the time about what I am spending money on. Not paying £132.95 per week would be 1 less thing to worry about.

Name: James (pseudonym)

Impairment: autism spectrum conditions

Age: 26

Ethnicity: Mixed Other

Preferred pronouns: He/him

I receive 12 hours of care a week, which I use to do activities run by a youth club called Keen 2 Go. They organise trips to the cinema, bowling, and theme parks such as Chessington World of Adventures.

When I was first assessed, the monthly charge was £16 per month for 10 hours of care each week. However, in 2020 during the onset of the pandemic, I was reassessed and my charge went up to over £300 per month. The local authority was not providing as much money from the financial assessment as before, and I had to make up the shortfall. Consequently, my mum and I struggled to make ends meet, which meant that we had to cut down on the volume of activities I could do. Previously, we were able to afford 12-13 activities per week during the holiday periods. Only being able to choose 1 activity per week annoyed and frustrated me, and I felt that I was being held back, as I could not do anything, and I missed my friends. I could not understand why I was unable to do the social activities which I had always been allowed to do. This frustration manifested itself in arguments with my mum, as I blamed her when I missed out on these opportunities.

Jenny (pseudonym)

As James' mum, the council's decision had a stressful, long-lasting impact on both of us. I am petrified every time an assessment comes through the door. To place additional pressure on James and myself during a pandemic is appalling. Under the charging system not everything is considered – such as James' obsessive behaviour - and I am fortunate that I have supportive parents and grandparents. At times, hard choices were made as I was unable to buy food and daily essentials for both of us. I worried about having enough money to pay for the petrol in my car, whilst trying to keep James on an even keel. I prioritised James' health and well-being over mine, leading me to go without if necessary. My life stopped so that I could support James.

Having that money taken from us meant that I struggled to pay the rent, forcing me to focus on just getting through the month. It had a detrimental effect on my health: I could not sleep, work, or eat properly, and I was crying often. We had no support or guidance from the local authority, which added to my burdens from an already stressful job. Emotionally it was draining having to continuously worry. Even with the payments reassessed now to £174 per month, it is worrying and we still face financial challenges. It still has an impact on James – his money only stretches so far. If there was no care contribution, James would not have the additional stress of having to afford care. As someone who has an impairment, it is unfair that he is penalised by having to pay lots towards his care.

Disability Law Service
Fighting injustice for disabled people

Name: Lisa (pseudonym)
Impairments: cancer survivor, physical and mental health impairments
Age: 64
Ethnicity: Asian British
Preferred pronouns: She/her

I have been receiving care since 2007, as I have multiple impairments. I receive 12.5 hours of care per week, for which I pay nothing. This includes personal care for me, but it also benefits my family by empowering me (for instance allowing me to prepare meals with my carers). Carers also ensure that the house is tidy and hygienic, and help to relieve my pain. The local authority provides 2 hours per week of household cleaning, whilst I pay privately for another 1.5 hours for £15 per week.

2 of my family members have impairments. For the first, a financial assessment determined that they were above the savings threshold, and would have to pay for their care themselves. They did not wish to do this because of the cost, and so receive no care. This has adversely affected their mental and physical health, as they feel isolated at times and exhibit impulsive behaviour. Their impairments of depression and challenging behaviour have worsened, especially during COVID, to the extent of feeling suicidal. It has also negatively affected me, as I have had to make up the shortfall by providing care and support to that family member, for instance fixing the relationships which they have broken. I have to do all the cooking, prompt them to take medication, provide emotional support, and navigate difficult relationships between myself and my other family members. I have to constantly accommodate their needs.

The second family member has multiple impairments and therefore very acute needs. They have also felt suicidal at points in the past, and were sectioned. They receive no support or care. This demonstrates a systemic failure with non-residential care. They are not receiving enough care at the moment, and are very isolated. Worrying about their safety and well-being has affected me psychologically.

Abolition of the home care charging system would mean that my family and I receive more support, and it would have a positive impact on my health and well-being. In its current state, the charging system means greater stress due to my inability to afford certain items. My house is not in an ideal state, which affects my mental health, as I want a clean, tidy house. Moreover, abolition of care charges would allow me to socialise more regularly, potentially freeing up money which would allow me to pay for cab fares to socialise. Currently I am always having to look at how much money I have, making a choice between things in the household I can afford to sort and those which I cannot.

If care charges were abolished then it would be much likelier that both of my family members would be receiving care and support. It would lead to them being more confident and have greater trust in the system.

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Fighting injustice for disabled people

Name: Morgan
Impairments: physical and mental health impairments
Age: 29
Ethnicity: White British
Preferred pronouns: They/them

I have received home care for over 4.5 years. I receive 17 hours per week, increased from 11, and am charged £100. The care involves personal care, domestic chores, flat maintenance, filing, meal preparation, and supporting me when I go into the community.

The biggest issue I have experienced with the home care charging system has been its lack of flexibility, specifically regarding disability-related expenditure (DRE), with a shortage of consideration for independent living. It is utterly inaccessible. More broadly, the general financial assessment process has been a nightmare, with the local authority spending 3-4 months ignoring my emails. Had there been no resolution, I would have stopped payments altogether, as I did not have the money.

The charging has impacted me financially. Prior to an unexpected inheritance, I was £6,000 in debt for a period of 2 years. There have been issues with my contributions since I started receiving care. Previously, I considered reducing the amount of care I receive because of the cost. However, to do so would place my tenancy at risk, with homelessness a possibility as a knock-on effect. I have no family support.

The non-residential care charges have also affected my mental health. I feel constant stress worrying if I have enough money when I get to the end of the month. The system itself is bureaucratic and convoluted to navigate. I get a ball of fear in my stomach when I email the local authority for help, and will be stressed for days and days. I cannot afford to purchase basic items, and I cannot understand how anyone can live independently on such a low amount of money which we are provided with. This is especially true given that the DRE is not tied to inflation, exacerbating the difficulties in affording necessities. Even when I purchase second-hand necessities, I worry that if they break, I will not be able to afford to repair them.

Abolition would allow me to live again: it would allow me to build a solid foundation for my mental health, stopping me lurching from crisis to crisis. I would be able to afford basic necessities; have my hair cut more often; purchase new clothes; and buy and replace furniture. Currently, I feel trapped in poverty.

Disability Law Service

Fighting injustice for disabled people

Real-life stories in the London Borough of Hammersmith and Fulham

Disability Law Service
Fighting injustice for disabled people

Name: David
Impairments: chronic juvenile rheumatoid arthritis with a visual impairment
Age: 73
Ethnicity: White British
Preferred pronouns: He/him

Before home care charges were abolished in H&F in April 2015, I paid a contribution for the home care I received. I paid about £20 a week. I remember the final figure I was charged was approximately £26 a week for 26 hours of care and support.

I have always been quite good at managing money and I adapted to the home care charges. The care contribution was deducted at source. My contribution was taken off my total direct payments before I received it. It meant I had less money to pay my personal assistants (PAs) with. I couldn't give my PAs pay rises as I would have liked to. My PAs didn't stay for that long as they had other things going on in their lives. Working as a PA was a temporary step in their lives. The financial assessments I had in H&F were not as rigorous or intrusive as I am aware they were in other local authorities.

I was a founding member of Hammersmith & Fulham Coalition against Cuts which campaigned for the abolition of home care charges in H&F. My objection for paying a care contribution was a matter of principle. I don't have children but I am quite happy to pay taxes for children to be educated. I think people should pay taxes without needing Disabled people to pay for their care and support. It should be paid for from general taxation. I think there are certain things that local authorities and government should be responsible to raise the revenue for.

