

“It’s the fairness isn’t it?”

Experiences of social care charging for disabled adults of
working age and their families.

A summary of a dissertation written for the UCL Masters in Social Policy
and Social Research, by Claire Bolderson, November 2023.

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Executive summary

Unlike health care, social care for adults in England is not free at the point of need. Disabled people and those with long term ill-health, who need help with personal care and daily tasks at home, can be supported by their Local Authority (LA) if they do not have savings of their own to pay for care. However, most still contribute to the costs through a “contribution” – or charge - determined by a means test. Earned income is exempt from the assessment. But welfare benefits, including most disability benefits, are taken into account.

This document is a summary of my MSc dissertation exploring the impact of care charging policy and practice on disabled people of working age (18-64), and family members involved in their care.

In-depth interviews were carried out in seven different English LAs. These revealed the financial hardship that charging policies can cause for a population heavily dependent on state benefits, and with relatively high levels of economic disadvantage.

Crucially, the research also suggests that charging practices can inflict emotional harm. People drawing on care and their family members feel devalued by the unequal and often humiliating way in which they are treated by a charging system that undermines autonomy and independence. The research also finds evidence of a connection between rising care charges, deepening poverty, and increased dependence on family for support.

The income means test for care clients with low or no assets reflects a policy that lacks a clear evidence base, and which is largely missing from discussions about the reform of adult social care.

This research provides insights that can inform those discussions. It suggests improvements for policy and practice (see section 4) that should be considered by government and LAs including:

- An evaluation of the assets and income of disabled care service users aged 18-64, including a review of what constitutes an adequate Minimum Income Guarantee (MIG).
- Ending the process of claiming for Disability Related Expenditure (DRE) and instead reforming the means test to exclude all disability benefits from the income assessment .
- A clearer legal definition of what constitutes a “reasonable” amount on which a disabled person is expected to live.
- LA reviews of systems to ensure that care charging is cost effective for the authority, and fair and transparent for the care service user.
- Greater government oversight of all the above to ensure more consistency and fairness across LA charging regimes.

1. Exploring experience and perceptions of care charging: focus and method

The document is a summary of my MSc dissertation exploring the impact of care charging policy and practice on disabled people of working age (18-64), and family members involved in their care.

The human factor

Unlike health care, social care for adults in England is not free at the point of need. Disabled people and those with long term ill-health, who need help with personal care and daily tasks at home, can be supported by their Local Authority (LA) if they do not have savings of their own to pay for care. However, most still contribute to the costs through a “contribution” – or charge - determined by a means test that includes most benefits income.

Care users must by law be left with a government-set weekly “minimum income guarantee” (MIG) to cover their daily living expenses - after housing costs and council tax. Rates vary according to age, whether a person has dependents, and the level of disability benefits received. Councils have discretion to set their own higher MIG rates. However, none of my study participants reported that in their experience, such discretion was being exercised.

Such a baldly stated description of the policy and practice of care charging necessarily misses the “human factor” – the lived experience and perceptions of people who receive services through their LA (or, in some cases, decline those services on grounds of cost).

The following pages shed light on that human factor. The research investigates what aspects of policy and practice contribute to experiences and perceptions and explores what might be done to mitigate some of the negative impacts. Importantly, it reveals that care charging policy not only lacks a clear evidence base but is largely missing from discussions about the reform of adult social care.

Methods

The research was carried out between May and September 2023. It was approved by the University College London ethics board and supervised by a UCL Associate Professor. Participants were recruited through charities, specialist newsletters, and social media networks. Of the seven interviewees, four were disabled people, two of whom had recently ended their LA support after significant increases in their assessed contribution. Three were parents managing the finances of young disabled adults.

The participants drew on care provided by LAs in the Northwest, Northeast, and North, in eastern England and southern England, and in two London boroughs.

