Disability Law Service
Fighting injustice for disabled people

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

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”.