Abolition meant that about £26 a week was liberated. I was able to give my PAs a much deserved pay rise. Before the abolition, the money for direct payments hadn't gone up for 3 or 4 years. The abolition has been useful in the retention of PAs. It is tiring to go through the advertising and interviewing process. It is better for my well-being not having to do this as often. I have had 1 PA for about 5 years, 1 for 2 years who worked for me previously and another for a few months. You don't have to keep training PAs. Being a visually impaired person I like to keep things where I know they are. If a stranger comes in, things tend to get moved. So, a PA who has been working with me for years knows I like things in their place. Simple things like they know to turn the lights off when they go. I have a good bond with my PAs, a strong, warm relationship. They bring their kids to work when they have childcare issues.

Following a review in 2021, my care and support increased. I now receive 32 hours a week, spread over 6 days. I receive support with personal care, household chores, admin and accessing the community.

Disability Law Service
Fighting injustice for disabled people

Name: Rudi
Impairments: tetraplegia, spinal cord injury
Age: 70
Ethnicity: White European
Preferred pronouns: He/him

I moved to H&F in about 1990. Before I lived in H&F, I paid for my personal support. Since moving, I don't think I have had to pay for this. I receive 24-hour support with all aspects of daily living. My care and support was split between H&F and the Independent Living Fund (ILF) until ILF stopped in June 2015. H&F guaranteed ILF funding for a further 5-year period.

The payments from ILF were unpredictable. It made life unbearable. ILF overpaid me 1 year, so they cut off my funding completely to make it up for 1 year. The year later it went back up to what it was before the overpayment. The overpayment issue was not resolved. ILF did not accept it had made a mistake. I had to pay it back over years in a manageable repayment plan.

I felt in a state of discomfort. I felt I was battling ILF. It was depressing and demoralising. I didn't feel in control of my own life. I felt everything was predicated by a third party. When I was happy with the amount of funding, the last thing I wanted to hear was that ILF was up for review as the funding could change again. I was deeply unhappy with ILF. I detested it but I had to keep it going. Overall, ILF had a negative impact on my life as I am prone to urinary infections and this can be impacted by stress.

Following the abolition of home care charges in April 2015, I no longer had to go through financial assessments either with H&F or ILF. I felt like an equal citizen. I didn't feel like a social pariah. I felt like my life was not under threat. I was able to live freely because I could get the level of support needed without having to go through a financial assessment. The impact was very significant. After 52 years of living with a spinal cord injury, you're likely to encounter more health problems but this is an aspect of your life that is not being threatened. It felt like a safety net. It was sacrosanct. I was not being emotionally threatened. Without doubt, my mental health and emotional well-being was better. It was 1 less thing to worry about day-to-day. That makes a huge difference. Having less stress will have impacted my physical health.

I stopped receiving home care in early 2021. I now receive continuing healthcare, so my support is funded by the NHS rather than H&F.

Name: Sarah (pseudonym)
Impairments: chronic pain & fatigue, depression
Age: 31
Ethnicity: White British
Preferred pronouns: She/her

Before I moved to H&F, I paid a care agency for private care through my Personal Independence Payment (PIP). I did not know I could receive care through my local council. I was never offered or advised about it. My local council at the time was more focused on aids and adaptations. Nothing has changed since then in terms of my needs. The care agency came out usually twice a week for about 2-3 hours each time. All the care I received was in the home-personal care and housework. I think I paid about £20 an hour, so at least £100 a week. Most of my PIP money went towards my care.

When paying for care privately, some weeks I had to go without. I couldn't reliably afford it. If there was something else that needed to be paid for, there was not the money left over to have the care. It was very stressful especially on the times I couldn't afford it. If you've got that worry of being able to afford the care, it hangs over you. When buying food, you always think can you really afford it. You cut out things. You think about going without. I felt guilty if I bought snack food and desserts.

If I didn't have the care, it made me feel less independent as I had to ask my husband for help with personal care. I really didn't like having to rely on him. My husband doesn't mind helping but I really value my independence. I can get quite snappy sometimes if I feel I am backed into a corner and I have lost some of my independence. I can take my frustration out on him. I don't feel it is fair that he has to help me. When my PIP was stopped in or around April 2020, I could no longer afford to pay for private care and I had to rely on my husband.

I have been receiving care from H&F for about 3 years and get about 5-6 hours per week. I receive support 4 days a week for personal care and housework on Mondays, Wednesdays, Thursdays and Fridays. The carer also sometimes takes me out on Thursdays to get out the house for a bit if I am well enough. It is a relief receiving care. Whilst I am grateful for the care I receive now, it's not very reliable and the carers are often late or sometimes don't come at all. The care agencies are pretty good and apologetic. They try to sort it out.

It is a weight lifting to be able to receive care at no cost. It has been good on my independent living. It is great that my husband is not having to pick up the slack on the house and helping me to get in and out of the bath. I feel less guilty to be less of a burden on him.

I have got my PIP back now. I feel grateful I won't have to use my PIP to pay for care. I can use it for hydrotherapy and acupuncture to help with my impairments. Both are not available on the NHS. I think my PIP also goes towards food. I was penny pinching. I don't have to stress as much. It gives me a little buffer.

Disability Law Service
Fighting injustice for disabled people

Name: Victoria
Impairment: tetraplegia
Age: 47
Ethnicity: White British
Preferred pronouns: She/her

I have received care and support from a local authority since I was 18. I previously had to pay a contribution for my care and support. I moved to H&F in 2002. I receive support 24 hours a day with all aspects of daily living from a team of 11 personal assistants (PAs). I work as a radio producer and receive Personal Independence Payment (PIP)-higher rate mobility and daily living component. I previously had to go through yearly financial assessments. Any bureaucracy is unwelcome. When you become disabled, no one warns you that you will face constant bureaucracy. It is another piece of paperwork that Disabled people face.

For me, it is morally wrong to charge Disabled people for a service that is absolutely vital to their quality of life. Social care is not a luxury. It is a human right. Without social care, some Disabled people will have no quality of life whatsoever. If you charge Disabled people for their care, you are taking away resources from them and driving them further into poverty, reducing their independence. You are providing a disincentive to better themselves and charging is a huge barrier to social mobility. You get the feeling that those in power don't understand the reality of living with an impairment. Many politicians say they want Disabled people to improve their lives but, at the same time, they still put these barriers in place for Disabled people to do just that. Charging Disabled people for their care is effectively a tax on disability. You don't choose to be disabled. Charging is also inconsistent with other aspects of social policy. You don't charge parents to send their children to school, households to take their rubbish, people to use parks, so why charge Disabled people for their care? Making Disabled people pay more towards local authority services is effectively treating them differently than non-Disabled people. It goes against the whole basis of equality and inclusion. It feels as if society is targeting Disabled people as they will find it hard to complain about it.

When home care charges were abolished in H&F in April 2015, Disabled people were no longer being penalised anymore, not being singled out for a tax that other people didn't have to pay. Abolition made me feel more integrated in society. Now that I no longer have to endure financial assessments, my quality of life has improved. Anything that can be done to reduce the amount of paperwork Disabled people have to face is very welcome. If a local authority needs to raise more money, there are fairer and more inclusive ways of doing it than charging for home care. A fairer way of doing it is to spread the burden of the cost across all groups. Abolishing home care charges throughout England would have a huge impact on Disabled people. It would have a major impact on improving Disabled people's quality of life, make them more integrated in society and improve their well-being. It would also end a major social injustice that is taking place at the moment.