Interviews of about an hour each took place via Zoom except for one conducted face-to-face. An established qualitative research method (Thematic Analysis) was used to analyse the content of the interviews.

2. Background to care charging: how did we get here?

The principle of charging for social care was introduced in the same 1946 law that created the National Health Service. The legislation gave Local Authorities (LAs) *a duty* to charge for care in a residential facility, and *discretion* over charging for social care at home. For the next three and a half decades few LAs imposed charges for home care beyond some specific services such as meals on wheels.

However, that changed in the 1980s when the ambitions of the Independent Living Movement coincided with successive governments that championed “choice”. Hospitals and other long-term residential care facilities for disabled people were closed in favour of people living in their communities, and preferably their own homes. This was a welcome development. However, funding of care at home came largely from the LAs responsible for administering it, rather than the NHS. And from the mid-1980s onwards, as councils took on more of this care, they were strongly encouraged by central government to pass some of the resulting costs on to the service users themselves.

It bears repeating that, as mentioned above, current social care policies and the practices that flow from them (notably the income means test for care clients with low or no assets) lack a clear evidence base and are largely missing from public debate about reforming adult social care.

This paper contains two appendices that explore the question “How did we get here” in more depth. Appendix 1 includes details of the many warnings issued at the time about the potential impact of charging. Several researchers, public bodies and campaigning organisations raised fears about the consequences for the poorest care clients - but to little avail. By 1995, almost all LAs practiced some form of client charging and the practice is now near universal in England.

Appendix 2 considers the justifications used over the years to defend the policy of care charging, with a particular focus on recent reforms.

3. Summary of findings

Carried out in seven different English LAs, the in-depth interviews highlight several urgent issues. For example, the data reveal the financial hardship that charging policies can cause for a population heavily dependent on state benefits, and with relatively high levels of economic disadvantage.

Crucially, however, the research also suggests that charging practices can inflict emotional harm. People drawing on care and their family members feel devalued by the unequal and often humiliating way in which disabled people are treated by a charging system that undermines autonomy and independence. The research also finds evidence of a connection between rising care charges, deepening poverty, and increased dependence on family for support.

A summary of these findings is presented below.

Feeling devalued in society

Interviews revealed considerable anger and even despair as participants described a care charging system that exacerbates a sense that as one participant put it, *“disabled lives are not valued.”* This was expressed in several ways.

Unfairness

- Participants pointed to the disadvantages experienced by disabled people compared to others dependent on state financial support. For example, while a non-disabled benefits recipient keeps the money they get from the Department of Work and Pensions, a disabled person must hand over a significant share of theirs to the LA as a “contribution” to the costs of their care.
- The perverse logic of this was not lost on participants. Central government assesses them as needing support, including additional funds to help cover the costs of living with disability. Yet, the LA immediately reduces that amount through care charging. As one participant put it, *“They give it to you in one hand and take it in the other hand.”*
- A sense of unfairness also arose in references to paid employment. For several participants, the percentage of their benefits income deducted through the care charge was significantly higher than basic rate income tax. This crystallised feelings about the way in which paid work is valorised in society, to the disadvantage of those disabled people who cannot work.
- Several participants compared their treatment to that of older people, another segment of the population not working, but who can have care needs and who receive state benefits. Some were aware that the MIG can be significantly higher for those of pension age than for the working-aged care client, and again saw this as unfair. Others felt the needs of older people dominated policy discussion while those of disabled people who need support throughout their lives were often ignored.

Powerlessness

- Charging practice gave rise to anger amongst participants and this was most evident in descriptions of the process for claiming Disability Related Expenditure (DRE).