Disability Law Service

Fighting injustice for disabled people

The London Borough of Hammersmith and Fulham model

Table of contents

Introduction

The London Borough of Hammersmith and Fulham (H&F) is the only local authority in England where non-residential care is free at the point of use for Disabled residents.

The abolition of home care charges by H&F was announced on the 3rd December 2014, [1] marking the celebration of the United Nation's International Day of Disabled People. [2] The policy was then implemented in April 2015, and was the result of over 8 years of campaigning by groups such as the Hammersmith and Fulham Coalition against Cuts (HAFCAC), who worked with H&F to prioritise the human rights of Disabled individuals. [3]

This document has been constructed to address the main issues relating to the abolition of home care charges. Firstly, we cover the social motivations behind H&F's trailblazing decision. Recognising that local councils may be concerned about the additional financial pressure on their budgets, we have analysed how H&F facilitates this policy, even in light of the financial impact caused by the COVID-19 pandemic. We consider how H&F uses the reablement process and regular reviews to facilitate the policy. We then focus on how the abolition of home care charges in H&F is a prime example of co-production and of being committed to ensuring that Disabled individuals live full and independent lives.

Therefore, through this document, detailing the H&F model, we are urging every local council in England to follow H&F's commitment to social justice, and abolish this "tax on disability". [4] This document will function as a case study example of H&F's policy of providing non-residential care to Disabled adults free at the point of use.

[1] 'Tax on Disability to Be Abolished' (2014) <https://www.lbhf.gov.uk/articles/news/2014/12/tax-disability-be-abolished> accessed 3 August 2022.
[2] 'Campaigners Rejoice as 'Tax on Disability' Is Abolished by Hammersmith & Fulham Council' (2014) <https://www.swlondoner.co.uk/news/05122014-campaigners-rejoice-tax-disability-abolished-hammersmith-fulham-council> accessed 3 August 2022.
[3] 'Hammersmith and Fulham Coalition against Cuts' <http://www.hafcac.org.uk/> accessed 18 July 2022.
[4] H&F (n 1).

Disability Law Service
Fighting injustice for disabled people

London Borough of Hammersmith & Fulham's motivations behind the decision to abolish home care charges

H&F is the only council in England to have abolished home care charges for Disabled people, getting rid of what was in effect a tax on disability. [1]

Introduction

There are various motivations behind H&F's abolition of home care charges. Firstly, it cares about working with Disabled people to provide home care; it wants to be a compassionate council that operates under an ambitious administration. The abolition of home care charges was also a manifesto promise which was successfully fulfilled. The decision aimed to mark the end of a difficult, long battle for local disability campaigners, who had campaigned for almost 10 years to see this tax on disability abolished. [2] This decision set a new standard for how councils should respond to the needs of Disabled people receiving non-residential care.

Reducing the impact of systemic failings on Disabled people

Nearly half of all people in poverty are either a Disabled person or live with a Disabled person. [3] A high cost of living, combined with low income and being less able to work make Disabled people more dependent on benefits, public services, social care and support provided by the NHS. [4] Given the context of Disabled people relying more on both state-funded benefits and a variety of public services as a result of their impairments, they are more likely to experience the detrimental effects of the government's cuts to benefits and services than non-Disabled people. Councils were left with difficult decisions to make on budgetary priorities, resulting in a crisis in social care. For a Disabled person, the budget cuts alongside the extra charges for non-residential care could mean a choice between greater independence, physical and mental well-being, or access to the services they may need for social mobility. Charging for non-residential care could also mean that a Disabled person would have to choose between receiving care and paying for food, heating, and other essentials. H&F's decision to abolish home care charges is proof that being a compassionate administration that puts the well-being of its residents first, reducing the impact of systemic failings on Disabled people is not only possible, but essential.

[1] 'Home Care' <https://www.lbhf.gov.uk/health-and-care/assistance-home/home-care> accessed 13 January 2022.
[2] 'Council Agrees to Scrap Home Care Charges' (2014). <https://www.disabilityrightsuk.org/news/2014/december/council-agrees-scrap-home-care-charges> accessed 13 January 2022.
[3] Joseph Rowntree Foundation, 'UK Poverty 2022 The Essential Guide to Understanding Poverty in the UK ' (2022) 57-58.
[4] Ibid.

Prioritising the needs of Disabled people

Social care budgets come from a range of sources including central government, and funds, such as council tax, that are raised by individual councils. Against rising demands, cuts from central government resulted in a 17.5% reduction between 2009/10 and 2019/2020. As of 2021/22, local government funding was still 10.2% below 2009/10 levels. [5] The impact of these cuts on Disabled people was side-lined and not given the attention it deserved within wider society. [6] Budget cuts fuelled the decision to abolish home care charges in H&F. This was to put the needs of Disabled people at the fore of conversations surrounding budget cuts, and to shed some light on the power and authority that councils already have to change people's lives for the better, should they prioritise such efforts. A proactive decision was made on the part of H&F to ensure that Disabled people were not among the worst affected by the budget cuts.

Rights-based considerations

Above all, the abolition of home care charges by H&F is a huge step in the right direction in terms of disability rights, as Kevin Caulfield, chair of HAFCAC at the time pointed out, "every other non-Disabled resident would view it as an absolute violation of their human rights if they had to pay an invoice from the council before they could use the toilet, get washed, and engage in day-to-day activities." [7] Within this context, the consideration of Disabled people's human rights by removing a tax on disability was an imperative motivation for H&F to push for its decision to abolish home care charges.

Conclusion

It is under these difficult obstacles and conditions that H&F took action to completely abolish home care charges in 2015. H&F is the only council in England to have taken this decision. According to Geoff Cowart, Head of Communications at H&F "it's just a case of priorities and what we choose to spend our budget on." "To us, this is of major importance and surely saves money down the line in all of our services." [8] H&F's administration has set an important precedent for other local authorities to follow in abolishing non-residential care charges that is meant to be replicated and customised according to the needs of residents.

[5] Graham Atkins and Stuart Hoddinott, 'Local Government Funding in England' (2023) <https://www.instituteforgovernment.org.uk/explainer/local-government-funding-england#:~:text=Local%20authority%20'spending%20power'%20%E2%80%93,fallen%20by%2016%25%20since%202010> accessed 20 July 2024.

[6] Phillida Cheetham, Thomas Gregory and Claudia Wood, 'Less Money Doesn't Have to Mean a Poorer Service for Disabled People... Coping with the Cuts' (2011) 17 <https://demos.co.uk/wp-content/uploads/2011/09/Coping_-_web.pdf> accessed 13 January 2022.

[7] DR UK (n 2).

[8] Tony Flower, 'Counting the Cost of Care' <https://talkback-uk.com/blog/counting-the-cost-of-care/> accessed 13 January 2022.

Disability Law Service
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Facilitation of the policy to not charge for home care services

Introduction

There has been a lot of pressure on local authorities' budgets over the last decade that has put the needs of Disabled people at risk. However, H&F's policy of not charging for home care services displays that it is, indeed, possible to achieve the abolition of home care charges through careful management and effective financial budgeting.

A 2018 study by the Independent Living Strategy Group states that charging for care and support raises "modest" sums of money (only around 12% of spending on community support) but, in turn, has a disproportionately "profound impact on the individual", with an average charge of over £2,000 per year. [1] This is essentially a "tax on disability". [2]

H&F has managed to facilitate its policy to not charge for home care services through 2 main changes to its budget - namely, the reduction of administrative and PR costs. [3] With regards to its other forms of cost-cutting, H&F adopts both a short-term and long-term approach to savings. This can be seen through its review of contractual costs and investments in assistive technology, respectively.

Reduction of administrative costs

The abolition of home care charges by H&F was, in large part, achieved through its reduction of administrative costs. H&F first abolished home care charges in 2015. In December 2014, 26% of the 1,287 home care service users in H&F were expected to pay for their care. [4] At a price of £12 per hour, this could have resulted in fees of £281 per person, per week. [5]

The 2015 decision to abolish home care charges therefore cost H&F an additional £324,000 per year. However, this extra cost was funded by £400,000 worth of cuts to public relations, council publications and lamp post banners.[6] H&F funded this by making major efficiencies, adopting a ruthless approach to cutting waste. H&F prioritised the rights of Disabled people over unnecessary costs through better negotiations and cutting spending in other areas.

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[1] Independent Living Strategy Group, 'Charging for Social Care: A Tax on the Need for Support' (2018) 19-22.
[2] 'Council Agrees to Scrap Home Care Charges' (2014) <https://www.disabilityrightsuk.org/news/2014/december/council-agrees-scrap-home-care-charges> accessed 7 March 2022.
[3] Ibid.
[4] Rachel Wigley, 'Abolition of Charging for Home Care Services' (2015) <http://democracy.lbhf.gov.uk/documents/s60431/06.3%20Abolition%20of%20Charging%20of%20Home%20Care%20Services.pdf> accessed 7 March 2022
[5] Alix Culbertson, 'H&F Scraps Elderly and Disabled Home Care Charges' (2014) <https://www.mylondon.news/news/local-news/hf-scraps-elderly-disabled-home-8236822> accessed 7 March 2022.
[6] 'Council Agrees to Scrap Home Care Charges' (2014) <https://www.disabilityrightsuk.org/news/2014/december/council-agrees-scrap-home-care-charges> accessed 7 March 2022.

H&F has managed to achieve these cost efficiencies in spite of the central government cutting its funding in real terms by 59% since 2010. [7] H&F also worked to secure better deals and reduce office-related expenditure, collectively amounting to £16 million worth of savings between 2015 and 2018. [8] This, combined with the use of "big data", has allowed H&F to predict future service demands sooner, resulting in a net reduction of costs. [9]

Other cost savings

H&F also takes part in other cost savings. As part of its short-term approach to savings, H&F's 2016 Annual Budget Report cites contract efficiency and procurement savings as a means of decreasing the cost of the adult social care services which were contracted through external providers. [10] Contract reviewing is key. The review of care pathways as a method of providing comprehensive care was expected to save £0.748m in 2016/2017. H&F also reviewed its Public Finance Initiative, saving £0.492 million through renegotiations. [11]

In terms of long-term cost savings, H&F created transformation projects that "aim to reduce costs by investing in assistive technology". [12]Investing in assistive care increases the number of telecare users by enabling them to stay home for a longer period, while also diminishing the cost of home care services. [13] This was expected to save £0.275m in 2016/2017. [14]

Conclusion

H&F prioritised its aim of achieving the abolition of home care charges by compromising on other costs. The idea of taxing Disabled people for being able to live an independent life seemed unnecessary given H&F's ability to tweak its other forms of spending.

All local authorities are capable of - and are indeed good at - cost-cutting. Scarborough Borough Council saved £185,000 a year because it switched from expensive printers to "small multipurpose ones". [15] Surrey County Council saved £500,000 simply by making small adjustments such as "reducing print and postage costs…and stationery costs". [16]

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[7] 'Being Ruthlessly Financially Efficient' <https://www.lbhf.gov.uk/hot-topics/being-ruthlessly-financially-efficient> accessed 7 March 2022.
[8] Ibid.
[9] Ibid.
[10] Andrew Lord, 'Revenue Budget and Council Tax Levels 2016/17' (2016) <https://democracy.lbhf.gov.uk/documents/s75150/Revenue%20Budget%20and%20Council%20Tax%20Levels%202016-17.pdf> accessed 7 March 2022.
[11] Ibid 4.1.4.1.
[12] Ibid 4.1.3.
[13] Ibid.
[14] Ibid 4.1.2.
[15] '50 Ways to Save: Examples of Sensible Savings in Local Government' (2012) 13 <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/39264/50_ways_2.pdf> accessed 6 April 2022 .
[16] Ibid 14.

We understand that each local authority is a different size and that such cost cuts may have varying impacts on each budget. However, these cost-savings make a real difference when considered cumulatively. Therefore, if all local authorities engage in these efficiency-based cost-cutting measures, whilst placing greater emphasis on social justice, then all local authorities will be able to work together in the fight against this tax on disability. H&F's methods have shown that directly including Disabled individuals in the growth of our local communities is not only possible, but achievable.

Disability Law Service
Fighting injustice for disabled people

Impact of COVID- 19 on H&F's policy not to charge for home care

Introduction

The impact of the COVID-19 pandemic has been unprecedented, creating an environment of uncertainty, instability and social isolation. This has contributed to an added strain on the provision of health and social care across England.

As a result, Disabled people have been pushed further towards the margins of social care. Not only did the government's Coronavirus Act 2020 enable certain Care Act 2014 obligations to be discretionarily provided, as opposed to mandatorily, but we have seen thousands of individuals face having services "cut or reduced against their wishes" as a consequence. [1] As WinVisible reported in April 2020, this left "thousands of Disabled people…completely abandoned". [2]

In spite of this, H&F managed to maintain its position as the only local authority in England that provides home care free at the point of use for Disabled adults. We recognise that it would be easier for H&F to maintain the provision of non-residential care free at the point of use for Disabled adults, than it would be for other local authorities to begin providing such a service. However, through highlighting the financial and social impacts of the pandemic, we hope to display how the impact on H&F has been similar to national trends. This will allow us to reach the conclusion that, despite the impact of COVID-19 being generally similar across the country, we still see a prioritisation of social justice by H&F, which could be replicated by other local authorities.