- Experiences of lengthy negotiations over even the smallest amounts of DRE were summed up by one participant who spoke of the “*powerlessness*” and “*humiliation*” she feels during a process which can require disclosure of the most intimate personal care needs.
- Most shocking was the parent who asked for a small allowance to help pay for a particular type of sanitary wear for her daughter. The LA said a claim could only be made for a substitute item which did not meet the young woman’s needs. This was not a case of suggesting a cheaper product. It was the wrong product, accompanied by the LA arranging what the parent felt was an unnecessary and intrusive medical appointment for the young person.
- This was by no means the only report of an LA response to a DRE claim that served to undermine both the wellbeing of the disabled person and the agency of a parent with long experience of their family member’s needs. As another participant said of negotiations with the LA “*It’s about ‘get back in your box, we’ll decide what’s best for you.’*”
- In all interactions over DRE, participants felt they had to explain their behaviour and their choices to higher authorities. Needs must be constantly justified, and deference paid to officials in decisions over even the most basic of human needs. What emerged was the participants’ depiction of themselves as supplicants “*going with a begging bowl*” to the LA. This sense of powerlessness enhanced the feelings of being devalued.

A struggle with the system

Throughout the interviews, participants implied that the negative impacts of care charging are intrinsic features of the social care system. Without exception they portrayed that system as unhelpful at best, and openly hostile at worst.

- All participants described a lack of communication and transparency over care charging decisions. One had not realised that charges are related to income rather than to the hours of care received. They had cut their hours to try to save money and been dismayed to discover that doing so had no impact on their contribution.
- All participants, including those who said they had good relations with individuals within their LAs, talked in terms indicating struggle. Unanswered phone calls and emails emerged as significant sources of frustration. There was no evidence of regular LA assessments of the care client’s finances – outgoings as well as income. Instead, participants reported statements arriving out of the blue with poorly explained information about their assessed charges, the MIG and DRE. Some participants said information about how to challenge LA decisions was very hard to find and that if they did manage to appeal, for example over DRE, that appeal could go on for months and even years.
- Despite this, and in contrast to the image of powerlessness, most of the interviewees described situations in which they had challenged the system. One had simply stopped paying the additional money when the care charge – which had already doubled - went up yet again. Two participants stopped accepting the care they had been assessed as needing when the charges rose, a form of resistance with potentially harmful implications.

Poor quality of life

The experiences described above have material outcomes for disabled people. All participants linked rising care charges to a deteriorating quality of life for themselves or their disabled family member – and in one case, both. They expressed anxiety about making ends meet now, and even more anxiety about the future.

- Some participants described living conditions of extreme poverty - eating poorly and irregularly and being unable to afford heating through the winter.
- For several, the pressures of the additional costs associated with living with disability had been exacerbated by the squeeze that rising care charges was putting on their finances. Some participants reported needing new adapted furnishings or household items that would relieve discomfort or aid independence but which they simply could not afford. Their wellbeing and quality of life were therefore significantly undermined.

Dependency

All three parent interviewees described subsidising their disabled adult son or daughter in order that they could have some quality of life beyond a basic existence.

- In one case this included paying all the recent rises in care charges out of their own pocket. Another paid for their daughter's weekly transport costs so that she could get out to socialise with other people. The third, dependent on a state pension, had limited funds of her own and helping her family member, for example by buying new clothes or paying for a day out, had a significant impact on her own standard of living. One participant, seeing her limited savings rapidly diminish, acknowledged that her situation would be much worse were it not for the support of a family member.
- There was a sense that such support was expected of families, whatever their own circumstances. As one participant put it,
"I think that's one of the things that people will rely on is that every disabled person will have a support system around them of relatives who will look after them in some way."
- That perception was underlined by the participants with no family nearby, or who were estranged from family. They appeared to live in the most disadvantaged circumstances. This included those who had given up their care because of the scale of their assessed contribution, both of whom described emotionally as well as materially deprived lives in which they were very isolated.
- One said that they would be better off if they had a partner to care for them. There would be no LA social care charge so they would keep all their benefits, and the partner could potentially claim carers allowance. Their conclusion that, *"families have to provide their own carers for any quality of life at all"* summed up a sentiment expressed in varying degrees by all participants.