Impact of COVID-19 on H&F

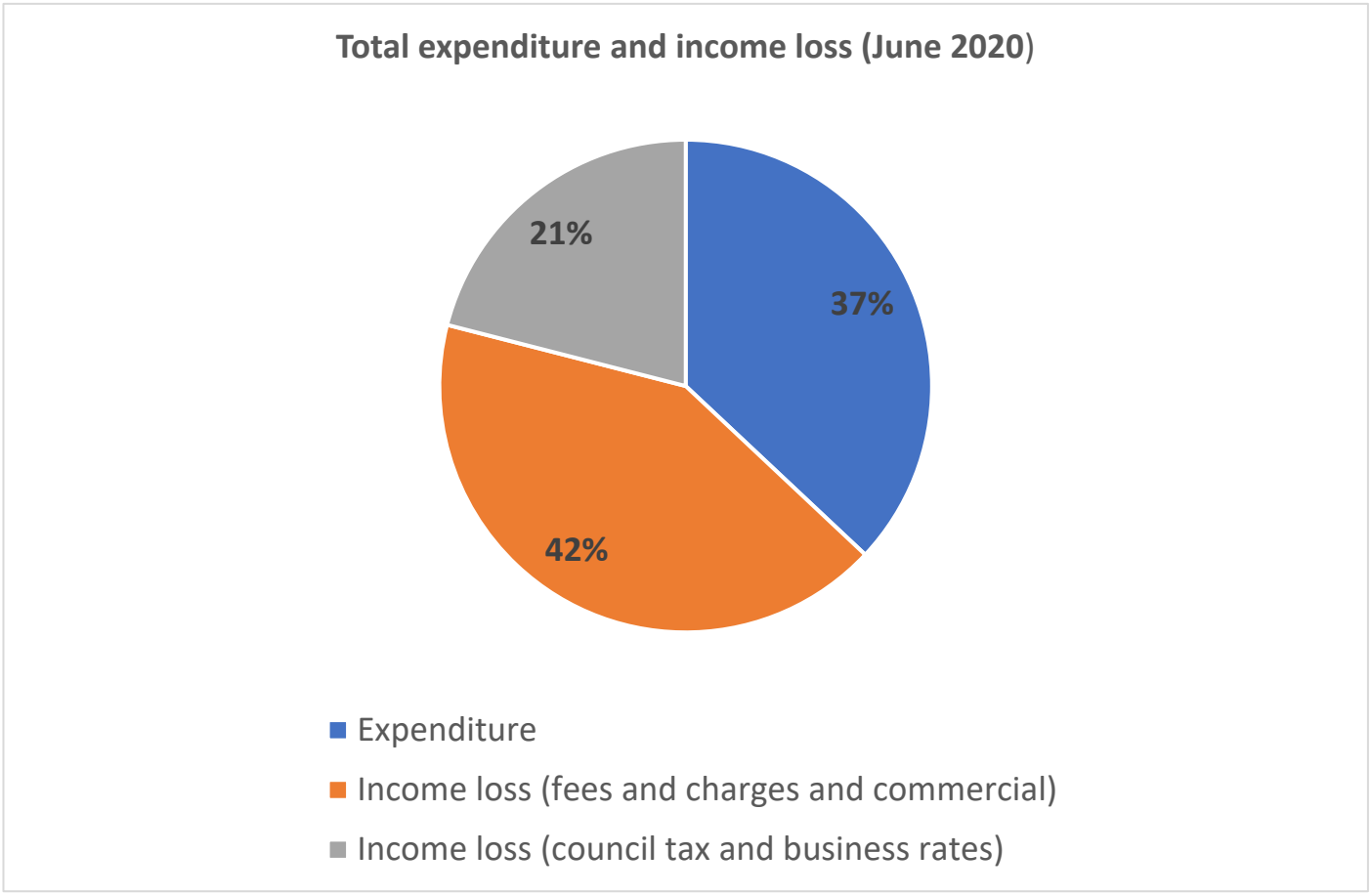
The H&F 'One Year On' report concluded that "COVID-19 further entrenched existing health and social inequalities across the borough". [3] Thus, the impact on H&F has been both social and financial.

Socially, we have seen how the number of COVID-19 cases reached its highest point at 2,198.8 cases per 100,000 people in January 2021. [4] As part of its aims to achieve a

[1] 'COVID-19: WinVisible Backs Hammersmith & Fulham's Support of Disabled People' (2020) <https://winvisible.org/2020/04/16/hammersmith-fulham-lead-by-example/> accessed 6 June 2022.
[2] Ibid.
[3] Linda Jackson, 'Covid-19 One Year On' (2021) 2 < https://democracy.lbhf.gov.uk/documents/s117632/Covid%20Update%20-%20July%202021.pdf> accessed 6 June 2022.
[4] Ibid.

"compassionate council" [5], H&F created 'Conversation Matters', which is "a support service for older and Disabled adults as well as unpaid carers", in order to tackle the problem of social isolation in March 2020. [6]

Economically, the pandemic has also caused "significant financial pressures" for H&F. [7] The pie chart below displays how H&F experienced both high expenditure and income loss, totalling £38.548 million in the short term, in June 2020. [8]



Despite H&F receiving un-ringfenced grants totalling £11.535 million in June 2020, H&F reported still feeling the repercussions of the £68 million worth of grant reductions between 2010/11 and 2020/21. [9] H&F decided to deal with these financial pressures in 2 ways. First, through continuing its approach of being "ruthlessly financially efficient" by attempting to

[5] Emily Hill, 'Financial Impact of Covid-19 on the Council' (2020) 2 <http://democracy.lbhf.gov.uk/documents/s113935/Financial%20Impact%20of%20Covid-19%20on%20the%20Council.pdf> accessed 6 June 2022.
[6] H&F (n 3) 3-4.
[7] H&F (n 5) 1.
[8] Ibid 5.
[9] Ibid 3-6.

cover its additional costs with the government grants. [10] Linked to this is its second method of characterising itself as being a "compassionate council" through making sure that the costs of the pandemic were not borne by the "most vulnerable residents" and that individuals still had access to food and services. [11]

Impact of COVID-19 on local authorities across England

The impact of the pandemic has also been felt by local authorities across England. The BBC reported that, as of August 2021, the pandemic "increased the demand for support and the financial pressures on a care system already in crisis" with Cath Roff, representative of the Association of Directors of Adult Social Services, describing councils as being '"really stretched" after "10 years of austerity". [12]

While H&F has managed to continue providing non-residential care free at the point of use for Disabled adults, it was found that Disabled individuals had an average increase of 13% in their care cost contributions across 83 local authorities, in 2 years. [13] These individuals went from being expected to contribute £369 million in 2018-19, to £420 million in 2020-21. [14] There were also cases where charges had fallen in local councils, but this had been met with a cut in the level of support received. [15]

Conclusion

The pandemic shone a light on the social consequences felt by Disabled adults. Namely, it displayed that the system of social care is not reliable in the way that disabled communities need it to be. Thus, COVID-19 really "exposed existing challenges within the social care system and exacerbated exclusion, inequality and poverty for many who rely on its support". [16] This is therefore the ideal time for local councils to reflect and make significant changes to their social care policies, prioritising the needs of their Disabled residents, making home care free at the point of use.

[10] Ibid 2.
[11] Ibid.
[12] Adam Eley, 'Social Care Charges: Disabled and Vulnerable Adults Hit by Steep Rises' (2021) <https://www.bbc.co.uk/news/uk-58259678> accessed 6 June 2022.
[13] Ibid.
[14] Ibid.
[15] Ibid.
[16] 'Understanding the Impact of COVID-19 Responses on Citizens' (2022) <https://www.scie.org.uk/care-providers/coronavirus-covid-19/commissioning/impact-on-citizens> accessed 6 June 2022.

Disability Law Service
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Focus on reablement and regular reviews

Introduction

Reablement is the provision of temporary home care in the face of an injury and/or impairment following discharge from hospital. [1] It must be provided for free at the point of use for a period of at least 6 weeks. [2] This intermediate care plan is to be under review in case it has to be amended. If an individual is found to need home care beyond the reablement period, reviews should be conducted on a regular basis throughout the duration of their care.

H&F provides free home care at the point of use for all Disabled adults. As a result, the reablement period can act as a "transitionary" phase whereby, after assessment, home care can continue to be provided for free at the point of use, if necessary. Therefore, in H&F, reablement is not a stand-alone solution to providing support. Rather, it serves as a short-term method of ensuring continuous human rights protection.

Reablement care and review

Reablement is a "strengths-based, person-centred approach that promotes and maximises [the] independence and well-being" of those who have been injured or who have an impairment. [3]

Home care support must be reviewed on a regular basis. A review should be "person-centred and outcomes-focused" in order to ensure that the necessary support is being provided. [4] If there is a display of sufficient change in the level of support required by an individual, there will be a reassessment. [5] H&F ensures the consistent and regular review of support plans for residents receiving reablement support and beyond. This is to ensure that every resident receives the support they require.

H&F takes the reablement and review process seriously. Reablement is an intense period in which the aim is to help residents "regain confidence and independence at home". [6]

[1] 'Care after Illness or Hospital Discharge (Reablement)' (2018) <https://www.nhs.uk/conditions/social-care-and-support-guide/care-after-a-hospital-stay/care-after-illness-or-hospital-discharge-reablement/> accessed 6 June 2022.
[2] Ibid.
[3] 'Role and Principles of Reablement' (2020) <https://www.scie.org.uk/integrated-care/intermediate-care-reablement/role-and-principles-of-reablement/> accessed 30 May 2021.
[4] 'Care and Support Statutory Guidance' ch 13 <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#using-the-care-act-guidance> accessed 30 May 2022.
[5] Ibid.
[6] 'Regaining your Independence (Reablement)' <https://www.lbhf.gov.uk/living-independently/care-and-support/supporting-independence/regaining-your-independence-reablement> accessed 6 June 2022.

Ultimately, "the team's goal is to support a resident's recovery through a focused, short period of care, that strengthens their independence". [7]

As home care free at the point of use is provided beyond the 6-week legal requirement, individuals do not feel pressured or disincentivised to seek the amount of support they actually need. This means that individuals are free to seek help, without having to worry about how they will afford it.

We can see that the provision of such support not only aids the service user, who experiences a higher standard of living and greater independence, but it also allows carers and family members to focus less on providing support, and more on spending time together with their relative. [8] This helps to achieve greater inclusion of Disabled adults in the community.

It is noted that local authorities do not, unfortunately, have unlimited resources. This is why the review process is so important. It is key to the overall "planning process". [9] For instance, H&F can redirect care from a situation where a person no longer requires support, to one where an individual requires substantial support.

H&F therefore reassesses the support needed by Disabled residents regularly and in a timely manner. This extends beyond the reablement period and also applies to Disabled adults receiving home care for a longer period. This is why H&F is then able to continue providing support indefinitely when necessary. H&F therefore combines being a "compassionate council" with being efficient in a way that promotes rights and independence. [10]

Conclusion

The provision of reablement care and reviews are a process. It requires timely planning that reflects a duty owed by local authorities to Disabled adults. It displays a recognition of how Disabled adults should not be paying to receive an adequate and inclusive life. H&F is able to ensure home care free at the point of use for Disabled adults beyond the 6-week ceiling, suggesting that all local authorities can also do so.

[7] Ibid.
[8] 'Reablement: A Guide for Carers and Family' (2020) <https://www.scie.org.uk/integrated-care/intermediate-care-reablement/reablement-guide/> accessed 6 June 2022.
[9] Department of Health and Social Care (n 4).
[10] Emily Hill, 'Financial Impact of Covid-19 on the Council' (2020) 2 <http://democracy.lbhf.gov.uk/documents/s113935/Financial%20Impact%20of%20Covid-19%20on%20the%20Council.pdf> accessed 6 June 2022.

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Co-production strategy with local Disabled people's organisations (DPOs)

Introduction

By abolishing home care charges, it is clear that H&F focuses a great deal on the inclusion of Disabled residents. This focus on inclusion can be seen through H&F's method of co-production.

In H&F, the commitment to co-production is defined as "local Disabled residents…working together with decision makers to actively identify, design, and evaluate policy decisions and service delivery that affect their lives and remove the barriers they face". [1] This allows developments to be made with Disabled residents in mind throughout the whole process, as opposed to just being an afterthought to the decision-making process. 8 co-production methods of governance have emerged from the recommendations of the Hammersmith & Fulham Disabled People's Commission (DPC) in its report 'Nothing About Disabled People Without Disabled People'. [2] This Commission has also influenced H&F's subsequent policy-making strategies. [3]

The DPC and the DPC Report

The DPC has been integral to H&F's efforts at co-production. The DPC produced its report, 'Nothing About Disabled People Without Disabled People' in June 2018. The report highlighted the "case for co-producing policies and services with Disabled residents" to combat the barriers experienced by disabled communities. [4] Tara Flood, Chair of the DPC stated that the report "has signalled a shift in culture and practice" in H&F. [5]

The report reached a number of key conclusions. These findings included that Disabled residents often face multiple forms of discrimination and that Disabled residents feel as though they are experiencing a lower quality of life than previously. The report also found that H&F staff would like to improve methods of working with Disabled residents and that "86% [of Disabled respondents] would like to be more of a part of the decisions that affect them." [6] The report concluded "that local Disabled residents and Disabled people's

[1] 'Nothing About Disabled People Without Disabled People' (2018) <https://www.lbhf.gov.uk/councillors-and-democracy/resident-led-commissions/disabled-people-s-commission/nothing-about-disabled-people-without-disabled-people> accessed 11 July 2022.
[2] 'Nothing About Disabled People Without Disabled People' (2018) 16-20 <https://www.lbhf.gov.uk/sites/default/files/section_attachments/hf-disabled-peoples-commission-final-accessible-report-june-2018.pdf> accessed 11 July 2022.
[3] 'October 2021 E-Newsletter' (2021) <https://www.aod.org.uk/2021/10/07/october-2021-e-newsletter/> accessed 11 July 2022.
[4] 'Hammersmith & Fulham's Disabled People's Commission Report' (2022) <https://www.youtube.com/watch?v=yMCaNGFAfDI> accessed 11 July 2022.
[5] Ibid.
[6] H&F DPC (n 2) 37-40.

organisations are the best people to point out how to get rid of the barriers that exclude" Disabled people and so, co-production should be the route forward. [7]

The co-production strategy

Co-production is not a box-ticking exercise. [8] It is about affecting real and inclusive change through including Disabled people in the decision-making processes that affect them. This is why H&F introduced the Co-production Implementation Group (HFCIG) in 2019, now known as Co-production Matters H&F, with the aim of encouraging the widespread use of co-production throughout the H&F community. [9] In this respect, 2 Disabled residents and campaigners, Tara Flood and Kevin Caulfield became the Strategic Leads for Co-production at H&F. Tara is still in this role. The Strategic Lead for Co-production supports the implementation of the co-production recommendations and other co-production initiatives by working with other H&F staff. H&F taking the decision to employ 2 Disabled rights campaigners shows its commitment to co-production and truly understanding the impact that its policies have on Disabled residents.