Participants in their own words

Unfairness

"The DWP give me more than job seekers because they recognise you can't live long-term on such little money (but) the council can say you don't need that, pay us £550 (per month)."

"We're not seen as valuable in terms of producing taxes. We're seen as soaking up... as people who're not contributing to society."

Powerlessness

"They will say, 'well you know you may be able to get this service free elsewhere' or 'can you go and shop somewhere different?' or 'do you think you could probably cut down a little bit?' So then you have to come back and justify that and then they might come and say, "ok two out of three we'll accept that, but we're not going to accept this".

"I hate the fact I have to go cap in hand when I feel like it's my money, you know?"

Struggle with the system

"The only functioning part of the care system is getting money out of people. Nothing else works. Nothing else works!"

"No one answers your calls, no one responds to your emails."

"The reason why it's so hard to challenge is because every local authority does it their own way."

Poor quality of life

"She (daughter) is now scared to wash her clothes more than once a week because it's too much money for the water and the electricity."

"I just can't describe how unbearable it is. It is the most dismal place to be where you're so cold."

"I wash my hair once a month that why it's always covered. Shower maybe once or twice a week. Flat is usually a Tip. I don't eat great" (Person who has ended LA care because of the rising charge)

Dependency

"Probably about 70% of my week is considering her (daughter) what I can do to make things better for her"

"I'm supporting her (daughter) independence, it's the cheapest way for the government, you know, for society."

"It's tough when you don't see people or know anyone can help when you're having a rough time. If I'm really sick no one coming in to ring the doctors." (Person who has ended LA care)

"I'm missing my appointments... I'm missing getting my medications, I've got no social inclusion." (2nd person who has ended LA care because of rising charge).

4. Conclusions

The aim of my research was to understand the impact of social care charging on disabled adults of working age, who are some of the most economically deprived users of social care services. Media coverage and charity campaigns had led me to expect that I would find evidence of financial hardship associated with social care charging in this group.

However, my findings go beyond the material impacts of charging to reveal the emotional damage inflicted by a system that generates troubling and sometimes perverse outcomes. Chief amongst those is the *giving* of benefits, including specific disability benefits, by one arm of the state (the government) and the *taking* of a growing share of them by another (the LA).

Participants told me that the deepening poverty, and fear of poverty caused by rising charges are sources of considerable stress. They also drew attention to another perverse outcome: increasing dependence on the support of family. This negates the significant efforts made since the late 1980s to empower disabled people to live independently, efforts originally driven by disabled activists and since enshrined in policy proposals under both Labour and Conservative governments. My research also provides some evidence that care charging can lead people assessed as needing care to reject it on cost grounds with potentially serious implications for their health and welfare. This is contrary to legislation that instructs LAs to promote, first and foremost, the wellbeing and the independence of people who request their support.¹

It is not just charging policies that participants described as causing harm. Indeed, the emotional and even psychological impact of some front-line charging practices appear equally, if not more, damaging. Nowhere was this more evident than in the participants' accounts of claiming DRE. Government guidance says that if a person is receiving disability benefits, they must be allowed to keep enough of them "to pay for necessary disability-related expenditure to meet any needs which are not being met by the local authority".² The guidance implies a relatively generous approach should be taken, and expenditure included even when it is outside the claimant's direct care and support needs. Evidence suggests this official guidance is not widely followed. My participants described a DRE claims process that engenders antagonism and humiliation in a very unequal relationship between care service users and LAs.

The parents who took part in my research recognised that the state expects them to provide considerable levels of care and financial support. Yet by failing to respect their understanding of their son's or daughter's needs, these participants felt that the same state treats them as lacking competence when it comes to interactions over care charging, particularly when making claims for DRE.

In their experience therefore, the system actively devalues the disabled person, and by extension their family member, by stripping them of autonomy. What is more, by focusing

¹ Care Act 2014 <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

² Department of Health and Social Care 2023 <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

on very specific medical needs, the DRE claims process appears to reinforce the disabling effects of impairment rather than to mitigate them.

Implications for policy

This research is a single, small-scale study which does not by any means cover the full experience and perceptions of care charging for disabled adults of working age. Nevertheless, it offers the beginnings of an evidence base that can be used to prompt better consideration of the working aged disabled care user in policy and research.

Given the potential for the care charging system to impose negative impacts on people who may already live in vulnerable circumstances, one can understand why most participants argued that social care should be free at the point of need. However, record government budget deficits and resulting pressures on LA finances suggest this is an unlikely prospect in the near future.

In the short term however, there are ways in which some of the policies and practices causing distress could be modified. The following are suggestions as to what these could be.

A starting point would be clearer definitions of terms. For example, the instruction, first introduced in legislation in 1983, that LAs “ensure that people are not charged more than it is reasonably practicable for them to pay” remains the official guidance. However, there has never been any indication of how the central government and councils should judge whether the policies and processes they have in place are reasonable. Government should therefore address this by creating a coherent framework through which LAs can assess, the real impact of their charges on the finances of individuals using their care services.

Transparent systems in which decisions are based on evidence of charging policies’ impacts would help to ensure that the duty to promote wellbeing enshrined in the Care Act 2014 is upheld. LA discretion over charging could remain to allow for adaptations to local circumstances. However, to be effective, clearer definitions of the law and greater uniformity in its practice would likely require more government oversight and monitoring.

Similar clarity and coherence are needed regarding DRE, for which, given the wide interpretations of the guidance, a more prescriptive approach would be beneficial. Alternatively, the DRE process could be abolished altogether, with the costs of disability paid instead by individuals from their disability related benefits and those benefits then excluded from the care charging income means test. This would end the humiliating process of negotiating over personal needs, and so help restore some autonomy and dignity to the disabled care user.

Income might also be restored through formal consideration of what constitutes an adequate minimum income on which to live. In January 2023, a written question in parliament asked what discussions had been held in government about the impact of the MIG on disabled people’s living standards. The Minister of State for Social Care replied that there had been no discussion and “no specific assessment has been made of the impact of the level of the MIG on disabled people and local authority budgets”.³ I suggest that this is a policy failure that should be addressed at the earliest opportunity. Equally, the lack of official

³ Question for Department of Health and Social Care tabled 26.01.2023 <https://questions-statements.parliament.uk/written-questions/detail/2023-01-26/133575>

information about the income and assets of working age care users⁴ should be remedied. A greater understanding of this population's financial circumstances could lead to more extensive and deeper consideration of their needs when it comes to care charges and in future policy deliberations.

Implications for further research

Achieving these changes could be helped by future investigation that builds on the evidence provided by my research. Issues pertaining to powerlessness, quality of life, dependency and self-image that yielded data of particular depth in my study could be explored more widely with a bigger and more varied cohort, or with multiple cohorts across more LAs. This could include quantitative research such as a survey of LA care clients, for which my study would assist in formulating questions that should be asked.

Lessons could also be learned from research in Scotland where care at home has been free for people over 65 since 2002, and for those under 65 since 2019. An important caveat is that free care in Scotland does not include many of the services that can be covered by LA social care in England such as help with shopping and cleaning. Similarly, in 2015, Hammersmith in London became the sole English LA to stop charging clients receiving care in their homes. My findings could prove valuable to evaluations of both, which should consider (a) the impact of funding free care for government and LA finances and, crucially (b) the impact on the quality of services provided, the numbers of people able to access services, and the impact on care clients' quality of life.

Finally, my research raises questions about the other side of the care charging relationship: the LAs that collect the charges and provide the care. Little is known about how local policies on care charging are decided. Further research in this area would help to put my findings into context and assist LAs in making their systems more transparent and responsive to their care clients.