H&F sees co-production as a method to produce a "real and lasting partnership" between "public and community organisations and Disabled residents". [10] "H&F sees co-production as an important way to make change happen, removing" the barriers faced by Disabled residents to live independently in the community.[11]

While the abolition of home care charges was implemented before the official call for co-production, it is a key example of it. This is because it was suggested and campaigned for by Hammersmith & Fulham Coalition against Cuts (HAFCAC), who put pressure on and built relationships with H&F and the incoming administration at the time. [12] HAFCAC was "a campaign group led by and for Disabled people". [13] Additional co-production-based objectives H&F has worked on include reinstating the Direct Payment Support Service, run by the local Disabled people's organisation, Action on Disability, and prioritising the means to achieve the independent living objective. [14] H&F is currently supporting 8 co-production resident-led groups on different topics, such as digital accessibility, implementing the Disabled people's housing strategy and increasing the take up of direct payments. [15]

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[7] Ibid 41.
[8] H&F (n 1).
[9] 'Co-production Matters H&F'<https://www.lbhf.gov.uk/councillors-and-democracy/co-production-doing-things-residents-not-residents/co-production-matters-hf> accessed 30 April 2024.
[10] H&F (n 1).
[11] H&F (n 9).
[12] 'Hammersmith and Fulham Coalition against Cuts' <http://www.hafcac.org.uk/> accessed 18 July 2022.
[13] Ibid.
[14] H&F (n 1).
[15] 'What We Are Doing' <https://www.lbhf.gov.uk/councillors-and-democracy/co-production-doing-things-residents-not-residents/what-we-are-doing> accessed 30 April 2024.

The example of H&F shows the benefits of co-production and why each local authority should be incorporating it in their decision-making processes. The Care Act 2014 suggests that it should be "used to develop preventative, strength-based services, support assessment, shape the local care market, and plan information and advice services". [16] The benefits of co-production lie in the fact that its core principles prioritise equality, diversity and accessibility in adult social care. [17]

Conclusion

While H&F abolished home care charges for all Disabled adults before officially adopting the co-production strategy, it is nonetheless a prime example of the motivations behind the strategy. It displays a method of governance that proactively includes Disabled residents in the decision-making process.

If co-production was consistently adopted by local authorities, the true impact of home care charges would be more easily understood. It should be noted that H&F is not the only council to make use of co-production, with councils in Greater Manchester and Cheshire adopting similar approaches.[18] Therefore, it is important to reconsider how co-production can best be used in order to understand some of the biggest obstacles facing Disabled adults. Once this is achieved, the injustice of home care charges will truly be recognised and, hopefully, they will be abolished.

[16] 'Co-production: What it Is and How to Do it ' (2022) <https://www.scie.org.uk/co-production/what-how> accessed 18 July 2022.
[17] Ibid.
[18] John Pring, 'New Disabled People's Panel Inspired by Ground-Breaking Projects' (2021) <https://www.disabilitynewsservice.com/new-disabled-peoples-panel-inspired-by-ground-breaking-projects/> accessed 18 July 2022.

Vision for independent living

Introduction

H&F's approach to home care charges has served as the starting point from which a wider vision for independent living for Disabled residents has developed.

H&F has defined independent living as meaning "Disabled people living in the community with the same choices, control and freedom as any other citizen", with the "removal of barriers to equality of opportunity", and where "any practical assistance is based on Disabled residents' choices and aspirations". [1]

At its core, the vision is about actualising the fact that Disabled residents should have the same rights and opportunities as non-Disabled residents. By abolishing home care charges for Disabled adults, H&F has recognised that these charges have acted as a "tax on disability" which, as a result, is simply an additional tax to be able to live comfortably. [2] These charges, therefore, create a greater sense of dependence for Disabled communities, working against the vision for independent living.

The vision for independent living

The importance of independent living can be seen in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This seeks to ensure that all Disabled individuals have the right to live independently, and be included within their society. [3]

It should be noted that independent living does not mean not supporting Disabled individuals. Rather, it is about adopting the social model of disability [4], and recognising the

[1] 'Independent Living Vision Statement' <https://www.lbhf.gov.uk/living-independently/our-vision-independent-living-hf/vision-statement> accessed 25 July 2022.
[2] 'Tax on Disability to Be Abolished' (2014) <https://www.lbhf.gov.uk/articles/news/2014/12/tax-disability-be-abolished#:~:text=Hammersmith%20%26%20Fulham%20Council%20will%20abolish,last%20night%20(3%20December).> 25 July 2022.
[3] 'Article 19 – Living Independently and Being Included in the Community' <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html> accessed 25 July 2022.
[4] 'Social Model of Disability' <https://www.scope.org.uk/about-us/social-model-of-disability/> accessed 1 August 2022.

need to support Disabled people in making informed choices in regaining a greater level of control over their lives. [5]

Disability Rights UK supports a campaign for independent living that "aims at enabling Disabled people to move out from institutions, be equal citizens with rights, live an ordinary life (rather than living in institutions) and positively participating in mainstream society". [6]

H&F and independent living

The aforementioned perspective is echoed in the approach adopted by H&F.

In the previous section, we discussed co-production and the H&F Disabled People's Commission (DPC). The DPC report suggested the creation of H&F's independent living strategy. [7] As such, it is to be implemented utilising the method of co-production discussed earlier. It will make use of the 12 pillars of independent living, as defined by Disabled people 50 years ago. These pillars include a fully accessible transport system, accessible and adapted housing and personal assistance to enable an independent lifestyle". [8]

Through this vision of independent living, H&F seeks that all Disabled residents will have full access to all things they need to live the best possible life and be fully part of and contribute to their communities. [9]

Therefore, while implemented before the official vision for independent living was announced, the abolition of home care charges has served as a key example of H&F's long-term dedication to removing barriers for Disabled residents. Not charging Disabled adults for their basic rights was a vital starting point for ensuring the independence of all Disabled residents and, as such, should be followed by all local councils. This is key to securing the protection of every individual's basic human rights – it is not right to charge Disabled people for simply being human beings.

[5] 'Independent Living' <https://www.disabilityrightsuk.org/independent-living-0#:~:text=It%20is%20living%20independently%20without,Rights%20UK%20endorses%20this%20approach.> accessed 25 July 2022.
[6] Ibid.
[7] H&F (n 1).
[8] Ibid.
[9] 'Our Vision for Independent Living in H&F' < https://www.lbhf.gov.uk/living-independently/our-vision-independent-living-hf>

Conclusion

The abolition of home care charges occurred before the implementation of the vision for independent living. However, it represents the spirit of the movement – that Disabled adults are to be treated equally and with dignity in order to create a culture of independent living, as opposed to institutional dependence. This is because the vision focuses on creating a culture of empowerment that aligns itself with the social model of disability.

Local councils should adopt the social model of disability and ensure that they fulfil Article 19 of the CRPD. In particular, local councils should consider how the abolition of home care charges would actively contribute to more independent, better lives for Disabled adults. With the support of DPOs, the abolition of home care charges can serve as the starting point for every local council's commitment to the independent living of Disabled adults.

Conclusion of H&F model document

The purpose of this document, detailing the H&F model, has been to advocate for the abolition of non-residential care charges for Disabled adults in England by using H&F as a case study example for other local councils.

We have discussed how H&F has been motivated in its actions by prioritising a rights-based approach to social justice. This has been possible through effective financial management. These financial pressures have been exacerbated by the COVID-19 pandemic and the ongoing cost-of-living crisis. However, they have not been fatal. This is why home care for Disabled adults free at the point of use can, and should, be provided beyond the reablement period, if necessary. This conclusion was reached by H&F through the decision-making process of co-production, which is essential for ensuring that Disabled residents play an active role in policy-making. It is only through these measures that we will contribute to a wider, national vision for independent living. The abolition of home care charges for Disabled adults is, thus, where we should start.

Whilst we recognise the cuts that local authorities have faced from central government, with effective budgeting and home care review processes, the abolition of home care charges is possible.