⁴ Department of Health and Social Care 2022
<https://assets.publishing.service.gov.uk/media/61d5d4bfd3bf7f1f6f74330f/adult-social-care-charging-reform-impact-assessment.pdf>

Appendix 1: A brief history of social care charging

While the principle of means testing for social care was established 75 years ago, the origins of current charging practices can be traced to two developments in the 1980s and 1990s: the campaign by disability activists for Independent Living, and the adoption by successive governments of neo-liberal social policies. The former was a cornerstone of the disabled rights movement's efforts to empower disabled people, an ambition which, in its early days, sat comfortably alongside neo-liberalism's emphasis on freedom and choice.⁵ The interests of campaigners and governments converged in the closure of long-stay National Health Service (NHS) institutions and their replacement by home-based care for the elderly and disabled.⁶ Responsibility for providing care in communities and, crucially, for financing it, thus shifted from the NHS to the councils, which were already responsible for domiciliary services such as meals on wheels.⁷ At the same time, central government began cutting funding for LAs and increasing pressure on them to use their discretionary powers to raise revenue directly from care users instead.⁸

It is here that unintended consequences of an otherwise welcome instrument of empowerment begin to be visible in the literature. By 1995, almost all councils practiced some form of charging of social care clients⁹ although they were not governed by any single coherent policy. On the contrary, what amounted to a significant shift in how care was to be paid for, was "being worked out on the ground".¹⁰

From the start, there were concerns about whether the full implications of charging care clients had been adequately considered. The guidance that nobody receiving care should be asked to pay more than is "reasonably practicable" first appeared in a law establishing the framework for charging, the Health and Social Services and Social Security Adjudications Act, 1983.¹¹ However, as Lunt and Baldwin pointed out in 1997, there was no definition of, or advice on what constituted reasonableness. Their research, based on interviews with council officials, welfare rights advocates and disabled activists in six LAs, concluded that the charges risked "reduced take-up and use of services; increased financial hardship for individuals". The authors also questioned the assumptions LAs made about how much

⁵ Colin Barnes, 'Independent Living, Politics and Policy in the United Kingdom: A Social Model Account', *Review of Disability Studies: An International Journal* 1, no. 4 (2005), <https://rdsjournal.org>.

⁶ Mike George, 'Charging for Care', *Consumer Policy Review* 5, no. 2 (1995): 42.

⁷ Pete Alcock and Gary Vaux, 'Reconciling Cash and Care: Home Care Charges and Benefit Checks in Social Services', *The British Journal of Social Work* 27, no. 4 (1 August 1997): 499–513, <https://doi.org/10.1093/oxfordjournals.bjsw.a011238>.

⁸ Association of Metropolitan Authorities, 'Commentary on Social Services Inspectorate (SSI Advice Note on Discretionary Charges for Non-Residential Adult Social Services).' (Association of Metropolitan Authorities, 1994).

⁹ Mark Chetwynd and Jane Ritchie, 'The Cost of Care: The Impact of Charging Policy on the Lives of Disabled People' (Bristol: Policy Press, 1996).

¹⁰ George, 'Charging for Care'.

¹¹ 'Health And Social Services and Social Security Adjudications Act' (1983), <https://www.legislation.gov.uk/ukpga/1983/41/section/17>.

money the users of care services had at their disposal, and the additional living costs they often incurred.¹²

Worry about the potential impact of care charging policies on the poorest service users is a recurring theme in the literature of the mid-to-late 1990s. In the early days of social care charging, the government discouraged LAs from collecting money from care users on Income Support, an additional benefit for people with extremely low incomes.¹³ However, by the late 1980s, official advice on this had changed, a development questioned by the Association of Metropolitan Authorities in 1994 “bearing in mind that these claimants are considered too poor to make any contribution towards the council tax and get 100% rebate.”¹⁴ Rebates on care charges for the poorest were one of the suggestions made by Alcock and Vaux in their 1997 research on welfare rights.¹⁵ The National Consumer Council agreed with this approach, and also questioned what it felt were widespread assumptions that a person’s disability benefits should be used to pay for their care.¹⁶

Around the same time, Bradley and Manthorpe discussed income assessment in a study of the effects of charging on relationships between care recipients and social workers. Where professionals were previously focused on determining need, they now reported being uncomfortable with having to conduct “intrusive and oppressive” financial assessments of the people they were supposed to be supporting.¹⁷

Yet despite the concerns raised by national organisations and academic researchers alike, as Chetwynd and Ritchie observed in 1996, little attention was paid to the lived experiences of care users themselves.¹⁸ Their own research, based on interviews with elderly and disabled people receiving care at home, is a rare exception and appears to confirm many of the apprehensions outlined above. Their study found that while some participants were financially unaffected by the new charges, some had declined care because they could not pay. Others had no choice but to continue with care while making sometimes drastic economies to pay for it. The authors also highlighted poor communication from LAs, and a lack of clarity about charging. They argued that there should be a national approach to practices that, they concluded, were “evolving on a piecemeal basis, without regard for their cumulative effect on the user”.

The findings of my research are consistent with some of these warnings about care charging’s potential to cause harm, particularly to the poorest service users, that were

¹² Neil Lunt and Sally Baldwin, ‘Charging Ahead in the Community: Local Authority Charging Policies for Community Care’, *Health & Social Care in the Community* 5, no. 6 (1997): 418–20, <https://doi.org/10.1111/j.1365-2524.1997.tb00139.x>.

¹³ Ken Judge and James Matthews, *Charging for Social Care* (London: Allen & Unwin, 1980).

¹⁴ Association of Metropolitan Authorities, ‘Commentary on Social Services Inspectorate (SSI Advice Note on Discretionary Charges for Non-Residential Adult Social Services).’

¹⁵ Alcock and Vaux, ‘Reconciling Cash and Care’.

¹⁶ National Consumer Council, ‘Charging Consumers for Social Services: Local Authority Policy and Practice.’ (National Consumer Council, 1995).

¹⁷ G. Bradley and J. Manthorpe, ‘Price of Care: Charging for Services for People with Learning Disabilities’, *Journal of Learning Disabilities for Nursing, Health, and Social Care* 1, no. 2 (1 June 1997): 84–89, <https://doi.org/10.1177/146900479700100207>.

¹⁸ Chetwynd and Ritchie, ‘The Cost of Care’.

issued nearly 30 years ago. The experiences related by my participants provide some evidence that Chetwynd and Ritchie were justified when they advised that “the impact of charging policies on service use needs to be monitored by local authorities”.¹⁹ There is, however, no evidence that the advice was heeded. In part, as participants told me, that may be because initially care charges remained relatively manageable or were not imposed at all. The recent steep rises that they described coincide with the period of government austerity that meant a 50 percent cut in government funded LA spending power between 2010/11 and 2021/22.²⁰ Adult social care is the largest single area of LA expenditure and this same period also saw rising requests for support, particularly from adults of working-age.²¹ My findings support the hypothesis that a shortage of funds has led LAs to cover some of their care costs by raising service user contributions. However, further research into changes in individual LA charging policies and charging rates over time will be needed to confirm this.

¹⁹ Chetwynd and Ritchie.

²⁰ National Audit Office, ‘The Local Government Finance System in England: Overview and Challenges’, 2021.

²¹ The Kings Fund, ‘Social Care 360’, 2 March 2023, <https://www.kingsfund.org.uk/publications/social-care-360>.

Appendix 2: Justifications for care charging

Given the negative aspects of care charging identified in this research, it is important to consider how the policy has been justified. For the most part, when challenged by care service users, charities or the press, defence of charging falls to individual LA's.²² Most respond that in charging care clients, they operate strictly within the law. However, there does not appear to have been any justification of the law and its implementation per se.