Although all local councils are different, the H&F model provides tangible solutions that other councils should consider. Local authorities can use the H&F model to reflect and evaluate their own home care charging policies, carefully analysing the detrimental impact that home care charges are having on Disabled residents. Abolishing home care charges will aid local authorities in moving to a more preventative model, ensuring that their resources are used sensibly. This will prevent more intensive home care services being needed further down the line, avoiding situations where Disabled residents need a higher level of assistance from a lack of support being provided at an earlier stage.

We urge all local authorities to move to abolish home care charges. This plan should be developed with Disabled residents fully involved at each and every step of the decision-making process. Local authorities should ensure that they are taking into account the likely extra demand there will be for home care services from their decision to abolish home care charges. Councils across England can work together to make this pioneering positive change for Disabled adults, making home care free at the point of use.

Conclusion

In an ideal world, the UK government would legislate for home care to be free at the point of use in England, but this appears unrealistic currently. Some of the devolved governments have gone further than the UK government with their proposals for non-residential care policies. Disabled adults in Scotland do not have to pay home care charges for personal care, but this does not include all aspects of non-residential care. [1] In Wales, there is currently a weekly maximum charge of £100 for non-residential care.[2] However, this soon may be increased by up to £25 a week following a consultation. [3] As part of its previous co-operation agreement with Plaid Cymru, the Welsh government agreed to look into the creation of a National Care Service which is free at the point of need. [4]

The UK government previously proposed the reform of capping lifetime care costs at £86,000. These reforms were to be implemented in October 2023, but were delayed by 2 years. [5] The new UK government has committed to implement these reforms.[6] As the reforms stand, care costs incurred before the reform implementation will not count towards the calculation of the lifetime care cap. [7] Whilst these reforms are better that the current home care charging policy, they do not go anywhere near far enough and would not help many Disabled adults paying home care charges.

In England, the London Borough of Tower Hamlets announced in March 2023 that it would abolish home care charges from April 2024. [8] Unfortunately, the council delayed the policy's implementation until April 2025. [9] In Greater Manchester, the mayor has committed to establishing the Greater Manchester Commission on Social Care with the Disabled People's Panel. The commission will look at "creating a roadmap towards a National Care Service approach, free at the point of need that supports independent living." [10]

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[1] 'Free Personal and Nursing Case: Questions and Answers' (2019) <https://www.gov.scot/publications/free-personal-nursing-care-qa/> accessed 9 December 2022.
[2] 'Charging for Social Care' <https://www.gov.wales/charging-social-care> accessed 15 July 2024
[3] India Pollock, 'Disabled Man to Sell Home over Care Cost Rise' (2024) <https://www.bbc.co.uk/news/articles/c3gddd1r204o> accessed 15 July 2024.
4 Julie Morgan, 'Written Statement: National Care Service – Expert Group' (2022) <https://www.gov.wales/written-statement-national-care-service-expert-group> accessed 9 December 2022.
5 Sally Hickey, 'Social Care Cap Delayed until 2025' (2022) <https://www.ftadviser.com/pensions/2022/11/17/social-care-cap-delayed-until-2025/#:~:text=The%20government's%20plans%20to%20limit,come%20into%20effect%20in%202025.> accessed 16 December 2022.
[6]Aine Fox, 'Streeting Promises Social Care Costs Cap despite Absence from Labour Manifesto' (2024) < https://www.independent.co.uk/news/uk/wes-streeting-labour-government-conservative-england-b2562586.html> accessed 15 July 2024.
[7] 'Adult Social Care Charging Reform: Further Details' (2022) <https://www.gov.uk/government/publications/build-back-better-our-plan-for-health-and-social-care/adult-social-care-charging-reform-further-details> accessed 8 March 2022.
[8]'Council Urged to Bring Forward Decision to End Social Care Charging' (2023) <Council urged to bring forward decision to end social care charging | Disability Rights UK> accessed 15 July 2024.
[9] 'Council Approves Budget with New Investment in Public Services and Support for Residents (2024) < Council approves budget with new investment in public services and support for residents (towerhamlets.gov.uk)> accessed 15 July 2024.
[10] <https://x.com/TeamBurnhamGM/status/1779821751494406476> accessed 17 April 2024.

Throughout our research report, we have illustrated the detrimental impact that home care charges are having on Disabled adults' lives in England. This impact will have been further exacerbated by the cost-of-living crisis.

Attendees' experiences of home care charges in our England focus group were overwhelmingly negative, not only financially but also mentally, physically and emotionally. Attendees spoke about the large financial burden imposed on them by home care charges, forcing them to make difficult choices between receiving home care and essentials such as food and heating. 1 of the England real-life stories depicted how home care charges have led Disabled adults to substantially change their diet to save money, leading to weight loss of 20kg. Similarly, the questionnaire to Disabled adults who are charged for their care found that nearly 50% of respondents answered that they were sometimes unable to afford their basic needs. Furthermore, nearly 75% said that increases in home care charges have had a negative impact on their lives. The comments left in the questionnaire were quite stark. In reference to their benefits being used to pay for their home care, 1 respondent said that they felt that their local council was "stealing" from them, likening the situation to a "school bully going right into the scrawny kid's lunch box". This depicts why home care charges are a tax on disability. Disabled adults should not have to pay for support with vital aspects of their daily living such as personal care. Their welfare benefits should be used to improve their independent living, not to pay for their support.

Given the substantial impact that home care charges are having on Disabled adults, one would hope that local councils are assessing this impact. From the freedom of information requests we made, it was found that very few local councils are complying with the public sector equality duty to assess this impact and a minimal amount are using their discretion not to charge Disabled adults.

The research carried out in the London Borough of Hammersmith (H&F) shows the positive impact that the abolition of home care charges has had on the lives of Disabled adults. The H&F focus group demonstrated that the abolition has been a net positive for residents, granting them greater independence and freedom. The questionnaire to Disabled adults who are receiving home care in H&F found that a majority of respondents had more money to afford their basic needs following the abolition. Nearly 65% of respondents said the abolition has had a positive impact on their lives. No respondent disagreed with the statement that home charges should be abolished in England more generally. In this respect, the H&F real-life stories illustrate that the abolition has had a positive impact on Disabled residents' mental well-being as Disabled residents feel like equal citizens and more integrated in society.

The document, detailing the H&F model shows how the council has managed to facilitate its free at the point of use home care policy. H&F has prioritised this policy as it is committed to a human rights-based approach to social justice. It has engaged in effective financial

management, in continuing to prioritise this policy in the face of the COVID-19 pandemic and the cost-of-living crisis.

The example of H&F shows to all other local councils in England what is possible with effective budgeting despite cuts faced from the UK government. We strongly encourage that all local councils in England address what they can do and take action to prioritise the needs of Disabled adults in line with a human rights-based approach. Non-residential care charges are a tax on disability and continuing this policy is unjust. Abolishing home care charges will also aid local authorities in moving to a more preventative model, ensuring that their resources are used sensibly. This will prevent more intensive home care services being needed further down the line, avoiding situations where Disabled residents need a higher level of assistance from a lack of support being provided at an earlier stage.

We urge all local authorities to move to abolish home care charges. This plan should be developed with Disabled residents fully involved at each and every step of the decision-making process. When developing this plan, local authorities should ensure that they are taking into account the likely extra demand there will be for home care services from their decision to abolish home care charges. Local authorities across England can work together to make this pioneering positive change for Disabled adults, making home care free at the point of use.

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