Focus on pension age population

Policy discussions about social care focus disproportionately on the pension age population - notably the potential for older people to incur "catastrophic" care costs which can wipe out their life savings and, if they move to residential care, cause them to have to sell their homes²³ In contrast, working age care users paying charges from their benefits have largely been neglected in proposals originating from both sides of the political divide.

The relative lack of attention to care client charges for disabled adults of working-age may reflect greater public concern for the needs of the growing elderly population, as expressed in some opinion polls.²⁴ Alternatively, it may be due to the absence of coherent planning²⁵ in this little known and under researched area of social policy. It could also reflect what my research participants felt was the inferior status and relative powerlessness of disabled people in society. As one of them told me, *"Sometimes (it) feels like no one outside this little bubble has any idea of what's going on."*

Recent reforms

The lack of policy attention to income-related charges is perhaps most clearly evident in recent government reforms of Adult Social Care. From 2025, the total amount anyone will pay towards personal care from their own assets, regardless of age or income, will be capped over the course of their lifetime at £86,000.²⁶ The upper and lower thresholds for means testing of assets will be raised to £100,000 and £20,000 respectively, with the result that more people will become eligible for LA care. The government's analysis predicts that by 2028 the number of older adults supported by state funded care will rise from a half of those with care needs, to two-thirds.²⁷

²² BBC, 'Social Care Charges: Disabled and Vulnerable Adults Hit by Steep Rises', *BBC News*, 24 August 2021, sec. UK, <https://www.bbc.com/news/uk-58259678>; OpenDemocracy, 'Struggling Care Users Are Being Referred to Debt Collectors', *OpenDemocracy*, 2022, <https://www.opendemocracy.net/en/cost-of-living-social-care-bills-people-cant-pay-exclusive-england/>.

²³ Parliament House of Commons, 'Adult Social Care Funding (England)' (House of Commons Library, 2023a), <https://commonslibrary.parliament.uk/research-briefings/cbp-7903/>.

²⁴ Ipsos Mori, 'Understanding Public Attitudes to Social Care Funding Reform in England' (Ipsos Mori Social Research Institute, 2018).

²⁵ George, 'Charging for Care'; Chetwynd and Ritchie, 'The Cost of Care'.

²⁶ Parliament. House of Commons, 'Proposed Adult Social Care Charging Reforms (Including Cap on Care Costs)', 2022, <https://commonslibrary.parliament.uk/research-briefings/cbp-9315/>.

²⁷ UK Government, 'Adult Social Care Charging Reform: Analysis', 2022, <https://www.gov.uk/government/publications/build-back-better-our-plan-for-health-and-social-care/adult-social-care-charging-reform-analysis>.

To illustrate the benefits of this, its analysis provides examples of the impact of the higher thresholds on people with at least £65,000 in personal wealth who need residential care for between two and ten years, i.e., older people who have amassed significant resources and who require support towards the end of their lives. The analysis says that little is known about the assets and incomes of working-age care users, but estimates that almost all of them are already in the LA funded system.²⁸ Independent analysis estimates that under the reforms, it will take these working age care clients much longer to reach the £86,000 cap than wealthier people who pay for their own care.²⁹ This is because only money spent from personal funds counts towards the cap; the value of the LA's share of the support is not included.

LA care clients who pay charges out of their benefits income, such as the participants in my research, will therefore be amongst those least likely to benefit from the reforms.³⁰ Meanwhile, their experiences of care charging practices are not addressed at all in the new policy.

²⁸ UK Government.

²⁹ Institute for Fiscal Studies, 'Does the Cap Fit? Analysing the Government's Proposed Amendment to the English Social Care Charging System', 7 February 2022, <https://ifs.org.uk/publications/does-cap-fit-analysing-governments-proposed-amendment-english-social-care-charging>.

³⁰ Institute for Fiscal Studies.